Parents' Adaptive Tasks and Coping Skills with Stimulant Titration and Shared Decision-Making Process Within the Context of a Child Living with an ADHD Diagnosis

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Legend

ADHD = Attention Deficit Hyperactivity Disorder

SDM = Shared Decision-Making

MTA = The NIHM Multisite Multimodal Treatment study on Children with ADHD

CTBMA = Comprehensive Task-based Model of Adaptation

A Model of Parental Adaptation = A Model of Parental Adaptation to their Child's ADHD Diagnosis Using Stimulant Titration

Abstract

This study aimed to understand how parents' experience of titration contributes to the adaptive tasks and coping skills associated with their child's Attention Deficit/ Hyperactivity Disorder (ADHD) diagnoses. The primary research question asks: How does participation in the stimulant titration and Shared Decision-Making (SDM) process help parents create adaptive tasks and coping skills? The participants included 4 parents who have undergone the titration and SDM process as a part of treatment that addresses their child's ADHD diagnosis. Analysis was conducted via an adapted grounded theory approach and resulted in 11 themes related to the core emergent theme of titration. Themes that were representative of the titration experience were related to the participant's source of stress, cognitive appraisal of the ADHD diagnosis, adaptive tasks, coping skills, outcomes, and suggested improvements. The results have important implications for improving the titration process. The results also emphasize how titration has promoted adaptive tasks and coping skills which assisted participants to feel more in control and create a new sense of normalcy regarding their child's ADHD diagnosis.

Keywords: titration, ADHD, adaptive tasks, coping skills, shared decision-making

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Study Purpose and Objective

This study aims to understand how parents' experiences of titration and shared-decision making (SDM) encourages the process of adaptation, through the creation adaptive tasks and coping skills associated with their child's Attention Deficit/ Hyperactivity Disorder (ADHD) diagnoses. Furthermore, it aims to understand how the participants' experiences can be applied to help parents going through a similar transition with their children. Specifically, the study analyzed the adaptive tasks that the participants engaged in to make sense of their child's diagnosis. Adaptive tasks are tasks that an individual under takes to reconstruct an aspect of the person's life that has been affected by a chronic illness. These tasks can be divided into five primary groups including: physical, psychological, social, spiritual and vocational (Samson & Siam, 2008). Subsequently, coping skills are the specific means that are utilized to achieve these tasks (Samson & Siam, 2008). The following primary research question guided this study: How does participation in the titration process and SDM aid parents in the creation of adaptive tasks and coping skills? And subsequently, how do these adaptive tasks and coping skills help them better understand their child's ADHD diagnosis? The following secondary question also was of interest: how can parental experiences of titration help titration administrators improve the organization of the stimulant titration process for children with ADHD?

Context

ADHD is a neurodevelopmental disorder that affects 5.3% of children worldwide (Polanczyk, Willcutt, Salum, Kieling, & Rohde, 2014**).** There are 2.6% Canadian children who are medicated for ADHD, and it continues to challenge practitioners to objectively diagnose and treat the disorder (Brault & Lacourse, 2012). Historically, titration has been used to determine the best medication dosage for a child with ADHD. Titration is a process of trial and error, in which the physician will assign stimulant dosages either based on the child's weight or based on predetermined dosages that increase daily. The clinician will then determine when there has been significant improvement or a reduction in side effects (Greenhill et al., 1996). At a Canadian academic pediatric hospital, practitioners have begun working alongside parents of children with ADHD to determine which medication has the maximum benefit and the fewest adverse effects

through the process of titration. (ADHD & DBD Clinic, 2016). This adapted form of titration involves the individuals directly involved in the child's life, which include the parent, teacher and doctor. SDM is a process which incorporates the parent's judgement and perspectives on which medication they believe is the best fit for their child, in conjunction with the physician's expert knowledge (Elwyn et al., 2012). Titration combined with SDM allows for both the child's doctor and parent(s) to provide input in the child's healthcare (ADHD & DBD Clinic, 2016). It is important for the child's well-being to understand how the parent's own perceptions, knowledge, and abilities can influence how they contribute to their child's treatment. Thus, the parent's involvement can provide them with a better understanding of their child's diagnosis, which can help them create a new sense of normalcy in their lives.

Literature Review

Attention Deficit Hyperactivity Disorder (ADHD)

ADHD is a neurodevelopmental illness that emerges primarily during childhood and continues to challenge individuals throughout their lives. Moen, Hall-Lord and Hedelin (2011) defined ADHD as a "neurological disorder that affects adaptive functioning related to the impairment of four executive neuropsychological abilities: working memory, self-regulation of affect, motivation arousal, and internalization and reconstitution of speech" (p. 442). It is characterized by either inattention and/or hyperactive-impulsiveness, which subsequently interferes with the child's functioning and development (Polanczyk et al., 2014). Specific inattentive behaviours include wandering off task, lacking persistence, inability to sustain their focus, and a lack of organization. Hyperactive behaviors occur in the form of excessive fidgeting, tapping, and/or talking, amongst excessive motor activities. Impulsive behaviours can include hasty acts that occur without thinking, difficulty in waiting their turn, and interrupting others (American Psychiatric Association, 2013). ADHD causes persistent and developmentally inappropriate levels of hyperactivity, impulsivity, and inattention in children (Finzi-Dottan, Triwitz, & Golubchik, 2011). As a result, these symptoms can cause academic failure, difficulty in social interactions, as well as behavioural disturbances. These issues can then lead to less compliancy, and negative actions such as being bossy and stubborn, as well as increased temper outburst and a low tolerance to frustration (Finzi-Dottan et al., 2011).

The elevated levels of externalizing actions associated with ADHD symptoms make it very difficult to follow parental instructions, which can cause parents to use punitive, over-

reactive and inconsistent discipline. This can consequently lead to more negative interactions between parents and their children with ADHD (Finzi-Dottan et al., 2011). These behavioural issues associated with a child's ADHD symptoms provide additional stressors and burdens on parents, who must use specific adaptive and coping skills in order to maintain a positive bi-directional relationship with their child (Podolski & Nigg, 2001). An essential component of the child's wellbeing is the parent's own experience of adapting and coping with their child's chronic problems. However, every aspect of the parent's daily life is impacted by the diagnosis.

Impact of ADHD on parents.

According to cohort study conducted by Gupta (2007), parents of children with ADHD reported higher levels of parenting stress as per the Parenting Stress Index (PSI) compared to parents of children with healthy controls, HIV infection and asthma. The nature of the behaviours associated with ADHD increases the caregiving demands of the parents and causes a disruption in normal parenting processes. The stressors experienced by the parent of the adolescents with ADHD were higher with respect to their child's challenging behaviours. Additionally, the parents have reported elevated stress related to feelings of social alienation, conflicts with their partner, feelings of guilt and incompetence, as well as stress related to role restrictions (Wiener, Biondic, Grimbos, & Herbert, 2016). Overall, "research suggests that a range of deficits in knowledge and coping skills with regard to ADHD predisposes parents to higher levels of parenting stress than those of normal or clinic-referred children without ADHD" (Harrison & Sofronoff, 2002, p. 704). These disruptions challenge the parents to their lifestyles in order to find a new sense of normalcy while raising their child with ADHD.

There are a variety of variables that have been found to be correlated with parental and child stress which were: overall ADHD symptoms, inattention, hyperactivity/ impulsivity, conduct problems, internalizing, parental depressive symptoms, and marital quality (Theule, Wiener, Tannock, & Jenkins, 2012). Sameroff's model of developmental continuity posits that with each ADHD and conduct related symptom, there is an increased probability of that the family will experience negative outcomes, especially in terms of parental stress (Theule et al., 2012). The symptoms associated with ADHD affects the daily life of parents and increases their individual stressors. Stressors associated with ADHD consequently affect the functioning of the couples, family, and their subsequent interactions with the wider community.

Parents' individually experience everyday struggles in setting routines, dealing with a

messy house, difficulty controlling impulses, and always being on guard to prevent an accident from occurring. Children with ADHD can also exhibit dangerous behaviours which entails the parents constantly overseeing and protecting their child (Lin, Huang, & Hung, 2009). This can lead to increased number of negative interactions with their child, causing the parent exhaustion, stress, and emotional distress (Harborne, Wolpert, & Clare, 2004). Parents of children with ADHD expressed emotional burdens in addition to the parental burdens. These parents struggle with feelings of helplessness, frustration, worry, and anger towards their child (Lin et al., 2009).

Additionally, parents of children with ADHD must cope with increased familial conflicts. Parents may disagree on what they believe is best for their child. Disagreements may include those related to treatment and medication, parenting techniques, and caregiving roles (Lin et al., 2009). Familial stressors can lead to increase conflicts between caregivers as well as siblings. Arguments between siblings can be caused by a lack of understanding in regard to the ADHD related behaviours. For example, a sibling may get angered over their sibling's messy behaviours which in turn can cause them distress and they will act out (Lin et al., 2009). Siblings also struggle to understand the severity of their sibling's functional, social, and emotional impairments (Nabors et al., 2013). This tension amongst individuals extends beyond the familial relations.

Children with ADHD and their parents can be negatively viewed by society due to the gap between how society believes the child can function, and the individual's own capability (Honkasilta, Vehkakoski, & Vehmas, 2015). These ill perceived misconceptions can also be extended to the parents, which in turn minimizes the social supports that they require for their own emotional wellbeing and that of their child's. This lack of understanding decreases parents' instrumental and emotional support (Honkasilta et al., 2015). Experiences of stigma can lead to the families feeling isolated, which contributes to their lack of instrumental and emotional support. Furthermore, stigmatization leads to social exclusion, labelling, loss of social status, stereotyping and discrimination (dosReis, Barksdale, Sherman, Maloney, & Charach, 2010).

Parents also face institutional barriers from unsupportive medical teams and practitioners whom do not provide the personalized care that they require to support the entire family, and not just the child whom is diagnosed. Healthcare providers have been described as providing low contact frequency and low instrumental support to the parents (Bussing, Koro-Ljungberg, Gary, Mason, & Garvan, 2005). This lack of individual, community and professional support can

impact how the child's diagnosis and treatment impacts the entire family.

ADHD Diagnosis and Treatment

When faced with a child's ADHD diagnosis, how the parent reacts to the diagnosis itself can affect how they positively or negatively adapt to their conditions (Samson & Siam, 2008). There can be issues that arise regarding how the parents can accept the diagnosis, which subsequently affects the treatment options and implementation of a treatment. Parents' perceptions of their child's problematic behaviours will influence the help seeking behaviours that they enact. For example, if parents thought that their child's problematic behaviours were due to their diet intake, they would not seek professional help which may lead to an ADHD diagnosis (Bussing et al., 2005).

Qualitative interviews have revealed four patterns that influence help-seeking trajectories regarding when parents decided whether and how they would medicate their child with ADHD symptoms (Leslie, Plemmons, Monn, & Palinkas, 2007). The first pattern indicates that it is common among youths with complicated clinical or environmental lives, and/or mainly inattentive ADHD symptoms to have a delayed diagnosis (Leslie et al., 2007). Another pattern emerged that parents initially chose for their child to undergo non-medication-based treatment. (Leslie et al., 2007) There was also a high reluctance to accept the ADHD diagnosis amongst low-income, Spanish-speaking families (Leslie et al., 2007). Lastly, patterns indicate that when a parent was quickly engaged in the use of medication for their child's treatment, there was a directed movement to use and maintain the medication treatment (Leslie et al., 2007). These patterns reveal the complexities of accepting and treating an ADHD diagnosis.

Parental views and decisions regarding their child's treatment can change overtime and are influenced by cultural and other background factors. It is important to recognize the chronic nature of ADHD that persists from childhood into adulthood. Throughout their lifetime, the child and the family are constantly interacting with different external environments and contexts which influence their development (Bronfenbrenner, 1986). The child's development is not only impacted by their genetics and direct family members, but rather there are "other major settings influencing development, such as hospitals, day care, peer groups, school, social networks, the world of work (both for parents and children), and neighborhoods and communities; and public policies affecting families and children" (Bronfenbrenner, 1986, p. 723). The child's care is influenced by wider societal factors, and consequently requires positive interactions between the

child and their active caregiver, including an informed and proactive healthcare team over an extended period (Brinkman & Epstein, 2011). How parents utilize treatment can be informative for understanding how the adapt and cope with their child's diagnosis and the resulting behavioural problems. There are a range of factors intertwined with treatment options that can encourage parental adaptation and coping.

Gender and culture.

The act of seeking professional help is influenced by the child's culture and gender. Depending on how the child's behaviours are perceived by the parent, the child may be described as misbehaving, endangered, reactive, or indisposed (Bussing et al., 2005). Female children were labelled by African-American mothers as misbehaving, and their behaviours were considered "stubborn", "bad", or "uncontrollable". Punishment and behaviour modification were utilized to control the child's misbehaviours (Bussing et al., 2005). African-American parents are more likely to describe their male child's behaviours as endangered, and therefore the child should be supervised constantly, and kept in control to prevent injury or physical harm to themselves or others (Bussing et al., 2005). These types of parents are more concerned with creating a safe environment for their child, rather than seeking external assistance (Bussing et al., 2005). Caucasian girls with ADHD symptoms have been described as reactive and adaptive according to their parents. Parents, teachers, and wider networks utilize rewards to support the child's development and control their behaviours (Bussing et al., 2005). Caucasian boys diagnosed with ADHD were most likely to be given professional treatment. However, what was deemed appropriate treatment varied within this support group, and many mothers wanted their voices to be heard within the treatment decision making process (Bussing et al., 2005).

Parental Adaptation and Coping Factors

Factors that enable positive adaptation tasks and coping skills have been identified by researchers for better understanding their child's chronic illness diagnosis. There are a variety of factors from cognitive, informational, and social that promote adaptive tasks and coping skills (Samson & Siam, 2011). The first factor that must be undertaken prior to other factors occurring pertains to the acceptance of the diagnosis. (Samson & Siam, 2011). Consequently, the parents will seek the best treatment for their child through trial and error, social support, information gathering, working alongside practitioners, and SDM and titration. Many of these supports interact with one another in order to provide additional resources for the parents to utilize.

The parents of children with ADHD can accept their child's diagnosis to better understand how to react to their child's illness. Parents recognize that once they have accepted the diagnosis they can learn how to be there for their child and create a new sense of normalcy. By accepting their child's diagnosis, parents can remove the blame from themselves (Lin et al., 2009). Through the recognition and acceptance of their child's ADHD diagnosis, they will seek out treatment. Recognition of the treatment that is best for their child requires a trial and error period. Trial and error was an essential component for finding the tools that helped these parents cope with the difficult position (Moen et al, 2011).

Support networks are an essential aspect of the parent's ability to adapt and cope. Friends and family can provide outlets for expressing concerns about their child's emotions, behaviours and overall health (Bussing et al., 2005). It is common for parents to report that they have lost the support of their family or their partner, however parents have received increased support from friends and coworkers (Bussing et al., 2005). On average, the parent's support network size may range from 6 to 12 individuals (Florian & Krulik, 1991; Weiss, 1991). Social networks are also influenced by culture. For example, "African-American parents' networks consisted of immediate family members (e.g., grandparents and parents' siblings) and teachers, whereas Caucasian parents took input from, and relied upon, a wide variety of network members (e.g., various groups of health professionals, friends, and neighbors)" (Bussing et al., 2005, p. 96). Additionally, parents have reported that they have received support from their practitioner (Bussing et al., 2003), which is important for establishing long-term relationships with individuals in the community and helping professions. There is also a reduction in blame attributed to the parents from community and societal persons with a formal diagnosis, because it recognizes that the chronic illness is not a result of the parents' actions or inactions towards their child (Goodwillie, 2014).

Attributions to how one perceives the controllability of an event will influence their reaction and coping mechanism(s) used to address the stressful event (Harrison & Sofronoff, 2002). Cappe, Bolduc, Rouge, Saiga, and Delorme (2017) found that "perceiving the situation as challenging and adopting problem-focused coping strategies predicted better quality of life" in parents of children with ADHD (p. 1283). It has been demonstrated that parents whom had learned more about how to cope with parenting their ADHD diagnosed child were able to let go of the thought that their child was challenging to raise (Dennis, Davis, Johnson, Brooks &

Humbi, 2008). Some of the tools that assisted the parents to become more well informed included increased utilization of routines, as well as, structure and discipline, which resulted in less externalized behaviours and aggression by the children (Dennis et al., 2008).

Parents with more knowledge regarding ADHD as an illness perceive that they have higher control over their child's behaviours (Harrison & Sofronoff, 2002). Additional knowledge allows parents to be able to respond to their child's behaviours in affective ways. SDM when it is incorporated into the child's treatment is a source of information gathering that parents can utilize to understand not only their child's treatment better, but also their child themselves. SDM combines cognitive and social supports through the interaction between the parents and their child's practitioner.

SDM is a clinically practiced model that has been increasingly incorporated into medical decision-making and has enabled parents of children with ADHD to engage in their child's treatment (Elwyn et al., 2012). SDM is an adaptive task that they can engage in and is one of the several tools that parents can utilize for treatment to discover the best medication dosage to address their child's behavioural issues (Brinkman & Epstein, 2011). SDM is defined as "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences" (Elwyn et al., 2012, p. 341). It is important to engage in this type of decision making model when there is more than one option available for a screening or treatment decision, when one option does not have a distinct advantage over another, and when different participants may benefit or be harmed by each option in a particular way (National Learning Consortium, 2013). The opposite of SDM is the expert model. In the expert model, the physician has all the control in dictating the treatment. The expert model may cause distrust, amongst other negative feelings in the individual if they do not agree with the expert (dosReis & Meyers, 2008). Distrust does not promote a positive context for adaptation and coping to occur.

Medical providers argue that using SDM helps the individual better understand their own diagnoses or their child's diagnoses (National Learning Consortium, 2013). The individuals who have a greater understanding of what their treatment will involve can lead to increases in treatment satisfaction of the children with ADHD, their parents and practitioners, and makes the individuals more knowledgeable and prepared for the process (National Learning Consortium, 2013). The practitioners can present their preferences for the ADHD treatment, but the

individuals can provide input based on their own values and assumptions as well (Faller, 2003).

Parents of the child benefit from the SDM process because they learn about their health conditions, they recognize that decisions must be made, and are informed about the options to be made (National Learning Consortium, 2013). Subsequently, the child and/or caregiver understands the pros and cons of these decisions that affect their health care, has the tools necessary for making an informed decision, and is better able to discuss these options with their health care provider. This process creates a collaborative environment between the individual and physician (National Learning Consortium, 2013). It is a partnership of equals between the individual with a diagnosis and physician (Fiks, Hughes, Gafen, Geuvara, & Barg, 2011). When the diagnosed individuals and caregivers are empowered, they are also more likely to follow through with the decision that was made (National Learning Consortium, 2013). This encourages both an informational and emotional based relationship between the practitioner and the individuals affected by the ADHD diagnosis (Faller, 2003). Therefore, SDM emphasizes that an individual will do what is right to protect their own well-being, whilst taking into consideration how the decision will be interpreted and understood by others.

Lastly, the therapeutic alliance between the caregivers and practitioner is a very important factor for promoting positive adaptation and coping. The long-term success of the children relies heavily on a strong therapeutic alliance between themselves and their practitioner. The therapeutic relationship is a working relationship between the physician and family which strives to meet the shared goals of treatment (Brinkman & Epstein, 2011). To incorporate the best form of treatment for the child, there needs to be knowledge transfers between the different agents who are responsible for the child's well-being, the physician, and parents (Robaey & Schachar, 2007). An aspect of treatment which combines practitioner and caregiver input is ADHD stimulant titration in conjunction with SDM.

Parental maladaptive processes.

A parent will appraise a situation as stressful when the situation demands outweigh the resources that the caregiver has access to or perceive as such (Harrison & Sofronoff, 2002), which occurs on a regular basis for parents struggling to understand and navigate their child's ADHD problems. This daily struggle without knowing how to adapt to and cope with their child's diagnosis can lead to maladaptive and ineffective coping strategies. Research on coping styles related to disciplinary actions and child behaviour, have found that parents who used

maladaptive coping styles were more likely to use authoritarian and permissive discipline. Dysfunctional discipline was also regarded as a maladaptive way of coping with their child's stressful behaviours and general inability to cope with daily stressors that the parents faced (McKee, Harvey, Danforth, Ulaszek, & Friedman, 2004).

Parents also experience a great deal of frustration in obtaining the correct tools that met their needs as a parent whilst coping with their child's difficult behaviours. Caregivers subsequently attempt to control their children through careful observation and restriction of their behaviours (Moen et al., 2011). This form of parenting has been described as protective vigilance. Protective vigilance is a strategy characterized by the parents managing the risk that their child presents to themselves, as well as others such as peers or siblings. However, this strategy has been described as controlling or overprotective (Goodwillie, 2014). Due to the negative perception of parental behaviours towards their child with ADHD, these parents are viewed by society as abusive or overindulgent. This reflects the less than sympathetic and appreciative views that society holds of children with ADHD and their parents (Goodwillie, 2014). The parents' temperamental impairments can influence their child's overall health through the bidirectional relationship (Parand et al., 2010). Parents who have higher self-efficacy have reported to be more confident in their parenting related skills and can provide more structure to their children with ADHD (Heath, Curtis, Fan, & McPherson, 2015). Therefore, researchers need to find more ways to empower families to cope with daily life and parental stressors to promote better individual and familial health (Parand et al., 2010).

ADHD Stimulant Titration Treatment

Based on research evidence, ADHD guidelines state that the physician should prescribe psychostimulant medication, and/ or behavioural therapy to children diagnosed with ADHD. "The treatment guidelines also recognize the importance of taking family goals, preferences, cultural values and concerns into account when developing a treatment plan (Brinkman & Epstein, 2011, p. 581). From 1992 to 1997, the NIHM Multisite Multimodal Treatment study on Children with ADHD (MTA Study), looked at several types of medication and behavioural based treatment options, combined treatments and standard community treatment (Richters et al., 1995; Greenhill et al., 1996). One of the randomly assigned treatment groups was titrated medication doses to find the best dose for the child (Greenhill et al., 1996). The treatment group consisted of "a titration-adjusted, optimal, medication management strategy attained by titrating a drug

(starting with methylphenidate) based upon judgements by double-blind pairs of raters" (Wells et al., 2000, p. 546). The double-blind procedure included an expert panel who decided the best dosage for the child upon completion of the titration (Wells et al., 2000). The MTA study observed to better understand how individualized treatments impacted symptoms of ADHD, since medication studies prior to the MTA did not reveal individual differences (Greenhill et al., 1996). Prior to the MTA Study, clinicians relied on the child's weight to determine the suggested medication dosage, which did not account for individual psychological, neurological or physiological factors. Alternatively, clinicians would continue increasing the medication dosage until they saw improvement in symptoms. However, this did not address how much improvement should be viewed (Greenhill et al., 1996). The titration utilized in this study adapted and improved the titration represented in the MTA Study.

At a hospital in Eastern Ontario, stimulant titration was adapted and developed to allow practitioners to work alongside parents of children with ADHD to both subjectively and objectively find the best treatment for ADHD. This form of titration enables parents to have a role in their child's medical treatment, and not rely on solely expert knowledge (ADHD & DBD Clinic, 2016). Titration involves a four-week trial where the child, each week, is given either a placebo, low, medium, or high dosage of a psychostimulant. ADHD guidelines recommend "that parent and teacher ratings of symptoms and side effects should be obtained after the child has been on a particular dose for at least 1 week and overall progress should be reviewed during an office visit after the first month of treatment" (Brinkman & Epstein, 2011, p. 582). The treatment consequently involves input from every aspect of the child's social context.

During the trial, the parents, teacher, and the physician take notes on the positive and negative effects of the medication without knowing what dose the child is on. The pharmacists prepare the tablets to ensure the anonymity of the dosages, and the order of the week is also random (ADHD & DBD Clinic, 2016). After the titration process, the parents and physician engage in SDM to select the preferred week of the titration, which determines the child's medication dosage. This process enables an unbiased assessment of the effectiveness of the medication and helps to determine the optimal dose for the individual child. Consequently, the process also allows the parents to have a larger and more equal role in their medical decisions for their child (ADHD & DBD Clinic, 2016).

The titration process at the hospital in Eastern Ontario allows individualized and

specialized medical treatment for the child. By engaging in SDM, parents can provide input on what dosage of medication they think is most beneficial for their child (ADHD & DBD Clinic, 2016). The parental voice in the treatment of their child is imperative for informing the child's psychosocial context (Goodwillie, 2014). Their insight is invaluable because they are the caregiver who spends the most amount of time with the child and knows them best. Whereas, the physician helps direct the parents through the process of testing different dosages and provides the technical information (ADHD & DBD Clinic, 2016). The parent is more invested in process, and they themselves are more astutely attuned to the outcomes. SDM in conjunction with stimulant titration, is a form of treatment which actively engages parents in their child's health care and can provide a better understanding of the child's diagnosis which helps the parents create functional adaptive tasks and coping skills.

Adaptation and Coping Model

A neurodevelopmental disorder such as ADHD, provides many challenges to parents whom must learn to create a new sense of normalcy within their lives and the lives of their family. There are specific factors that can help parents to adapt to their child's chronic illness. To better understand how parents, adapt to and cope with their child's illness, this study will aim to understand the process of adaptation that is encouraged through the engagement in titration and SDM. The comprehensive task-based model of adaptation (CTBMA) provides the theoretical orientation that describes how individuals positively or negatively adapt to a chronic illness (see Figure 1) (Samson & Siam, 2011).

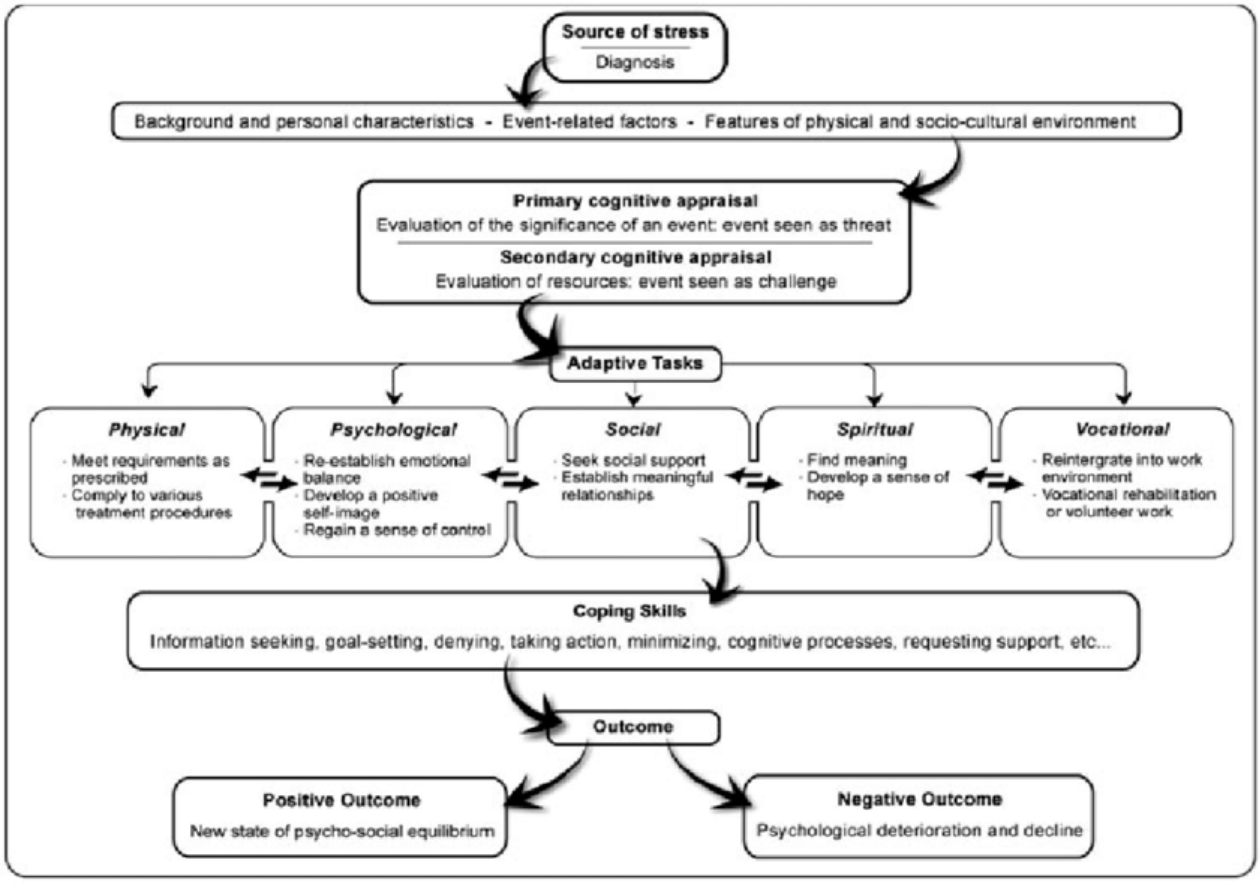

Figure 1.

Comprehensive Task-Based Model for Adaptation (CTBMA) (Samson & Siam, 2011, p. 246)

According to CTBMA, it is an individualized process for one to adapt to and cope with a chronic illness diagnosis. This an integrative and individualized approach recognizes that there are no sequential stages in the adaptation process, but rather each person's subjective experience of their illness is constantly changing and being cognitively reappraised (Samson & Siam, 2008). CTBMA posits that individuals affected by chronic illness must make efforts to reconstruct aspects of their life to restore a sense of control (Samson, Siam, & Lavigne, 2007). The process of adaptation either ends with a positive or negative outcome. CTBMA is composed of five components including: individual's personal history and context, the individual's cognitive appraisal of the disease, their adaptive tasks, coping skills, and the positive or negative outcome (Samson et al., 2007).

One component of the adaptation process is the individual's personal history and context,

also referred to as the affective involvement in the clinical process (King, Currie, & Peterson, 2014). The context includes their individual situation when the diagnosis is proclaimed. Furthermore, this context is influenced by the person's personal history which consists of ethnic origin, socioeconomic status, quality of social support networks, as well as their experiences with life transitions (Samson & Siam, 2011). The second component of CTBMA is cognitive appraisal, which consists of evaluating coping resources and alternatives in a crisis. Specifically, the person appraises the difficulties, restrictions and demands the illness imposes on life (Samson & Siam, 2008). The first cognitive appraisal involves appraising the source of stress, and through this phase parents recognize that they do not have the resources to cope and adapt. This form of appraisal influences how the parent receives the news of the diagnosis (Samson & Siam, 2008). Secondary appraisal is how the parents perceive their child's illness, and if this perception changed what they learned to do (Samson & Siam, 2008)**.** This secondary form of appraisal allows the parents to engage in the adaptation process.

Upon receiving the news of a child's ADHD diagnosis, the parents cognitively appraise how they perceive the diagnosis, and this perception will conceptually impact both their lives and their child. Depending on how the individual interprets the behaviours associated with the diagnosis will inform how and when they seek treatment. Adaptive tasks include the work that is undertaken by the people affected by the behaviours illness in an effort to resolve their life challenges. These tasks can be divided into five primary groups including: physical/ medical, psychological, social, spiritual and vocational (Samson & Siam, 2008).

The physical/ medical tasks involve completing and meeting the medical requirements that have been prescribed to the caregiver by the health care provider (Samson & Siam, 2008). Psychological tasks enable the individual to regain a sense of control over their own life, while maintaining an emotional equilibrium. Within the treatment process, this sense of control is referred to as client engagement. Client engagement is defined "as a multifaceted state of motivational commitment or investment in the client role over the treatment process. The notion of 'role' acknowledges the importance of a negotiated and changeable client–therapist relationship (King et al., 2014, p. 4). The individual's involvement in the treatment process is influenced by their hopefulness, conviction, and confidence regarding the treatment. These characteristics are consequently derived from the parents' interactions with a practitioner whom can optimize the engagement processes of willingness, reception, and the individual's self

efficacy (King et al., 2014). Practitioners are most effective when they can create conditions that empower the client through trust, their own personal power to bring about change, and belief in the effectiveness of the treatment itself (King et al., 2014).

Engaging in social tasks encourages the parent to seek social support from friends, family and other important persons in their lives (Samson & Siam, 2011). Spiritual tasks seek to give meaning to the illness and the consequences of the illness. Lastly, vocational tasks regard the parents' involvement in work which helps them to discover meaning in their life, pursue social status and create a personal identity (Samson & Siam, 2011). Coping skills help individuals to perform the adaptive tasks.

Coping skills are the specific means in which the individuals complete these adaptive tasks (Moos & Tsu, 1977). The coping skills required for adaptation can include either cognitive and physical aspects. Coping skills can include but are not limited to: denying or diminishing the seriousness of diagnoses, obtaining relevant information, enlisting reassurance and emotional support, learning procedures related to the illness, setting concrete limited goals, rehearsing alternative outcomes and finding a general purpose of meaning during events (Samson & Siam, 2011). The coping skills that one possesses may have been present prior to the diagnosis or developed through the process of adaptation to the chronic illness (Samson & Siam, 2008). The entire process of adaptation including appraisals, tasks and skills can result in either a positive or negative outcome. A positive outcome occurs when the individual sees the diagnosis as less intrusive, and they can establish a new sense of normalcy. Whereas a negative outcome would be indicated by psychological decline or deterioration (Samson & Siam, 2008).

SDM and titration provides a research context to study how the parents may successfully or unsuccessfully adapt to a chronic disorder through the creation of a new sense of normalcy (Samson & Siam, 2008), while striving to better understand how parents experience numerous stressors associated with their child's diagnoses. For the purposes of this study, the parents will have engaged in titration and SDM, which subsequently informs their adaptive tasks and coping skills as described by the CTBMA (Samson & Siam, 2008). The object of this research is to understand and describe how parents adapt to their child's chronic illness. More specifically this research will try to identify and describe how engaging in the titration process can encourage the adaptation and coping skills necessary for having a positive outcome while managing their child's ADHD diagnosis.

Methods

Philosophical Assumptions

To obtain an in-depth understanding of the parents' experiences, the research project is a grounded theory study conducted via semi-structured interviews. This particular study is constructed in the interpretivist tradition which is based in the ontological belief that reality is socially constructed, constantly changing and is very complex (Creswell, 2013). It is important to understand how the participants interpret and make meaning of their own reality. An individual's experience is socially constructed through the interaction between the individual's perspective, with the thought and language of the wider society (Glesne, 2015). Qualitative approaches, such as grounded theory, report the sole experience of the participant, and the researchers attempt to understand the phenomenon from the participant's perspective (Tomiak et al., 2007).

The grounded theory approach provides a level of rigor that addresses a social constructivist standpoint (Thériault & Gazzola, 2010). A social constructivist interpretive framework recognizes that an individual's perspective is constructed through their mind, which interacts with language and wider societal experiences (Glesne, 2015). As a social constructivist researcher, it is essential to acknowledge that our own backgrounds shape our interpretations, and it is necessary to position ourselves within our research (Creswell, 2013). Hence, this study is informed by my personal experiences and training in counselling psychotherapy. The social constructivist approach also examines a "process" between interacting individuals. Thus, the interpretive lens will recognize the complexity of the process and that all constructs that arise are valid because they are based on individual's experiences (Creswell, 2013).

Ethics Approval

Research Ethics Board (REB) approval was obtained from the study site. Once the REB approval was obtained from the site, the ethics proposal was submitted and approved by the University of Ottawa REB through administrative review.

Research Design and Approach

An adapted grounded theory approach was selected to theoretically explain and describe the social phenomena of stimulant titration and SDM (Corbin & Straus, 1990). This study is adapted from a grounded theory approach because it did not fully saturate the data, thus a theory is not proposed at the end of this study. Nevertheless, the study provides a rich description of the parent's experiences and provides a conceptual structure, with a formal theory to be postulated

later (Thériault & Gazzola, 2010). This adapted approach using grounded theory was utilized to better understand the experiences of parents of children with ADHD diagnoses taking part in the titration process. As a result, the model explained within the context of this paper provides a preliminary understanding of how titration can be used by parents to adapt and cope with their child's ADHD diagnosis.

The grounded theory approach is a methodological framework developed by Glaser and Strauss (1967). Grounded theory methodology approaches the research process from an inductive position, with the end goal of generating a theory that aids in creating a verifiable hypothesis for future research (Glaser & Strauss, 1967). Specifically, the grounded theory approach is used to generate a theory that is grounded in the systematically generated and analyzed data (Glaser & Strauss, 1967). An adapted grounded theory approach was used to comprehend how undergoing the process of titration and SDM helps parents to positively or negatively adapt to and manage their child's diagnosis. A positive adaptation to the chronic illness would be characterized by a new sense of psychosocial equilibrium, in which the illness is seen as less disruptive and is integrated into the parents' lives (Samson et al., 2009). Whereas, a negative outcome can result in the individual's psychological decline or a deterioration in their mental state (Samson et al., 2009).

The described tasks and skills were generated during the data collection and analysis, through the constant comparison of the data collected (Straus & Corbin, 1994). This process allows for more informed data collection tools, such as more meaningful interview questions and probes, which are updated as the interviews developed. Within the concurrent data generation and collection process, researchers also engage in constant comparative analysis (Glaser & Strauss, 1967). This process includes the researcher's continuous comparison of collected data and emerging themes. Overall, organization and coding of the data was conducted at multiple levels through open, axial and selective coding to create a comprehensive understanding from the data (Glaser & Strauss, 1967).

Instrument development

The purpose of semi-structured interviews was to obtain data that is intended, as well as capture unintended data that may emerge from the unique perspectives of the participant (O'Leary, 2013). Semi-structured interviews were conducted by the graduate student researcher, and the interviews were used for the primary data collection (see Appendix A for Interview

Questions).

The interview protocol was created by the lead physician conducting the titration, through the consultation of relevant research and medical professionals working with ADHD patients and their families. The protocol was adapted from the literature review presented above, in addition to The Multimodal Treatment of Attention Deficit Hyperactivity Disorder Study (MTA), which compared treatment options for children with ADHD (Richter et al., 1994; Greenhill et al., 1996). Although little research has been conducted on the experiences of parents of children with ADHD undergoing titration and SDM, findings of relevant research indicate that parents of children with ADHD, as a group, differ in their understanding of the condition, and often delay the use of medication for the condition as long as possible (dosReis, Mychailyszyn, Myers, Riley, 2007; dosReis & Myers, 2008). Additionally, decisional conflicts abound initial treatment negotiations can increase the likelihood that parents will delay the finalization of their decision, change their mind about the chosen option, regret their decision and/or blame the physician for negative outcome (dosReis et al., 2007; dosReis & Myers, 2008). The interview questions were compiled specifically to explore these various domains aforementioned.

The 10-question interview protocol ensures participants the flexibility to focus on particularly salient issues in their experiences, whilst probing evidence-based topics such as medication side effects. Interview questions were organized to facilitate the development of trust between researcher and interviewee. The questions were open-ended and humanistic in nature to promote participants' introspection and examination of their experiences (Yardley, 2000). Interviews were collected from one half of the parental dyad. Each interview was recorded via a digital recorder and transcribed verbatim. Exact wording and structure of the interview questions was not predetermined. Consequently, the interview questions evolved "to reflect and deepen the ongoing analysis in an iterative process which moves from data generation and data analysis to category verification and elaboration" (Thériault & Gazzola, 2010, p. 237).

Sample

The sample is comprised of parents whom had undergone the stimulant titration process at a hospital in Eastern Ontario with their child. These parents were selected because they have the unique experience of contributing to their child's medical treatment through the SDM model which is integrated into their child's titration treatment process. Inclusion criteria stipulates that participants did not have a psychiatric or medical illness that would prevent them from

participating in the interview or giving informed consent. Participants had to be able to communicate in English for the one interview to be conducted and transcribed by the graduate student researcher. French participants were also eligible to be interviewed but were not to be included in this analysis due to the nature of translation services available. Participants meeting the inclusion criteria, provided their children have met the criteria for the experimental component of this study, were recruited for the study. If the parents met inclusion criteria, then there were no exclusions.

The population of potential recruits and subsequent participants included 33 families whom have completed the titration process with their child. A short list of participants was compiled based on participant's titration dosage, duration since the completion of the titration, their ability to communicate in either English or French, and their knowledge of the titration process. As of November 20, 2017, a list of 10 potential interview candidates was confirmed by the lead physician and graduate researcher based on the aforementioned criteria. Of the 10 potential participants, the sample size included four individuals whom have undergone the titration process with their child at the hospital. Participants recruited for the purposes of this study had undergone the stimulant titration process, involving the SDM model with the medical team between 2009 and 2015.

Data Collection

The lead physician oversaw contacting the potential candidates to maintain their privacy, and to keep their medical records confidential. Candidates were approached during a regularly scheduled meeting with the physician or he called them if they have been discharged. The lead physician informed the parents about the study and asked them if they consented to be contacted by a research assistant to learn more about the study, with the possibility of participation. This means of recruitment is in line with the Personal Health Information Act of Ontario and removes the possibility of coercion by the lead physician, as a third party asked the parents if they would be interested in participating in the study (Personal Health Information Act, 2004). If an eligible participant indicated that they have no interest in participating in the study, the researchers would make no further contact with the individual.

Special consideration was made to ensure that parents did not feel as though they were required to participate in this study since they participated in the titration trial. Specifically, potential participants were contacted by the graduate student to arrange the interview time. If the

parents had any questions regarding the study or express interest in participation that would be relayed to the researcher. The consent process was also conducted by the graduate researcher. Therefore, the parents were not obligated to participate in the study as a favor to the lead physician who conducted the stimulant titration process.

To increase participation, the parents were spoken to regarding the importance of their unique perspective in the involvement of titration and SDM, and how their experience can be informative for many other parents going through a similar process. Participants were selected upon a first come, first serve basis. Recruitment will be continued beyond the scope of this study and until the data has been fully saturated.

If the candidate was interested in participating in the interview, they were provided with a Consent to Contact form (Appendix B). The candidates who signed the Consent to Contact form were able to select whether they preferred to be contacted by the interviewer via email or telephone, or both. If the candidate was interested in participating but was unable to sign the Consent to Contact form due to distance, the lead physician obtained verbal consent to be contacted, and signed the form on their behalf.

Once the candidate had signed the Consent to Contact form, which included the candidate's contact information, they were telephoned or emailed by the interviewer. Participants were asked whether they prefer to conduct the interview in either English or French. Depending on their language choice, they were assigned an interviewer. All contact with participants was tracked in the Contact Tracking Log in Excel.

The interviewer contacted the candidate upon receival of the Consent to Contact Form based on their preferred contact method. Each time the interviewer contacted or attempted to contact the candidate, the interviewer recorded the date, form of contact and any notes concerning the contact in the Contact Tracking Log. This was done to ensure that potential participants were being contacted in their preferred manner, and the interviewer could be held accountable for their interactions with the participants.

The graduate research assistant conducting the interviews offered the participants the option of conducting the semi-structured interview at the hospital at which the titration was conducted, from the comfort of their own homes or via Skype/ phone call. If participants opted to meet the researchers at the hospital, the date of the interview was to be scheduled to coincide with the participants' child's next appointment, whenever possible, to facilitate parents'

participation in the study. Participants who opted to meet the researchers at the hospital, the interview was to take place in the medical team's office. Participants who chose to partake in the interview at their home were asked to designate a private room where the interview would take place and where only the interviewer and the participant were present. Participants could also select to participate in a Skype video conference or telephone call. All four participants chose to conduct the interview over the telephone. The research assistant conducted the interviews from a private office, with the participant being asked to participate on the phone/Skype interview in a private room as well. Once the interview had taken place, the participant's Skype information was to be deleted from the research assistant's Skype history to maintain their privacy and confidentiality.

Participants were given the opportunity to ask questions or bring up any concerns about the interview during or after the conversation to arrange the time and the place of the interview. If a candidate did not want to arrange an interview after they have spoken with the interviewer, they were not to be contacted again. The reason why they chose not to participate was to be recorded in the Contact Tracking Log. Prior to commencing each interview, the researcher reviewed the Participant Information and Consent Form (Appendix C) and ensured that the participant understood the interview process. The interviewer described the purpose of the study and explained each section of the consent form to ensure informed consent. Candidates who chose to participate signed two copies of the Consent Form or an electronic copy was duplicated. One copy was provided to the participant, and the other was kept by the research team. The interviewer witnessed the participant sign the Participant Information and Consent Form, and interviewer signed both copies as well. If the consent form was signed over email, the participant was sent the consent form with the interviewer's signature attached and was asked to send their signed form back to the interviewer.

The participants were informed that the interview will take approximately 45 minutes. If the participants required a break, they were instructed to apprise the interviewer, and they would stop the recording. The interviewer asked each interviewee 10 interview questions and sub-questions. If the participant was uncomfortable answering a question, the interviewer would skip to the next question. Upon completion of the 10 study questions, the interviewer asked if the participants had any additional comments or questions, and when finished would turn off the recording device. Following the interview, the interviewer would thank the participants for their

participation and involvement in the study. Participants were also informed, that if necessary to collect additional data after the interview, the participant will be contacted via their preferred method of contact. Otherwise, only participants who selected that they want to know the results of the study were to be contacted again after the completion of the interview.

Following the completion of the interview, the interviewer transferred the recording to a password protected USB. Audio recordings were labelled and saved based on the participant's study ID number and date of interview. Interview recordings were immediately transcribed verbatim after each session for best recall of the interview session. After each verbatim transcription was completed the researcher highlighted and took notes on possible themes that should be added to subsequent interview protocol in the form of questions or probes.

Data Analysis

Data collection and analysis took place simultaneously (Glaser & Straus, 1967), in order to help shape interview questions further and to guide the data collection to promote a better understanding of the participant's experiences (DiMillo et al., 2013). Between each interview memoing took place to note and track emerging themes and ideas (Creswell, 2013). Each interview was coded via open and axial coding, which saturated categories, identified emerging conditions, and illuminated an individual category of main interest (Thériault & Gazzola, 2010). Follow-up interviews were only to be required if an area of saturation was missed or not elaborated upon thoroughly during the initial interview. Coding was completed by the graduate student researcher. The first step in the coding process was open coding.

Open coding was used for the purposes of labelling or naming an event, idea, incident, or act using a descriptive "code" which is used to represent the data as closely as possible (Thériault & Gazzola, 2010). Throughout and upon completion of the interviews, open coding was conducted to discover a central theme, which reoccurs throughout each of the participant's experiences. The codes that arise during open coding are primarily elementary labels which represent common elements across interviews, which are both abstract and more comprehensive (Thériault & Gazzola, 2010). Open coding asks the following questions regarding the interview data: What is happening in the data? What is the main concern facing the participants? What perpetuates this concern? (Holton, 2007). Upon completion of open coding, axial coding was completed. "Axial coding uncovers relationships between categories, such as, for example, causal, cyclical, or interactional patterns. Comparing instances of observed phenomena allows

for the specification of conditions that gave rise to a category and the context in which it appears" (Thériault & Gazzola, 2010, p. 236). Depending on the number of labels and categories generated, more participants were to be approached to fully saturate the themes that arose from the interviews (Creswell, 2013).

Several measures were utilized by the researcher to improve credibility and trustworthiness of the analysis, including: continuous comparison analysis, immersion in the topic of study, and persistent observation of the participants (DiMillo et al., 2013). Dependability was adhered to through the consistent execution of study procedures. Furthermore, transferability was increased through the use of engaging in rich data descriptions, thorough questioning of the study participants, in addition to coding and analysis (DiMillo et al., 2013). To ensure methodological rigor, the coding was first be coded by the primary author. Upon completion of the first round of coding, the same data can be coded by an additional research assistant who did not take part in the interview process (Thériault & Gazzola, 2010).

Participant reflection was used to confirm that the participant's experience was accurately portrayed through debriefing questions (Thériault & Gazzola, 2010). For example, debriefing questions included: Do you feel as though I have summarized your experience accurately? Are there any additional comments that you would like to add to further articulate your understanding of the experience of titration?

Results

The results explored below reflect the experiences of four adult mothers, whose average age was 48.5 years old at the time of the interview. The children's ages at the time of the trial ranged from: 7 years, 2 months, to 9 years, 8 months. The average age for the children during the time of the titration was 8 years old. The stimulant titrations took place between October 2011 and May 2014.

Due to the nature of the participant experience, the central theme that emerged from the interviews was the titration process itself. Specifically, there was an emphasis on the four-week period where the participants did not know what medication dosage their child was receiving for the purposes of finding the best fit for their child. Discussions related to the titration also included the participant's decisions as to why they decided to engage in the process, and their reflection on what they learned from undergoing the titration. Additionally, the results emphasize the adaptive and coping skills they engaged in in order to contest the challenges faced by raising

a child with ADHD. Participant 4 described the experience as:

> … it was just feeling good that something was finally being done, and it kind of felt like this is right way to proceed in terms of figuring out what he needed and what was working, and it just seemed like the most logical way of proceeding. So, I was generally very pleased with going through the process, despite it being challenging at times, but it was necessary, and I felt like, yeah it was important to do.

Overall, the sentiment was that going through the titration was a necessary and helpful process for assisting their child.

During the axial and selective coding phases, there were 12 primary themes that emerged, which were common amongst at least two out of the four participants. The chart below (Figure 2.) outlines the experiences of parents adapting to their child's ADHD diagnosis using stimulant titration. Various sub-themes, such as types of individualized coping skills, also emerged during the analysis that were common to multiple participants but are not all specified below.

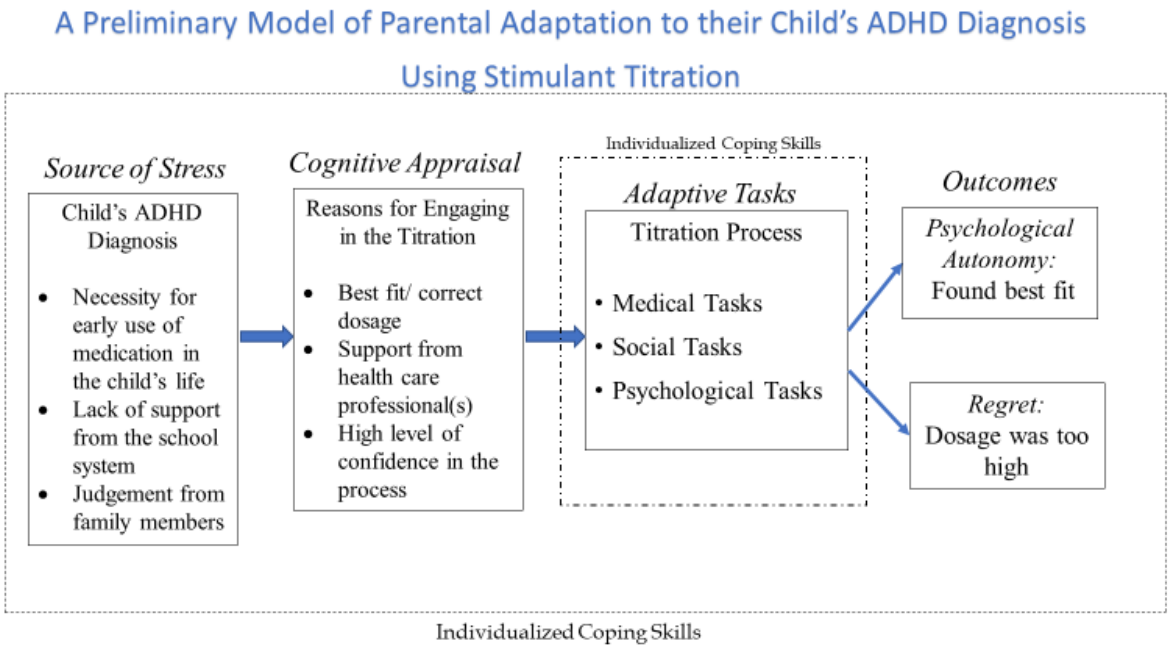

Figure 2. A Preliminary Model of Parental Adaptation to their Child's ADHD Diagnosis Using Stimulant Titration. Also known as A Model of Parental Adaptation for purposes of this paper.

Source of Stress: Child's ADHD Diagnosis

As outlined, in A Preliminary Model of Parental Adaptation to their Child's ADHD

Diagnosis Using Stimulant Titration, the process first acknowledges that there is a source of stress experienced by each of the participants. Namely, this source of stress is their child's ADHD diagnosis. Due to the emphasis on the titration process itself, there is little background history on the participants. However, common factors emerged which described their stressors related to their child's diagnosis, and the subsequent steps they took to address this stress.

Each of the participants had struggled to manage their child's ADHD diagnosis and symptoms. Consequently, they had all previously decided that medication was either the only option or best treatment option to assist their child manage their ADHD. Three out of the four participants described how they placed their child on ADHD medication at an early age due to a lack of additional resources. Participant 2 described her child as having difficulties focusing on toilet training and was unable to attend kindergarten without the help of medication. He was placed on medication at the age of three and a half years old. The concern for the need to place children on medication is discussed by Participant 4 below:

> No one was offering anything else other than drugs, and I remember having discussions with the initial doctor we saw at [the hospital name], it wasn't [lead physician's name]– saying that we should put him on antipsychotics and I said "no". Like, they just went through a whole bunch of stuff and I just said "no". I mean, if it's not his fault and no one is sort of willing to deal with thoroughly what seems to be happening here, "you should just put him on drugs".

Participant 4 thought putting a young child on antipsychotics was extreme. This suggestion made her suspicious and subsequently led her to seek other options. The participant's struggle to manage their child's symptoms and their need to place their children on medication at an early age was coupled by the lack of support from the school system to assist their children.

Participant 4, whom had to remove her child from school temporarily, described the situation as follows:

> It just seemed like the medication was sort of the first way of trying to get things under control, but like I said, so much of it was driven by the school and their unwillingness or inability to provide any kinds of resources or accommodation, reflection, or support.

According to the participants, the schools tended to rely on the medication as the solution, rather than assisting the child further. The lack of support for accommodations and the encouragement of non-medicinal treatment was reiterated by Participant 2, who described how the schools "don't have the material for those kids". Moreover, she expressed that the schools are "trying to

put ADHD children with others, so they're stronger from them, but they don't have enough teachers to help them". For example, her son needs one on one support when completing his math work. Otherwise, he will rush through the work because he is focused on finishing first rather than completing the work properly. An additional example of the lack of support is exemplified by Participant 1 and 2 both having to pay for private assessments of their children for them to get accommodations at school. Unlike the others, Participant 1 described how her child in high school does have the accommodations he needs now, such as a standing desk. However, Participant 2 is still waiting for the assessment to be completed. Participant 3 also expressed a lack of support from the school system, but specifically during the titration process itself.

In addition to the lack of support from the school system, the parents stress was increased by judgement from some family members. Participant 2's family expressed concern for her son going on medication at such an early age, but ultimately she knew it was necessary. Participant 1 seemed to feel the need to defend herself to family members. When asked about whether she experienced judgement about placing her child on medication she reported:

> You know there was- my family were very much "oh do you know what you're doing to him?" And everything else like that. And ah, you know my answer to them was "I didn't tell you how to parent your child, so I would prefer if you don't tell me". For myself, it was just for [child's name] to cope and being able for [child's name] to sit-down, oh [child's name] stop fidgeting.

In the end, the judgement from family members did not stop the parents from doing what they thought was best for their child. Overall, there was no stigma or embarrassment expressed by the participants associated with putting their child on medication for ADHD. However, the lack of support from the school system, in addition to the uncertainty of using medication to treat the ADHD symptoms in part led the participants to the titration process. Overall, the stressors experienced by the participants highlight how the families' lives are impacted when they engage with the outside world. The stressors associated with individuals and groups, whom are meant to provide social support, are compounded when they are unable to aid or had preconceived judgements as to what is best for the child. Consequently, this lack of social support makes it more difficult for the parents and children to adapt to the ADHD diagnosis.

Cognitive Appraisal: Reasons for Engaging in Titration

The second stage outlined in A Model of Parental Adaptation is cognitive appraisal. How

an individual cognitively appraises the stressor i.e. the diagnosis, informs how they adapt to the to the chronic illness (Samson & Siam, 2008) or in this case their child's ADHD diagnosis. According to the CTBMA, the primary appraisal is how the individual conceptualizes how the diagnosis will impact their wellbeing. Whereas, the secondary appraisal consists of the individual's evaluation of their resources available for coping with the difficulties associated with the diagnosis (Samson & Siam, 2008). The titration provided the parents with an opportunity to reappraise how they initially conceptualized their child's diagnosis. Furthermore, the titration process allowed the participants address the concerns initially involved with the diagnosis and symptoms and re-evaluate how best to address these concerns.

A common theme expressed by the participants was that they decided to do the titration trial to find the best fit for their child. As discussed, many of the participants had used medication for their child at an early age to address the ADHD symptoms, but the titration allowed them to find the correct dosage and best fit for their child.

Participant 1 expressed concerns with the initial medication dosage her child was placed on after receiving his ADHD diagnosis. She stated that both she and her husband, as well as her son, appraised that his medication was too high. They felt the medication "was too strong for his schooling because he became a zombie in the morning, if you can use that term. And in the afternoon, he would, he was still extremely hyper". Participant 2 ultimately described the decision as:

> …so difficult, but we had to think that it was for himself, we had to find the good medication for him, we had to find the good doses also. So, for us we put that in our minds even though he was so difficult. We had to put it in our minds that it was for our child's health.

Not only did the participants express that they thought that the titration process would allow them to find the best fit for their child, they also had the utmost confidence in the titration process itself. Participant 4 described the decision to engage in the titration process as:

> …important for ensuring that we are using the right medication and the right doses. Different kids respond differently, and by going through that process I felt that confident that we were doing the right thing and that we had figured out what the best dose was, and ideally that's what we do.

For Participant 4, the titration process was suggested by lead physician as a systematic way to discover the correct dosage for her child. Participants expressed concern whether their child's

medication dosage was correct or not and the lead physician was able to provide them with the opportunity to address these concerns. Participant 1 said the lead physician "explained it to us very well. We had an understanding of it, but with the titration, it gave us an even more in-depth way of thinking about things". Furthermore, Participant 2 was happy to help contribute to research for not only her child, but also to help other children. She stated, "I was really confident with that its research, so no matter what, one day they need to find new elements, new stuff to help the kids today". Overall, there were a lack of resources from support systems, such as their families and the school system. As a result, the participants were encouraged to cognitively reappraise their child's diagnosis, and systematically address their concerns through the process of stimulant titration.

Adaptive Tasks and Coping Skills: The Titration Process

The next step in A Model of Parental Adaptation is the titration process itself. The titration process enabled the parents to engage in several types of adaptive tasks, which assisted in the reconstruction of their life adjusting to their child's diagnosis (Samson et al., 2009). Throughout the process of adaptation to a chronic illness, the individual will attribute meaning to the diagnosis, and this causes them to evaluate what resources they have to cope with. This appraisal of resources is constantly changing and informs how the individual perceives the tasks necessary for adaptation (Samson & Siam, 2008). The titration process encompasses three distinct types of adaptive tasks: physical/ medical, social and psychological (Samson, 2009). Each of these types of tasks are reflected in the common themes that emerged during the four-week titration process whereby each participant did not know what medication their child was on each week. The common themes that occurred during the titration process include: consistency in providing the medication, quick recognition of the placebo, additional requirements for parents to complete, and medication related side effects, the medical team's support, and teacher participation. Each of these themes are related to either medical or social adaptive tasks and assisted with the creation of psychological tasks as well. Furthermore, to address their child's changing behaviours and needs, the parents engaged in specific coping skills to allow them to complete the adaptive tasks associated with the titration process. Cohen and Lazarus (1979), defined coping as an effort that aims to minimize, manage, and/or tolerate restrictions, challenges, and demands that are associated with stressful life events. Coping skills are summarized as "a cognitive or a practical ability to accomplish a specific task" (Samson, 2009,

p. 1). These skills can exist prior to the diagnosis or are learned through the adaptation process (Samson, 2009).

Medical tasks and coping skills. As per the requirements of the titration, the child received a daily dosage of the same medication for one week, over a four-week period. Each week the dosage was either low, medium, high or a placebo. All four participants reported providing the medication consistently to their child. This part of the titration process has been categorized as a medical adaptive task because it involved the participants adhering to medical requirements, which can include intake of medication and compliance to the stimulant treatment (Samson, 2009). Participant 3's coping skills related to this task was joking about how necessary it was to provide the medication: "we were consistent – we had to be… Those things happen. Like you can put the pills in front of the kid, and they miss that day… You know, that's why they have ADD right? [*laughs*] Part of the game". In addition to the medication administration, two participants discussed the additional medical related task requirements associated with completing the titration process. Participant 3 highlighted how on multiple occasions she had go to a new pharmacy to pick-up the randomly assigned medication each week. Whereas, Participant 4 emphasized that the process was labor intensive, because "there was lots of paperwork. Every week we had to fill out, and the teacher did as well, an assessment". Because of their adherence to the medical adaptive tasks, the parents and children had to deal with the side effects associated with the different strengths of dosages.

Each parent entered the titration process knowing the associated side effects of ADHD medication, however this process allowed them to see how each dosage affected their child differently. Several participants noted the extreme effects of the highest dosage on their child. Participant 3 noted that her child was "almost zombified". She went on to say that the highest dosage made her son "too quiet" and "basically knocked him out", so much so that she could hardly recognize him one day at school. All four participants also noted their concerns with the medication impacting their child's ability to sleep, as well as their appetite. Moreover, Participant 1 discussed how the changes in medication over the four-week period impacted her child's mood. She described it as follows:

> His emotions were like the week after, and always seemed to be one week later, catching up to what the medication was doing. And I found him to be, whenever anything but the right dosage that he had, I found him to be depressed. Not depressed like manic depressed, but like "I'm no good", "I can't do this", very low self-esteem.

The constant changes in the child's moods, behaviours, and abilities led to the common theme of frustration for two of the participants. Participant 2 stated that "some weeks it was a perfect week. Some of the weeks it was horrible because he was crying, screaming and a lot of frustration. Nothing was going right". Participant 1 said the most frustrating part was that they were used to having a controlled amount of medication, and therefore, the hardest weeks were "on the top and the bottom". i.e. the highest dosage and the placebo.

To address their frustrations, the participants had to engage in specific coping skills. These coping skills included their abilities to remain calm and tolerant. Participant 1 described the titration as a soul-searching opportunity to learn about herself about when it was necessary to stay calm. She described the experience as: "that was my learning, for myself, was always remembering that it is not a normal day. He's trying his best, and you know it's for his benefit. So, to stay calm, and understanding at certain points". Multiple participants discussed how this ability to stay calm and patient was coupled by the need to step back and remind themselves that they were doing this for their child.

Since each of the participants had previously placed their child on medication, there was also the theme of quickly recognizing when their child was on the placebo week. The participants engaged in the coping skill of utilizing past experiences to compare how their child behaved on versus off medication. Consequently, the participants used their skills of assessment to understand how their child was reacting to the trial. Participant 2 said she was able to tell her son was on the placebo within a day or two, and she described the placebo week as very difficult because to parent:

> … because he was not listening at all. Sometimes when we were talking to him that week, and he was not even looking in our eyes. So, trying to – "no don't do that, no", it was like don't even try, he won't listen to you.

Similarly, Participant 3 stated that it was easy to guess the placebo week, and they decided to place her son back on his regular medication for that week, since he would not be tolerated at school during that time. The decision to place the child back on his regular medication is one of the many ways the parents tried to cope with the changing behaviours and needs of their child during the titration process.

Additional coping skills related to medical adaptive tasks included information seeking.

Participant 2 utilized her knowledge about ADHD medication from working with family physicians. This obtained knowledge shielded her from being surprised or worried about the side effects. Whereas, Participant 4 made sure to do a lot of research about ADHD medication prior to the trial. The information seeking continued after the trial as well for Participant 1. Participant 1 described how her, and her husband attend meetings and listen to specialists to continue learning about ADHD. At one of the meetings, the speaker was discussing how she later in life discovered that she had ADHD, and this led Participant 1's husband to discover about himself that he too had ADHD. By learning more about their child's ADHD, these parents were able to learn more about their own capabilities, as well as their limitations.

In summary, the participants utilized adaptive medical tasks to help to adjust to and reappraise the diagnosis, whilst working towards a new sense of normalcy. The medical adaptive tasks included: providing medication, filling out daily assessments, learning about side effects, and obtaining the necessary materials to engage in the titration. The specific coping skills associated with these tasks included utilization of past knowledge, information gathering, consistently providing medication, reverting to old medication, joking, and assessing and evaluating the child's changing needs and behaviours.

Social tasks and coping skills. The titration incorporates social adaptive tasks into the process itself, through the involvement of medical team and the child's teacher in the SDM aspects of the process. Social adaptive tasks typically aim to obtain social support from family members, significant others, and friends (Samson, 2009). In the case of these participants, the titration required the child's teacher to blindly evaluate the child while they were going through the four-weeks of different medication dosages. Some of the participants appreciated the teacher's involvement and support to find the best dosage, however one did not. Participant 1 and 2 reported how necessary it was to have the teacher's involved in this process. Participant 2 stated that it was important to have the school's support because they too knew something was wrong and this was the way that they could help. Furthermore, Participant 2 said that on "the week when he was not on any medication, they saw the real [child's name]". Participant 1 echoed the need for the school to be involved in the process:

> You can't do it without them because if the school board and teachers are not informed, and you're doing this test, than the child gets picked on, or reprimanded for things that he wouldn't normally get reprimanded for because he's on a different level of medication. And if the teachers don't know this, than it's well like, why are you doing this? They'll

> use punishment, and stuff like that, so at least this way everybody was aware. It was hard on the teachers but like so be it, this is what I have to do to help my child.

The same participant elaborated that the time spent with counsellor providing the medication at school became the child's "special time", and that she expected this of all schools. In the case of Participant 3, she believes that the teacher's involvement in the titration process led to her son receiving a higher than necessary dosage to address his ADHD. Although not all participants received support from the schools, all the parents reported a positive impact from the medical team's support during the process.

The appreciation for the medical team's support is echoed during the process itself. Unlike in most medical situations, both the parent and the physician worked together to decide what the best fit for the child was. Rather than provide expert knowledge and tell parents exactly what to do, the physician gave them the opportunity to collaborate and see for themselves the effects of the medication, and what they thought was best for their child. Not only was the parent's voice heard, but so too was the child's'. Participant 1 valued that the lead physician encouraged her child to speak for himself since they were not in the child's body and could not fully understand how he was feeling. Participant 2 similarly said that she was happy to have another person for her son to talk to.

Three out of the four participants agreed that going to see the lead physician was not like going to another physician. The participants appreciated that the lead physician listened to how both the parent and child were doing and encouraged them to make decisions that were best for their family. The other participant was regularly exposed to working with physicians and did not elaborate on any differences. Participant 4 described the physician as "very good at thinking through what we're saying, and not sort of jumping to conclusions or rushing through things. He's very sort of considerate in how he responds". Participant 1's description of her experience with the lead physician goes beyond the support of a healthcare provider, since he and his team also helped to inadvertently provide emotional and familial guidance. Participant 1 emphasized that:

> …one thing that I always remembered from our meetings with [lead physician's name], is that they have a fish bowl. Every night that fishbowl has to be filled up because in the morning if it's empty, it's going to be a bad day. Full of love and encouragement and stuff like that.

Therefore, the medical served as a form of social and emotional support necessary for adapting to the challenging task of managing an ADHD diagnosis. Participant 3 emphasized that she appreciated how the medical team was also blind to the medication in the process because that allowed them to remain objective and unbiased. Most of the participants seemed to be unphased by the requirement to remain blinded during the trial. Consequently, the participants relied on the medical team, as well as the teacher, to engage in the social adaptive tasks and associated coping skills. The social support necessary for adapting to a chronic illness also applied to the participant's familial experiences.

A few participants expressed that they dealt with concerns from family members about the use of medication and this resulted in a lack of social support. However, a couple participants relied on their own familial related experiences to cope with their decision to engage in medication usage. Participants 1 and 2 made comparisons on how mental health issues and disabilities were perceived when they were young compared to their children now. This comparison reinforced their decision to proceed with the titration process. Participant 1 wanted to do everything she could to help her son, because in the past people with disabilities were not treated fairly, including herself who was diagnosed with dyslexia. She described her childhood as:

> You only strived for perfection, and you were very disappointed when it didn't happen. So, from my mentality growing up, it was hard too. And that's why I can empathize with [child's name] in many different types of situations, because I remember what I was like as a child growing up, not knowing that I had - ADHD, not knowing what it was and just getting mad at me for being a kid.

Therefore, the participant utilized her own past experiences to cope with the task of placing her son on medication. The participants emphasized the increased amount of support for children with ADHD today compared to when they were children. Furthermore, these participants acknowledged that by labelling ADHD as a neurodevelopmental disability, and not as a child with problematic behaviors, allowed the children to receive more support. This shift in appraisal of the diagnosis aided in a better understanding of why the children behave the way that they do. Through an openness to learning and exploring new options on how to best assist their child, all four parents entered the titration process with the confidence and knowledge that they could find the best fit for their child. Thus, the social adaptive tasks and co-occurring coping skills helped reconstruct part of their life which was changed by the ADHD diagnosis (Samson, 2009).

Overall, the participants engaged in various social adaptive tasks to adapt to their child's ADHD diagnosis. These tasks included working with the child's teacher to obtain assessments for the titration. Of most significance was the social support that the participants received from the medical team to make it through the titration, and beyond. The specific coping skills they used to adapt to their stressors included utilizing past experiences, having open and honest discussions with the medical team, engaging with the teacher during the titration, remaining calm and tolerant when behavioural issues occurred, and believing in themselves and the medical team to find the right fit for their child. These tasks not only allowed the parents to cope, but also the child as well. Furthermore, through successful engagement with social tasks and coping skills, participants could also utilize resources to assist with the psychological tasks necessary for adaptation.

Psychological tasks and coping skills. Psychological adaptive tasks are defined as a task that "involves maintaining satisfactory emotional equilibrium and regaining a sense of control over one's life" (Samson & Siam, 2008). As displayed on the Model of Parental Adaptation, the coping skills are outlined around the adaptive tasks of the titration process. Additionally, the coping skills encompass the entire model because there are specific skills that happened during, as well as before and after the titration process. Consequently, many of the psychological related adaptive tasks took place before, during and after the titration process.

The skills utilized and/or learned through the titration process varied between each participant, though several psychological-related skills were commonly used. A contributing reason as to why the parents decided to embark on the titration process was to find the best dosage for their child. Accordingly, many participants had to rationalize with the process itself to explain what they and are child were experiencing. Rationalization for the purposes of this study is defined as giving another explanation for something, such as a behaviour or thought, in the face of a changing reality (Grohol, 2017). For example, Participant 1 when her son was misbehaving, she would tell herself: "you can't think that way because he's not on his right meds, you know? His brain is not working properly, so you have to stop and say well it's not his fault". When Participant 3's son would say "opps, I don't know" where the wallet is for example, she described her parenting as follows:

> So, as a parent you basically start going and understanding that it comes with the territory, that's the way their brains work. No matter how much yelling or screaming, it's not going to change that. So, basically, it's the parent that has to adapt to the condition,

> it's not going to adapt to me.

Participant 3 recognized that it is she who must adjust to her child's condition, and a way she achieves this is through rationalizing what her child can do and how he thinks. Similarly, Participant 4 attributed "the differences in terms of his behaviour in relation to the medication, rather than him just kind of doing whatever". Thus, these participants displayed a thorough understanding of what the medication could or could not do to help their child, and they rationalized the child's behaviours based on the effects of the medication.

By the time the parents had undergone the titration period, they had already dealt with the unexpected behavioural disruptions that are associated with ADHD. Therefore, they utilized their past knowledge of their child's capabilities, and their understanding of ADHD. For example, Participant 3 has two children with ADHD, and she recognized the need "to give up special things, especially in the evening when the medication has worn off you're not going to get anything out of him".

Two of the participants emphasized not only how they coped with the diagnosis and titration, but also how their child had learned about themselves as well. Participant 3 said that both herself, and her son were still learning about how to cope, and that she is trying to train him to manage. She hopes that when her child grows up that "they will learn their own coping mechanisms". Whereas, Participant 1's son actively likes to learn about his own ADHD and will watch documentaries to understand it better. She describes her how her son can too reflect on the process:

> Well, for [child's name], it taught him that he can cope with no medication and with different dosages. [Child's name] is at the age, where he refers back to it and it's funny that after all these years, that he refers back to it and he has more control and understands what's happening to his body when he doesn't take his medication. It gave him, it gave us an awareness of what the real look at it is, and it also gave [child's name] the confidence to know the difference I found.

The titration also provided a place for the child to be understood and heard, which promoted their own self growth. For example, Participant 1 described how the lead physician encouraged her son to speak his own mind, and it gave him the confidence that his "mom doesn't have to do everything for me, and this doctor will listen to me openly to what I say". Participant 2 similarly described that the titration process enabled her son to be heard and helped him make sense of

what was going on.

Additional coping skills utilized by the different participants included, acceptance, support from partners, confidence in themselves, resiliency, bravery and empathizing with their child. For example, Participant 1 emphasized the importance of self-esteem for both her and her son: "self-esteem is big. It's like, it's the root of all evils - I find, in my life. Stress wise, relationship wise, learning, education - anything, it's self-esteem. If you have - if you believe in yourself, you're halfway there". Whereas, Participant 2 recognized that not all parents are willing to place their child on medication and that "they're afraid for that, but I'm not afraid". Overall, all four participants recognized how hard and challenging the process itself was, but they coped by reminding themselves that it was the best for their child. Participant 4 did state that the titration process and being blind did "make it a lot harder to cope". Nevertheless, she knew the

> … process itself was a way of stepping back and saying, oh okay, let's think this through and not feel like we have to make assumptions or jump into solutions or possible solutions that may not necessarily be what he needs.

Participant 1 similarly said: "I had to step back and stop, and say [participant's name], 'you're on this for him, for his benefit so you've got to'". Participant 2 also described the hardship: "some nights it was difficult to have to put this in my head, that it is for my child, for my child's health, even though it was hard… I remember some days I was crying a lot". She continued to say to her husband that "we cannot do nothing right now, we have to find the good dosages and then after that maybe we can find the good medication for him".

Overall, the psychological adaptive tasks included increasing self-esteem, recognizing the challenges and their abilities to cope with the challenges, and putting their child first. The specific skills used to accomplish these tasks included rationalization, positivity, discussing their feelings with their spouse, bravery, and resilience. Coping skills and adaptive tasks were essential for understanding their child' ADHD diagnosis and navigating the titration process to obtain the best results for their child and themselves.

Titration Outcomes

Upon completion of the four-week trial, the participants and the lead physician met to discuss what was the parent's preferred week. The lead physician, along with the participants engaged in the SDM process to determine based on the parent and teacher ratings, what the preferred week of the titration was. Ultimately, it was the parent's decision to pick the preferred

week, and not until the parents had decided what the preferred week was, did they find out the results of each week. Once the families have learned the results of the preferred week, there is then a discussion as to whether they want to move forward with the selected preferred week dosage, and subsequently, how to implement the medication. This overall process allows researchers to better understand how the parents adapted to their child's ADHD through the titration trial. According to the CTBMA, the process of adapting and coping with a chronic illness will either result in a positive or negative outcome (Samson et al., 2009). Coinciding with the CTBMA (Samson et al., 2009), the results of undergoing the titration process, revealed two distinct outcomes experienced by the participants. Although all four participants expressed that they were glad that they participated in the titration, and three out of the four believed that they did succeed in finding the best fit for their child's ADHD medication.

As per the CTBMA, a positive adaption and coping outcome results in the individual obtaining a new state of psychological equilibrium, along with a "re-established sense of normalcy" (Samson & Siam, 2008, pg. 4). Consequently, the illness is regarded by the individual as less disruptive in their life (Samson & Siam, 2008). In the case of the three participants who experienced a positive outcome, they felt as though they had found the best fit/ correct dosage based on the preferred week they selected. When Participant 2 described the best week, she said her son was behaving well, listening to what they said, he could focus on his work, and the family did not have to stay at home. Consequently, her and her family's life, specifically their social life, was no longer being as disrupted by her son's ADHD symptoms upon finding the best dosage for him. Participant 1 similarly described that her son "on his best weeks he was happy, no issues, no bickering, just an all-around general, good person. He was a happy little camper", and that he had great listening skills. Participant 4 noted that "I guess the best weeks were when I didn't notice a big difference, when things seemed to go smoothly, and it wasn't sort of a noticeable improvement from my perspective". She was also relieved that he did not end up with the highest dosage:

> I think so much of the weeks where he did best were not necessarily the ones with the highest doses. I think he did end up with the second highest dose as the most appropriate… So, like you know, realizing that the extra medication didn't seem to have any sort of perceptible effects. And that was important right? Because you don't want to be giving them more than what's necessary.

For Participant 4 it was important to know that she was not providing her son with a higher

dosage than what was necessary.

For the participants who were satisfied with the outcome of the titration, there was an increased sense of autonomy and control over their child's ADHD diagnosis. Participant 4 emphasized the importance of finding the correct dose, and how her participation increased her confidence in addressing her child's ADHD symptoms: "by going through that process I felt that confident that we were doing the right thing and that we had figured out what the best dose was, and ideally that's what we do". She also highlighted the fact that the children will be on this medication for years, so it is important to find the best fit for each individual child. For Participant 2, going through the titration process reaffirmed that they had good family doctors, the support of the medical team and were on the right track for helping her child to succeed now and later in life.

For the participants, the use of medication was an early form of treatment which was necessary to treat their child's ADHD symptoms. The feeling of the necessity to place their child on ADHD medication can result in parents feeling like they were not in control or being forced into this option as the only option. These feelings can also result in them feeling guilty about placing their child on medication. However, the titration allows them to have their own opinion heard based on their own observations of their child. Since none of the participants selected the placebo week as the preferred week it reaffirmed this need to place their child on medication. The parent's involvement in the trial can subsequently remove the guilt associated with having to administer medication to their trial and can make them more confident in how they have been managing, adapting and coping with their child's diagnosis. However, for one participant, she was not satisfied with the outcome.

For Participant 3, she regretted how the decision came into fruition as to what the preferred week was for her child. Upon reflection of her participation in the trial, she was surprised that her child had ended up on the highest level of medication. She stated that it was not until at least one year after the completion of the trial, that she was approached by the teacher who participated and was informed that the teacher thought she had selected a dosage that was too high for the child. The teacher told her that she thought the boy was too quiet, and the mom described him as "almost zombie-fied". She felt as though the teacher's opinion was too biased, and that she selected the one that "basically knocked him out and he was extremely quiet". As a result, the one thing she regretted was having him complete the trial while he spent most of his

time at school. Participant 3 believed that by "not seeing the entire picture, I'm pretty sure that the highest dose was picked, because he was – it totally knocked him out". Since the child was young, 7 at the time, and grew a bit, the family never changed the medication. Yet, Participant 3 still thinks that the titration: "is the best thing, that you can definitely identify what is the best dosage for the kid, and but yeah, not necessarily - at least in our case… it did not necessarily work out".

Although the titration did not have the intended consequence that Participant 3 would have preferred, there is no indication that there has been a psychological decline or deterioration, like the ones described by negative outcomes associated with the CTBMA (Samson & Siam, 2008). Nevertheless, the participant did experience a sense of not being in control or autonomous because of the amount of weight placed on the teacher's preferred week. She stated that she thought "the evaluation of the parent is not heavy enough with the teacher [and] they have to be really on board and understand what's going on". According to Participant 3: "I've taken that it should have been, *should* have been a very nice way to find the dosage – should have been the best way".

Discussion

ADHD is a neurodevelopmental disorder that causes hyperactivity, impulsivity, and inattention, which can result in negative behavioural interactions between a child with ADHD and their parent (Finzi-Dottan et al., 2011; Polanczyk et al., 2014). This study aimed to better understand parental experiences associated with the stimulant titration process, and whether the experience contributed to the adaptation and coping associated with their child's ADHD diagnosis. Treatment guidelines for ADHD "emphasize the importance of promoting productive interactions between an informed, activated patient, and family with a prepared, proactive practice team in order to improve ADHD functional and clinical outcomes" (Brinkman & Epstein, 2011, p. 584). Thus, research, such as this study, highlights the importance of parent-physician interactions, and how the relationship and cooperation can lead to a better understanding of the child's diagnosis, the parent's ability to adapt and cope to create a positive outcome (Brinkman & Epstein, 2011). The process of titration can be further improved to assist more parents struggling to cope with an ADHD diagnosis.

The outline created from the adapted grounded theory analysis closely follows the CTBMA model (Samson & Siam, 2008), and represents the titration process as a series of

adaptive tasks. As a result, A Model of Parental Adaptation to their Child's ADHD Diagnosis Using Stimulant Titration has provided a better understanding of how parents have used the titration process to make sense of and address their child's ADHD diagnosis. Furthermore, it represents a new preliminary theory on how parents whose child has received a diagnosis can adapt and cope with their new circumstances. The selective analysis resulted in 11 reoccurring themes related to the core category (Holton, 2007), the titration process and various subthemes related to coping skills. Themes emerged regarding the parent's source of stress, and subsequently their cognitive appraisal to engage in the titration process. Specifically, the parents thought that the titration process should be and was the best way to find the correct dosage of stimulant medication. This study recognizes that there is not a single cause and effect as to how or why the outcome was positive or negative (Jones & Passey, 2005), but rather acknowledges that there are many factors that contribute to the ability to adapt and cope to a child's ADHD diagnosis.

Source of Stress and Cognitive Appraisal

The preliminary Model of Parental Adaptation highlights the cognitive appraisals which led the participants to address their source of stress by utilizing titration. All four of the participants were determined to find the best dosage for their child, after they had struggled with the early usage of medication in their child's life, adverse side effects, judgement from family, and a lack of support from the school system. These sources of stress led them to agree to participate in the titration process. Charach, Skyba, Cook and Antle (2006), found that lack of support from schools and judgement from family members, in addition to the risk of side effects also impacted parent's decisions to engage in stimulant medication treatment. When Charach et al., (2006) explored the adherence of stimulant medication for ADHD, they similarly found that parents engaged in the use of medication because they believed it was best for their child, and the benefits outweighed the costs. However, the study also found that parents who decided not to continue with medication administration cited the same reasoning. The reasons why parents did not continue to medicate their child included side effects, the child's unwillingness to take the pills, and/or stigma associated with the ADHD diagnosis and treatment (Charach et al., 2006). Despite these concerns, the participants of this study persevered with stimulant medication to help regain a sense of control over their child's diagnosis.

The participants decision to participate in the titration process was influenced by their

own experiences as children, a high level of confidence in the process itself, support from their healthcare providers, and overall to find the best fit for their child. As discussed by Lin et al., (2009) parents recognize that once they have accepted the diagnosis they can learn how to help their child and titration is a form of this acceptance. As a result, through acceptance of their child's diagnosis, parents can remove the blame from themselves and seek treatment (Lin et al., 2009). The participants believed the titration was a positive way to provide additional support to their child in a systematic and objective way. Furthermore, the parents had control over the final decision as to what the preferred week will be, whilst being supported by the healthcare team. Similarly, Leslie et al., (2007) found that families who engaged in medication commonly decided to do so because they believed in the biomedical explanation for their child's behavior and had "supportive extended networks, and positive interactions with school and medical systems around diagnosis and treatment" (p. 183). The participants recognized the importance of engaging in medication usage to address their sources of stress and concerns. Additionally, the lack of support from social networks such as the school board and unsupportive family members enabled the participants to cognitively reappraise their situation and seek support elsewhere. Overall, the support that the participants received and the benefits of trying to find the best dosage for their child empowered them to participate in the titration process.

Adaptation and Coping

Within the context of adapting and coping with a challenging ADHD diagnosis, the titration process consists of a variety of adaptive tasks that provide an opportunity to lend support to the families. Consequently, the titration process provides researchers with a better understanding of how parents' experiences with titration can help overcome the stressors associated with their child's diagnosis. As per the CTBMA, an adaptive task is typically one of the five categories: medical/ physical, psychological, social, spiritual and/ or vocational (Samson & Siam, 2008). The titration process itself encompasses three out of the five types of adaptive tasks. Titration requires the parents to adhere to the medical/ physical tasks required for administering and providing consistent medication to their child. Furthermore, the process promotes social supports through the integration of the physician and child's teacher into the process. Lastly, the titration process helped to restore the psychological and emotional balance (Samson & Siam, 2008), by providing the parents with a result that gave them confidence and reassurance that they were doing everything they could to help with their child's diagnosis. For

example, "parents who report high self-efficacy may have stronger skills or greater confidence for providing the structure and support needed for children exhibiting ADHD symptoms" (Heath et al., 2015, p. 199). Higher self-efficacy has also been linked to my favourable behavioural treatment outcomes because the parent is more confident in their abilities to effectively carry out the treatment (Heath et al., 2015). Similarly, Participant 1 explicitly highlighted the need for higher self-esteem and thought that self-esteem was one of the largest factors contributing to the successful completion of the titration and her son's overall well-being.

An additional theme related to adaptive tasks, were the parents' adherence to providing consistent medication to their child before, during and after the titration trial. Monastra (2005) found that adherence rates for ADHD medication were 95% after three information sessions, when followed-up with 2 years later. When information sessions were not included, a lack of information provided by clinicians revealed a major barrier to parents seeking ADHD medication treatment for their child (Montoya et al., 2011). Additionally, the deficiency of "information also had an impact on maintaining treatment as most treatment discontinuations were due to fear of medication usage or side effects experienced by parents and patients, as well as to the persistence of emotional, behavioral, or social problems" (Montoya et al., 2011, p. 170). Each of the parents in this study highlighted the necessity to keep their child on medication to provide stability and allow them to thrive more in school. This highlights the importance of parents being informed and able to provide consistent medication to their children to address the symptoms and continue to adapt to the misbehaviours associated with ADHD.

The participant's outcomes because of titration was directly linked to the completion of their tasks. This study highlights the importance of engaging in medical and social tasks, which also helped to promote the completion of psychological tasks. The three participants who were able to engage in the medical adaptive tasks and had dedicated support from their support networks i.e. the medical team and child's teacher, were able to achieve more psychological autonomy and felt an increased sense of control over their child's diagnosis (Samson & Siam, 2008). In comparison, Participant 3 lacked the social support necessary to have a positive outcome in terms of finding the best dosage for her son. Rather, she regretted utilizing the social support associated with involving the teacher in the titration process. Support networks such as friends and family are meant to be outlets for expressing concerns about their child's emotions, behaviours and overall health. Yet, parents of children of ADHD tend to report a loss of support

from family members and their partner (Bussing et al., 2005). Thus, the impact of one or more adaptive task, despite the participant's individualized coping skills, can lead to a positive or less desirable outcome. Overall, all four participants felt they had done what was best for their child by entering in the titration process, and this in part is due to the coping skills they utilized throughout the titration.

Coping skills were broadly conceptualized as an effort that aims to minimize, manage, and/or tolerate restrictions, challenges, and demands that are associated with stressful life events (Cohen & Lazarus, 1979). The coping skills in this study were not restricted to one period, but rather occurred before, during, and after the titration had taken place. Once the parents had recognized that their child needed assistance, they were willing to engage in coping behaviours in addition to the adaptive tasks to address these challenges (Lin et al., 2009). Common coping skills utilized amongst the participants included increased tolerance and patience, rationalization, utilization of past knowledge and knowledge seeking behaviours. Other skills utilized participant(s) included acceptance, support from partners, confidence in themselves, resiliency, bravery and empathizing with their child. Lin et al., (2009), similarly found that their participants who were faced with coping with their child's ADHD diagnosis also engaged in primarily social and cognitive coping skills. Parents whom had learned more about how to cope with parenting their ADHD diagnosed child were able to let go of the thought that their child was challenging to raise, which has a positive impact on the parent-child dyadic relationship (Dennis et al., 2008).

Information seeking was one of the coping skills used during medical adaptive tasks and played a key role in the administration of the titration process. Parents with knowledge regarding ADHD as an illness perceive that they have higher control over their child's behaviours (Harrison & Sofronoff, 2002). Furthermore, individuals who have a greater understanding of their treatment plan can lead to increased satisfaction in the treatment for ADHD, increased satisfaction with their partners and practitioners, and makes the individuals more knowledgeable and psychologically prepared for the process (National Learning Consortium, 2013). Many of the participants utilized information seeking as a way of better understanding ADHD and the best options for treating ADHD. The titration process and beyond also proved to be a learning experience for the mothers, one father, and some of the children. The importance of continuing to learn and undergo psychoeducation is reiterated by a study conducted by Montoya, Colom, and Ferrin (2011). In a systematic review, the findings revealed psychoeducation programs

related ADHD clinical outcomes were positive in a variety of factors. For example, three studies found that psychoeducation resulted in a statistically significant reduction of core ADHD symptoms. One study also found that with teacher related psycho-education there were reports of improved academic achievements in the children (Montoya et al., 2011). Thus, the information provided to the teacher may have an impact on the child's ability to thrive at school. Additionally, two studies reported improvements in parent's capacity to manage their children's behavior after parental psychoeducation (Montoya et al., 2011).

Coping skills are a valuable part of the adaptation process because they allowed the parents to endure through the adaptive tasks and they contribute to whether the outcome is positive or negative (Samson & Siam, 2008). Through the recognition of the parent's ability to cope with their child's diagnosis, we can empower parents to adapt and address the concerns that are most pertinent to them and their family (Parand et al., 2010). If parents can engage in positive coping skills when feeling frustrated or overwhelmed by their child's behaviours, then it can result in a healthier, and less coercive or controlling relationship between the parent-child dyad (Goodwillie, 2014). If parents can rely on positive coping skills and adaptive tasks, then when temperamental impairments occur within themselves, it is less likely to have a negative impact on child's health through the bidirectional relationship (Parand et al., 2010).

Further analysis may also provide a better understanding of what coping skills are most effective. For example, Cappe et al., (2017) found that emotion-focused coping skills, which can include hoping for a miracle, led to lower poorer parental adjustments. Whereas, social-support seeking coping and problem-focused coping strategies were more positively correlated with improved parental adjustment, which resulted in decreased anxiety, anger, depression, negative mood symptoms, and increased positive moods (Cappe et al., 2017). Consistent parenting behaviours has also been associated with more positive parenting towards the child, and less parental stress (Li, Lansford, & Dubow, 2018). If the parents engage in more consistent behaviours, which results in less stress, then it is less necessary to teach parents coping skills because they already have an established sense of control and can engage in their skills by themselves (Li et al., 2018). In the case where the participant did not receive the same type of emotional balance from the outcome of the study, she nevertheless was able to engage in coping skills which helped her to individually navigate the challenges associated with raising a child with ADHD. The results of this study reflect how the parents did utilize social-support seeking

behaviours because of the titration process itself and engaged in problem-focused behaviours throughout their history of addressing their child's ADHD diagnosis. However, the extent of each coping skill's usefulness and effectiveness is unknown.

Outcomes

Through engagement with the titration process, the parents utilized adaptive tasks and coping skills to achieve a positive outcome. The positive outcome resulted in the parents having an "re-established sense of normalcy", and the ADHD is seen as "less disruptive and becomes increasingly comprehensive in the [participant's] life" (Samson & Siam, 2008, p. 429). The participants were able to be confident and reassured that they had found the best fit for their child, which could provide their entire family with more stability moving forward. This finding is comparable to the "reinvested family" described by Kendall and Shelton (2003). The "reinvested family" was described as a family whom was able to put energy back into lives and achieve a sense of control over their situation, despite the disruptions associated with an ADHD diagnosis (Moen et al., 2011). Families who are "reinvested" are clinically recommended to focus on the needs of the entire family unit. Furthermore, these types of "families need support in transferring responsibility for the management of the disorder onto their adolescent children and helping them build supports for the academic, occupational, and social challenges their child will undoubtedly face" (Kendall & Shelton, 2003, p. 276). Thus, the titration helped to provide stability during this time in the child's life, but the family will require additional support to further promote positive adaptation and coping skills as the child and family grows (Kendall & Shelton, 2003).

In the past where there was speculation as to whether medication is being over prescribed (Jensen et al., 1999), the parent's experience emphasized the need for medication to address concerning behavioural disruptions. However, the medication alone is unable to solve the problematic behaviours associated with ADHD. For example, the theme related to the need for increased support from the school system is consistent with other studies (Leslie et al., 2007; Lin et al., 2008). The participants emphasized the need for more support from the school boards, behavioural interventions, and alternative options to only relying on medication to address problematic symptoms and behaviours. Other resources that can help improve outcomes can include but are not limited to finding smaller class sizes, finding programs and extracurricular activities that meets the child's needs, providing a healthier diet, and different parenting

techniques (Charach et al., 2006). Research has also shown the benefits of teaching both parents and children mindfulness. Results indicated that mindfulness has helped parents to listen to the children better, without preconceived judgements, and it increased the child's compliance to requests (Singh, Lancioni & Winton, 2010).

The theme of improving the supports necessary to help families adapt to an ADHD diagnosis further highlights the importance of social support systems. The parents and children are not isolated individuals, but rather parents and children act as a dyad, and they are a pair within a larger ecological system (Bronfenbrenner, 1986). The child and their diagnosis remain at the center of the ecological system, but it interacts with different subsystems and structures, such as their relationships, their school, the community, and wider societal levels. Consequently, how the child's ADHD interacts with these subsystems will have an impact on how the family adapts (Mullins et al., 2015). For example, in the case of Participant 3, the teacher had a significant impact on the outcome of the titration process, which influenced how the mother was able to adapt to her child's ADHD symptoms.

No matter the outcome the parents experienced, they all agreed that medication cannot solve the problem alone. See below their responses regarding the use of medication alone:

> Participant 1: I found with [child's name], you can be on the proper medication, but if you don't have the self-confidence, and you don't have the encourage and love that you need, those medications don't work. Well not that they don't work, but just the medication that's just there, it's not enhancing any improved qualities. But with the medication, and self-encouragement, and everything else, then I think the medication works even better.

> Participant 2: Umm, no it cannot, it cannot solve… medication is going to help you, but it cannot solve like a one-hundred percent, right? So, now it's up to us to when he's on the medication to show him the right, right parenting skills. Sometimes it's difficult, but we came through with that.

> Participant 3: The medication alone? No. I think medication definitely is able to help, you know with the agitation, but I think no. Having raised two kids with ADHD, you understand how there is patience, there is sometimes learning to give up special things, especially in the evening when the medication has worn off you're not going to get anything out of him. It's a lot of a different understanding of the way the mind of somebody who is on medication for ADHD.

> Participant 4: Oh no, not alone. I mean, experience from the previous two years had demonstrated that, like obviously the medication was an important part of it, but inability to sort of succeed at school at the level that I thought he should or could, clearly, he needs more at school, to provide any sort of support. You know, it's just a piece of it.

Consequently, all the participants provided testimonies on how there is a need for behavioural interventions, more support from the school system, and certain coping skills, such as patience and sacrifice, to improve their lives and reduce their stressors associated with an ADHD diagnosis.

Suggested Improvements

The secondary research question associated with this study was to determine if the parental experiences of titration could help titration administrators improve the organization of the stimulant titration process for children with ADHD. Two out of the four did not have any suggested improvements. Participant 3, who regretted the selection of the preferred week, suggested that the trial period could be longer. She felt as though she was unable to see her child enough during the titration period to accurately observe the effects. The participant provided the following explanation:

> School finishes at one to two, two-thirty, and then they go to day care, and you pick them up from day care at five-thirty, quarter to six, and then they go home. You see them, what, at the end of the medication, for four or five hours, and by eight-thirty, nine o'clock they get to bed. You know, the parents don't see anything… No, so that's the one thing that I think we have to put in consideration that the evaluation of the parent is not heavy enough with the teacher. They have to be really on board and understand what's going on.

Consequently, the participant did not feel as though what she observed was enough to outweigh the evaluation the teacher provided. She added that the teacher's needed to understand the long term and side effects, and the effects that are not observable at school more clearly. Participant 4 suggested having an online evaluation, such as phone application, since she thought it would be easier for the parents to fill it out every day rather than a paper form.

Gender and Culture

Gender and culture did not appear as themes in the analysis, since all the participants were mothers who self-identified as female, and their cultural background was not a part of the inquiry. Past research has indicated that mothers do engage in a wider variety of coping behaviours compared to fathers, and that mothers are more likely to contact a medical team to

address a child's illness or impairment (Katz, 2012). Therefore, our participant's decision to engage in the titration process itself may have been influenced by the coping behaviours that are more often utilized by mothers compared to fathers. Additionally, it must be taken into consideration the participant's socio-economic status, which could not be determined just based on their postal code alone. This is important to note, because research has found that parents from lower socio-economic statuses are less likely to place their child on medication as a treatment for ADHD in the first place (Leslie et al., 2007).

Shared Decision-Making

Surprisingly, the results did not emphasize the SDM aspect of the titration process. Accordingly, many of the themes that emerged were directly linked to the titration process and the parent's experience of working with lead physician, rather than the input they provided to make the decision regarding the dosage of medication. The lack of emphasis placed on the parent's comparing and subsequently deciding on the medication may be due to the long duration between the titration process and this study. Several participants did have difficulty describing the comparison process. More explicit questions to prompt the parents to reflect on their final discussion with the lead physician to select the preferred week may be necessary to evoke those related responses. Even though the parents did not explicitly state that their decision-making in the titration allowed them to feel more in control associated with a new psycho-social equilibrium (Samson & Siam, 2009), and they were all happy with their decision to engage in the titration to find the best dosage for their child.

The participants sense of autonomy could have also been impacted by their role with lead physician. In the case of the physician-parent relationship, the physician still represents as source of expertise. Thus, due to the nature of their relationship, they can still be viewed as the knowledgeable one, when in fact the parents are the experts of their own children and got to see the first-hand effects of the titration trial. This view held by the participants of the medical team may diminish the parent's sense of autonomy and their contributing role in the process. In a study conducted by Balling and McCubbin (2001) on parental control and expertise for their child's chronic illness treatment, only 20% of the parents believed they should be equal partners with the health care professionals. Parents in the study noted that they would step in a take charge, but only if their trust in the physician had diminished (Balling & McCubbin, 2001). Consequently, parents may feel that they do not need to exert control or be the expert, if they

trust that the physician is doing the best thing for their child. Nevertheless, titration provides an opportunity for the practitioners to present their preferences for the ADHD treatment, but the individuals can provide input based on their own values and assumptions as well (Faller, 2003). In the case of the current participants, they all trusted and had a positive relationship with their healthcare provider. Practitioners are also most effective when they can create conditions that empower the client through trust, believe in their own abilities to bring about change in their life and have a strong belief in the effectiveness of the treatment itself (King et al., 2014).

Limitations and Future Research

There are limitations that must be considered when understanding and implementing the results of this study. In particular, there was a large gap in time between when the initial titration took place and the interview was conducted, which could have impacted the participants recollection abilities and thus the accuracy and perspective of the participant could have changed over time. As well, there are two of the participant groups from the titration process whom are missing from this analysis i.e. the teachers and the children. Research related to the evolution of the titration process in its entirety should include a better understanding of the teacher's experiences, which were not included in the scope of this study. For example, the teachers may express diverse types of coping skills to deal with the changing behaviours compared to the parents. Additionally, the teachers' experience may result in a dissimilar outcome because they did not cognitively appraise to be involved in the titration process for the sake of their own wellbeing. Furthermore, it would be of interest to know how they would improve the titration process, and what part of the experience could influence those suggested improvements. When the titration process is applied in a broader scope, and includes older adolescents, similar studies to this one will be required to include the individual receiving the medication. For example, Participant 4 raised the concern that her son was too young to fully understand what was going on with his body and mind during the trial. Therefore, the individual's self-assessment could have important implications for how the process is administered and whether the preferred week would change based on the individual's ratings. Nevertheless, this study provides a good snapshot of how parents utilized the titration process and their individualized recommendations for improving it. Lastly, future research regarding the titration process could be administered by a physician whom has not had a relationship with the participants prior to the titration trial to see

if there is a difference in the amount of control they exert during the preferred week discussion, when the parent does not know the physician.

This study was limited by the homogenous group of participants represented. Only mothers were represented in this study, and it is the mother's experiences related to raising a son with ADHD. Therefore, this study lacks a father's perspective, which has been proven to differ from mother's experiences (Bussing et al., 2005). As well, it is unclear whether the adaptation and coping skills are different for raising a female child with ADHD. It would be of interest to see if the parenting adaption and coping skills were different for a female child with ADHD, since females tend to have less conduct related problems than males do (Bussing et al., 2005). Furthermore, parenting stressors associated with ADHD have been found it be higher when the child is younger (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992), which was the case for many of the parents represented in this study.

Due to the time frame required for data completion, the number of participants was limited to 4 individuals. For fully saturation, the study would have ideally included upwards of 30 participants for a grounded theory study (Creswell, 2013). An increased number of participants would have allowed thorough data saturation and substantiation of the themes and subsequent outline that emerged. Typically, a grounded theory study halts data collection once all the themes are saturated and no new themes emerge (Creswell, 2013). However, many common themes emerged during the initial interviews, and it is unclear if all the participants whom have undergone the titration process did experience differences from the themes that emerged amongst the initial four interviewees. Thus, researchers can continue to explore the experiences of this sample of participants over time to continue to analyze and further substantiate the data represented here (Egan, 2002). Overall, qualitative studies are meant to better understand the experience of the participants, instead of generalizing the findings to whom all they may apply to (Creswell, 2013).

In terms of data analysis, there was also only a single coder analyzing the transcripts. Thus, the themes that emerged are based on one person's interpretation of the data and my own worldviews (Kolb, 2012). Future analysis can be done to validate and test the credibility of the coding by another researcher triangulating the coding via a thorough review and analysis of the independent coder (Thériault & Gazzola, 2010). Peer review or debriefing can also be utilized to further triangulate and validate the emergent themes (Creswell, 2013). To counteract the personal

biases that could have emerged, data analysis was conducted immediately after each interview to enhance the validity of the study (Kolb, 2012). Furthermore, participants who had selected different preferred week dosages were also sampled to provide a broader perspective of the titration experience and reduce the bias associated with theoretical and convenience sampling (Kolb, 2012). Lastly, reflexivity and negative cases were utilized to reduce personal biases associated with qualitative analysis. Reflexivity occurred through the incorporation of continuous awareness of how and why the analysis was being conducted, and the researcher's relationship with the participants and study members throughout the study (Kolb, 2012). A "negative case" was also included to highlight the various perspectives that can occur within the experiences of the individuals represented (Kolb, 2012).

Future research should explore the application of the titration process to adolescents and adults. Thus, the titration process can also be improved and adapted to youth and young adults. This potential adaptation has implications regarding the effectiveness of self-assessment, as the participants would be old enough to have their own objective input during the process. Additionally, there could be research conducted on the effectiveness of expanding the titration process to more hospitals and clinics to see if it can be adapted for more individuals. This would require adapting the titration process to online or mobile system, that could be accessed by more participating families. For example, a pilot study for an online system could be integrated into the upcoming stimulant titration appointments.

There are further opportunities to also examine the mechanisms of the relationship between parental stress and ADHD, and not just that parents with children that have ADHD have more stress than parents with non-clinically diagnosed children (Theule et al., 2012). Furthermore, there is a general lack of involvement in the participation of medical decision making by direct family members as well as the public (Litva et al., 2002). Lastly, inventories could be used to corroborate parental coping skills and the perceived helpfulness of these strategies, such as The Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Patterson & Cauble, 1983; Jones & Passey, 2005). Similarly, the Parenting Stress Index (PSI) used by Gupta (2007) or the Family Stress and Support Questionnaire (FSSQ) which has been used in the past to inquire as to what stressors parents faced while raising a child with a developmental disability (Minnes & Nachshen, 1997; Jones & Passey, 2005).

Conclusion

Overall, this study has provided a better understanding of how the represented parents addressed the challenging issues and behaviours associated with their child's ADHD. The preliminary model substantiated through the experiences of the four individuals shows how adaptation and coping can be applied to not only the individual whom has been diagnosed but can also assist the family members impacted by a diagnosis. As exemplified by the participants' participation in the titration process, when information is in a parent's hands, it is up to them to do what they think is best for their child. Through the process of titration in conjunction with SDM, the participants had a unique experience of having as much information possible given to them to help their child in the best way they know how. As described by Harrison and Sofronoff (2002), parents with more knowledge regarding ADHD as an illness perceive that they have higher control over their child's behaviours. The way in which this knowledge informs their own experiences with their child reflected how positive adaptive tasks and coping skills were utilized amongst the stressors associated with the ADHD diagnosis. Participation in SDM encourages the parents to be the experts in the well-being and health of their child. Thus, titration provides a context which allows researchers to better understand how parents of children with ADHD create and maintain adaptive tasks and coping skills that address their child's disorder. Specifically, the adapted grounded theory approach provided a new, qualitative understanding of the process involved in the adaptation and coping with a child's disorder through the individualized experiences of the parents. Furthermore, the adapted grounded theory approach provided a rich description of these parent's experiences. However, future research can be used to saturate the data and provide a more extensive theory on how titration has informed the parent's adaptative tasks and coping skills used to address their child's ADHD diagnosis.

The findings represented here are unique because titration provides a treatment option that not only addresses the medical stressors associated with an ADHD diagnosis, but also the social and psychological factors associated with that stress. The titration process itself revealed a series of adaptive tasks that parents can engage in to make improvements in their own life, and the life of their child. Adaptive tasks ranged from providing medication to their child to interacting with the medical team and child's teacher. The medical/physical tasks the participants underwent enabled them to engage in psychological tasks as well which helped to bring a sense of balance and equilibrium to their stressful situation. Each participant also utilized their

individual coping skills to help navigate the stressors associated with an ADHD diagnosis. Coping skills that the participants engaged in included but were not limited to rationalization, patience, joking/ laughter, and utilization of past knowledge and experiences.

Benefits of engaging in the titration trial included finding the best dosage for their child, increased parental involvement in their child's treatment, and an increase in the parents support networks. The titration process is a learning experience for parents and, yet it can be improved to assist other parents going through similar transitions with their children whom have been diagnosed with a chronic illness. Overall, the outcome of the titration process empowered the parents to feel positively about how they were handling their child's ADHD diagnosis and the associated challenging behaviours. The adaptation and coping skills used within and after the titration process helped the parents to find a new sense of control over their stressors. Thus, the titration process should be considered a viable option for all parents and children undergoing stimulant medication.

Titration is a process that not only helps to find the best dosage for the child, but also encourages the parents to make connections with a variety of social supports. As well, titration helps them to learn more about themselves and their children. The suggested improvements that arose during this analysis will assist future participants to increase the accessibility and administration of the process itself. The model discussed within the scope of this paper, provides a preliminary understanding of how titration can be uniquely utilized by parents to adapt and cope with their child's ADHD diagnosis. Overall, by utilizing titration, parents knew that they were doing everything possible to find the best fit for their child, which in turn provided them with the adaptative tasks and coping skills necessary to positively adapt to their child's ADHD diagnosis.

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Appendix A

Participant Interview Questions

Interview date:
Demographics
Gender:
Age:
Family Structure:
Postal code:

To be verbalized to participant by interviewer. As part of a study on the experiences of parents of children with ADHD diagnoses, I would like to ask you about your experiences. Please describe your experiences with as much detail as possible and to the best of your ability. There are no 'wrong' answers and no judgment will be placed. If a question makes you feel uncomfortable, please let me know and that question will be skipped. I would like to remind you that you are free to quit the study at any point during the interview with no repercussions from your doctors or the researchers. Would you like us to clarify anything before I begin?

Participant's overall experience of titration process

1. You participated in an ADHD medication titration process with your child. Could you please tell me what you remember about that experience?
   Follow up questions/prompts (if not mentioned spontaneously):
   a. What sticks out most in your mind about that process?
   b. What do you think about the fact that you and the teacher did not know the dosage (blinding) when completing the questionnaires?
   c. Tell me about your child's "best" week during the titration process.
   d. Tell me about your child's "worst" week during the titration process.
   e. Were there any obstacles for you or your child during the titration process?
   f. How did the experience affect you on an emotional level?
   g. How did you react when you discussed the results of the titration with the doctor? Were you surprised?

Participant's experiences prior to titration experience

2. Please describe for me the experiences that brought you to the titration process.
   Follow up questions/prompts (if not mentioned spontaneously):
   a. Why did you consider medication for your child's ADHD?
   b. Why did you think titration was a good idea? Please describe for me any expectations you had for the titration process.
   c. What was your level of confidence in the titration process? Explain why?

Participant's views on use of ADHD medication prior to titration process

3. Amongst the secondary effects of ADHD medication, please describe for me any hesitation or fears you may have had/ or have regarding your child's use of the medication.
   Follow up questions/prompts (if not mentioned spontaneously):

   a. Did you worry about side-effects ("zombie effect")? About the efficacy of the treatment? About stigma/embarrassment for you, for your child? About the way diagnosis and treatment were done? About the public image of medication in children? About long-term effects (growth, dependence, any other)?
   b. Did you feel you knew enough about medication? How did your doctor explain it? Did you try to have other information? How?
   c. How long did you take to accept the idea of giving medication? What did you go through to accept it?
   d. How consistent were you in providing your child with his/her medication doses?
   e. How did your child respond when given the doses of medication?

Participant's experience of working with physician during titration process

4. Please describe to me your experience in interacting with your child's physician during the titration process.
   a. What did you find most helpful in your interactions with the physician during the titration process?
   b. What, if anything, did you feel was lacking from your interactions with the physician during the titration process?
   c. How did you feel, as a parent, speaking to your child's physician during the titration process? Was it different from a regular visit to a physician? If yes ask: What was different? Please describe for me the level of power you felt during these interactions.
   d. How do you think the fact that the physician did not know your child's medication dosages affected your discussion with him about the results?

Participant's views on use of ADHD medication after titration process

5. Please tell me about your experiences of comparing the different medication dosages and placebo.
6. How did the titration process influence your views and feelings about your child and their use of medication to help manage their ADHD symptoms?
7. How did any changes in your child's behaviour during the titration process affect your parenting experience?
8. Do you think that the medication can solve the problem alone? Did the titration affect your view of other things that can be done, at school, at home, etc. (behavioral intervention, parenting)?

Outcome of participation in titration process/Concluding remarks

9. What do you feel you have taken or learned from this titration experience?
10. What advice would you give other parents of children undertaking the titration process?

Interviewer will summarize the answers of the participant.

11. Have I summarized your experiences well?
12. What would you have liked me to ask, that I did not ask?
13. Would you like to add anything?

Appendix B

Consent to Contact

Consent to Contact

Protocol Title: Parents' Coping Skills and Adaptive Tasks Associated with Stimulant Titration and Shared Decision-Making Processes

I, _____ (print name), hereby agree to be contacted by [research teams' names], for the purpose of arranging an interview. Once I have agreed to be contacted, I will either be phoned or emailed to arrange a meeting time for the interview.

[Student's name] will be contacting participants via phone call or email from the following number and/or email address:

I agree to be contacted by the following method(s):

- ☐ Email: _____(provide email)
- ☐ Phone number: _____(provide number)

I prefer to be contacted during the following time(s) of day (please select):

- ☐ Daytime (weekdays): _____
- ☐ Evenings (weekdays): _____
- ☐ Weekends: _____

_____	_____	_____
Printed Participant's Name	Participant's Signature	Date

☐ The caregiver was contacted by phone and verbally accepted to be contacted.

_____	_____	_____
Physician	Signature	Date

Appendix C

Consent Form

Information & consent form

Protocol Title: Parents' Coping Skills and Adaptive Tasks Associated with Stimulant Titration and Shared Decision-Making Processes

For more simplicity, the word "you", when used in this form, means "yourself" or "your child".

You are being invited to join in a research study about "Parents' Coping Skills and Adaptive Tasks Associated with Stimulant Titration and Shared Decision Making Processes". You are being invited to join this study because you and your child have been involved in a stimulant titration process. Before agreeing to take part in this study, it is important that you read and understand this document.

Taking part in this study is voluntary. Your decision to participate or not in this study will not affect the care you receive at the hospital. You are free to withdraw from the study at any time and there will be no penalty to you or your child.

Why is this study being done?

This study is being done because there are different ways to organize the titration of stimulant medication for children with ADHD and/or we hope to find out how does participation in the stimulant titration and Shared Decision Making (SDM) process affect parents' adaptation and coping skills with their child with ADHD.

How many people will participate?

We expect to have 30 people participate. The study is expected to be recruiting for two years.

What will I have to do? You will be asked to participate in an interview. This interview is about your overall experience with the titration process, your experience with ADHD care prior the titration, your view on use of ADHD medication before and after the titration, your experience of working with the physician. This interview will be digitally audio-recorded. The health record of your child will be examined to verify the diagnosis.

If you decide to participate in this study, you will be asked to participate in the interview, either in person at home or at the hospital, or through phone/Skype. The interview will take place during a time that is convenient for yourself and the research assistant. Interviews will take approximately 45 minutes, and will ask you questions about your

experience of undergoing the stimulant titration process with your child.

Are there any risks to participating?

There are no known risks associated with taking part in this study. If you feel uncomfortable with some question being asked, you may choose not to answer a question.

Are there any benefits to participating?

If you decide to participate, you will not benefit from participating in this study; however, we hope to that the information you will provide will help change clinical practice, especially in shared decision making.

Will I be paid to participate?

You will not be paid to take part in this study.

Will I be told about new information?

We will inform you of any new information that might influence your decision to continue to participate in this research project. We will ask you again if you still want to be in the study.

You can receive a copy of the study results at the end of the study. Please let the research assistant know if you would like to receive the results of the study.

What about confidentiality and privacy?

For this study we will be collecting your gender, age, family structure, postal code for the research purposes described in this consent form. This information will be retrieved for demographic and socio-economic status purposes. Your name and contact information will be kept on a master list that links you with a study ID. The study ID will be used in all of the research data to as the identifier in order to protect your privacy. The master list will be stored on the physician's computer in his office, which is password protected. The master list itself will also be password protected. Any personal information about you that leaves the hospital will be coded with the study ID so that you cannot be identified by name. Representatives from the Research Ethics Board may look at your records at the site where these records are held, to check that the study is following the proper laws and guidelines.

Your personal information will be kept strictly confidential except as required or permitted by law. Any information that would indicate that a child was being harmed or at risk of such harm, would not be kept confidential and instead be disclosed as appropriate to the appropriate authorities.

Representatives from University of Ottawa will receive information for data analysis and/or quality assurance. Any personal information about you that leaves the hospital will be coded so that you cannot be identified by name.

The data (audio recording) produced from this study will be stored in a locked cabinet in the physician's office and will labelled by study ID number. Only members of the research team and the individuals described above will have access to the data. Following completion of the research study the data will be kept for 7 years after the last publication of this study. They will then be destroyed.

You will not be identified in any publication or presentation of this study.

A copy of the signed consent form will be provided to you.

Is the research team benefiting from the study

The research team members are not benefiting personally, financially or in some other way from this study.

What if I have questions?

If you have any questions concerning participation in this study, contact:

This study has been reviewed and approved by the Research Ethics Board. The Research Ethics Board is a committee of the hospital that includes individuals from different professional backgrounds. The Board reviews all human research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Research Ethics Board, for information regarding patient's rights in research studies___ although this person cannot provide any health-related information about the study.

Consent form Signatures

By signing this consent form I agree that:

- I am voluntarily agreeing to participate in this research study;
- I understand the information within this consent form;
- All of the risks and benefits of participation have been explained to me;
- All of my questions have been answered;
- I allow access to my medical records and/or personal information as described in this consent form; and
- I do not give up my legal rights by signing this form.

A copy of the signed Information Sheet and/or Consent Form will be provided to me.

Signatures

Obtain the appropriate signatures, which should be based on capacity.

Printed Participant's Name	Participant's Signature	Date
Printed Parent's Name	Parental Signature	Date
Printed Name of Person Who Conducted Consent Discussion	Signature of Person Who Conducted Consent Discussion	Date

Use this section if a translator or impartial witness is required.

If the consent discussion has been conducted in a language other than English, and an impartial qualified translator is required.

Printed Name of Translator	Translator Signature	Date

The "Signature of the Witness" line is intended for an impartial witness which is necessary when either the subject or the subject's legally authorized representative (LAR) speaks and understands English, but cannot read and write or is visually impaired

Printed Witness Name	Signature of Witness	Date