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Faculty of Community and Health Sciences

Department of Psychology

RESEARCH THESIS

Caregivers' experiences of weaning their children from ADHD medication

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DECLARATION

I, Casey Brandy Botha, hereby declare that the research entitled, *Caregivers' experiences of weaning their children from ADHD medication*, is my own work. It has not been submitted before for any degree or examination in any other university. All the sources used or quoted were acknowledged and fully referenced.

Signed:  Date: 09 September 2022

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Firstly, I would like to thank God, for His faithfulness, love and mercy. Thank you for guiding me, giving me strength and hope, and for never giving up on me. Thank you for all You have provided, and for this path You are leading me on.

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Abstract

Attention-deficit/hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterised by levels of inattention and/or increased hyperactivity/impulsivity. Medications have been widely used as an effective ADHD treatment for many years. Despite the benefits of medication, many caregivers are hesitant when it comes to starting and continuing ADHD medication. The aim of this research project was to explore caregivers' experiences of weaning their children from ADHD medication. An exploratory research design was employed to explore caregivers' experiences of weaning their children from ADHD medication and the impact of the discontinuation of medication on family functioning. A qualitative methodological framework was utilised. Purposive sampling and snowball sampling were used to recruit caregiver participants. The data collected were analysed using thematic analysis. Ethics guidelines as specified by the Humanities and Social Sciences Research Ethics Committee at the University of the Western Cape (UWC) were followed. The study determined that caregivers discontinued their child's ADHD medication due to the negative experiences associated with the medication. The rationale for discontinuation of medication was attributed to the side effects observed, family judgement regarding ADHD as a legitimate disorder, fears of substance dependence, as well as caregivers wanting their children to reach their true potential without using medication. It was also found that the discontinuation of medication negatively impacted family functioning and increased conflict and stress within the family. It also required additional hard work from the parents. In addition, all caregivers had one thing in common — discontinuing the medication was in the best interest of the child and finding an alternative method that would suit the child, even if it meant more responsibility for the caregivers. The knowledge, information and insight gained

through this research may be used to inform community-based interventions which are essential to public health provision in South Africa.

Keywords: Attention-deficit/hyperactivity disorder (ADHD), medication, medication discontinuation, weaning, caregiving

Glossary

1. Caregiver: a family member or primary caretaker who regularly looks after a child or a sick, elderly, or disabled person.
2. Weaning: Accustom (someone) to managing without something which they have become dependent on.
3. Drug holidays: A drug holiday (sometimes also called a drug vacation, medication vacation, structured treatment interruption, tolerance break, treatment break or strategic treatment interruption) refers to a period of time when a patient stops taking medication(s); anywhere from a few days to many months or even years.

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Foreword

I was motivated to explore this topic due to my past and current experience with a family member who was diagnosed with ADHD. Most importantly, I had an interest in understanding the challenges parents encounter and their reasoning for discontinuation of medication, and their perceptions around mental health and medication use. I personally feel that the use of medication for the treatment of ADHD symptoms or any neuropsychological disorder is a treatment method that is worth pursuing in order to improve a child's lived experience. My view will always be to do what is best for the child, regardless of the method used.

Conducting research within the context of Covid-19 and making provision for my safety and that of the participants has been a new experience. Participants were warm and quick to open up about their experiences around discontinuing their child's ADHD medication and the reasoning behind their decisions. Participants shared both good and bad encounters with the side effects of the medication which was the leading reason for discontinuation. All participants emphasised how they wanted to help their child reach their true potential, even if that required more effort from the caregiver themselves, which stemmed from a place of love for their child. Information communicated to me during the interviews made me respect the parents for opening up and sharing their experiences, which required them to relive some experiences that may have been very challenging for them. I acknowledge their will to persevere through those trying times to provide a better lived experience for their children. The sense of love, deep motherly bond and adoration for their children were evident in each and every interview.

My thoughts around medication use for the treatment of ADHD medication have not changed; I still believe that parents should use the treatment method that they feel best suits their

child. Through this study, I was able to acquire knowledge on how to better assist parents to move forward and manage their perceived challenges.

What I learnt about myself during this process was that I was able to separate my personal feelings and prevent it from influencing the manner in which I built rapport with the participants.

Outline of thesis

Chapter One: Introduction

This chapter provides the background of ADHD by looking at ADHD as a psychiatric disorder, medication used to treat ADHD and the impact of ADHD on family functioning. The rationale of the study identifies the gap in needing to explore caregiver's experiences of weaning their children from ADHD medication. This study will allow researchers to contribute towards the awareness and understanding of the impact of the discontinuation of ADHD medication on family functioning; the experiences caregivers encounter after the discontinuation of ADHD medication and the strategies caregivers use to manage the child's difficulties after the discontinuation of ADHD medication.

Chapter Two: Literature review

This chapter presents a review of literature relevant to this study. The literature review focuses on ADHD medication and drug holidays, negative responses from family and public, conflict and stress within the family, family as a support system and speaks to Bowen family systems theory which conceptualises the study.

Chapter Three: Methodology

This chapter will provide an outline of the methodological approach employed in the study. It will present a brief overview of qualitative methodologies. Proceeding this, the research design, research context, participants and sampling, data collection techniques, the procedure that was followed, and data analysis methods will be discussed. Lastly, the ethical considerations will be provided.

Chapter Four: Results

This chapter reports on the results of the study and discusses the findings of this study relative to the research questions set out in Chapter One. The research findings were identified through thematic analysis, where themes were identified through the analysis of the transcripts formulated in the research process. Below is a table summarising the demographic information of all the caregivers who participated in the study. This chapter examined the data collected through the interviews employed for the study. The Atlas Ti. Software was used to analyse and code the results collected. The results of this chapter will be further interpreted in order to address the objectives of the study.

Chapter Five: Discussion

This chapter provides a detailed analysis and interpretation of the experiences of caregivers who have discontinued their child's ADHD medication. Specific focus was placed on the caregivers' reasoning for discontinuation, the impact of discontinuation and caregivers' experiences after discontinuation and how they managed these perceived challenges. Eight sub-themes were identified which will be reported on in this chapter.

Chapter Six: Limitations, recommendations and conclusion

This chapter reported on the limitations, recommendations and conclusion of the study. The limitations reported on the characteristics of the study that impacted or influenced the interpretation of the research. The recommendations proposed areas for future research, areas for intervention and provide policy and practice suggestions, and the conclusion provided an overall summation of the dissertation.

Chapter One: Introduction

This chapter outlines the background of ADHD, the problem statement and the rationale of the study. The background touches on ADHD as a psychiatric disorder, medication used to treat ADHD and the impact of ADHD on family functioning.

Background and Rationale

Attention-deficit/hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterised by levels of inattention and/or increased hyperactivity/impulsivity (Boland et al., 2021). ADHD affects pre-schoolers, children, adolescents, and adults around the world (Boland et al., 2021). According to Boland et al. (2021), ADHD affects up to 5 to 8 per cent of pre-school children. ADHD is commonly associated with comorbid disorders (Boland et al., 2021) and is more commonly diagnosed in males as compared to females (Mowlem et al., 2019). Comorbid disorders refer to when an individual has more than one disorder (Jang et al., 2013). For example, if a person is diagnosed with both ADHD and autism spectrum disorder (ASD), these two disorders are seen as co-existing disorders. Autism Spectrum Disorder (ASD), Oppositional Defiant Disorder (ODD) and General Anxiety Disorder (GAD) are examples of conditions that are commonly comorbid with ADHD (American Psychiatric Association, 2013). The most common criteria characterised by ADHD are persistent impulsivity, pervasive inattention, and disruptive behaviour (American Psychiatric Association, 2013).

ADHD can result in a poor quality of life, increased risk taking, lower school performance and lower self-esteem (Toomey et al., 2012). Although medications have been widely used as an effective treatment for children, adolescents, and adults, psychopharmacotherapy is inadequate as a sole intervention for ADHD (Chronis et al., 2006; Sprich et al., 2015; Wilens et al., 2006). On average, stimulant medication has shown to lower the symptoms of ADHD when used in

conjunction with behavioural therapy (Toomey et al., 2012).

For many years, the most common drugs used to treat ADHD were stimulant medications like methylphenidate, dextroamphetamine, and mixed amphetamine salts (Vereb & DiPerna, 2004). These stimulants reduced the impulsivity, inattention and overactivity of patients with ADHD (Faraone et al., 2006). Despite the benefits of medication, many caregivers are hesitant when it comes to starting ADHD medication and commonly discontinue treatment soon after (Toomey et al., 2012). Many non-stimulant medications have shown to be efficient, while stimulants have been the foundation and chief support for ADHD pharmacotherapy (Faraone et al., 2006). Non-stimulants include tricyclic antidepressants (TCAs) and bupropion (Faraone et al., 2006).

On a global scale, studies have focused on the use of ADHD medication and its side effects, and the relationship between ADHD and other disorders (Antshel et al., 2013; Castle et al., 2007; Dalsgaard et al., 2014). These quantitative studies, one of which being a long-term follow-up study; report mostly on the use of medications to treat ADHD in children and adults, and the child's relationship with the stimulant medication (Antshel et al., 2013; Castle et al., 2007; Dalsgaard et al., 2014). Some studies have focused on the discontinuation and non-adherence of ADHD medication in order to manage side effects and tolerance in children (Ahmed & Aslani, 2013; Chacko et al., 2010; Forsberg, 2018; Ibrahim & Donyai, 2015).

A study conducted in the USA found that approximately 20% of patients discontinue medication after their first prescription (Chacko et al., 2010). Another study conducted in Australia established that the rate of non-adherence ranged between 15 and 87% in children and adults (Ahmed & Aslani, 2013). The non-adherence to medication is a result of experiences of adverse effects, stigma, treatment inefficacy and family history of ADHD (Ahmed & Aslani, 2013).

Although some existing literature focuses on the discontinuation of ADHD medication and the challenges associated with it globally, there is lack of literature specifically within the South African context. Therefore, there is a need to explore caregivers' experiences of weaning their children from ADHD medication and the challenges the family environment faces within this context.

Families are the most fundamental units in all communities (DeFrain et al., 2009). The family environment is important since it is the child's first intimate environment in which they are exposed to affection, socialising and teachings (DeFrain et al., 2009). The health of the caregiver-child relationship determines the family's resilience which leads to healthy family functioning (Walsh, 2003). Child ADHD may have a negative or positive impact on the affected family's mental wellbeing, functioning and caregiving styles (Harpin, 2005; Peasgood et al., 2021). Children with ADHD symptoms may take significant strain, especially when not treated (Currie & Stabile, 2006). Consequently, there are far-reaching negative results on child development (Currie & Stabile, 2006). Given the demonstrated lack of studies concentrating on the weaning of ADHD medication and the impact it has on caregiving behaviours or family functioning, the purpose of this research study was to explore caregivers' experiences of weaning their children from ADHD medication and the impact of the discontinuation of medication on the family functioning.

Medications for ADHD have been widely used as an effective treatment for many years in children, adolescents and adults (Raman et al., 2018). Understanding caregivers' first-hand experience of the discontinuation of ADHD medication is important to create understanding and awareness within the broader community. This research contributes to the awareness and understanding of the impact of the discontinuation of ADHD medication on family functioning;

the experiences caregivers encounter after the discontinuation of ADHD medication and the strategies caregivers use to manage the child's difficulties after the discontinuation of ADHD medication. The knowledge, information and insight gained through this research may be used to inform community-based interventions which are essential to public health provision in South Africa.

Aim and Objectives

The aim of this research project is to explore caregivers' experiences of weaning their children from ADHD medication. The objectives of this study are as follows:

- To explore the reasons for discontinuing ADHD medication
- To explore the perceptions of the impact of the discontinuation of ADHD medication on family functioning
- To explore the experiences caregivers encounter after the discontinuation of ADHD medication
- To explore the strategies caregivers use to manage the child's perceived challenges after the discontinuation of ADHD medication

Research Questions

1. What are the reasons for discontinuing ADHD medication?
2. What are the perceptions of the impact of the discontinuation of ADHD medication on family functioning?
3. What are the experiences caregivers encountered after the discontinuation of ADHD medication?
4. What are the strategies caregivers use to manage the child's perceived challenges after the discontinuation of ADHD medication?

Chapter Summary

In this chapter, the background of ADHD was discussed by looking at ADHD as a psychiatric disorder, medication used to treat ADHD, and the impact of ADHD on family functioning. The rationale of the study identified the gap in needing to explore caregivers' experiences of weaning their children from ADHD medication. This study will allow researchers to contribute towards the awareness and understanding of the impact of the discontinuation of ADHD medication on family functioning; the experiences caregivers encounter after the discontinuation of ADHD medication; and the strategies caregivers use to manage any difficulty experienced by the child after the discontinuation of ADHD medication.

Chapter Two: Literature Review

This chapter presents a review of literature relevant to this study. The literature review focuses on ADHD medication and drug holidays; negative responses from family and public conflict; and stress within the family; and family as a support system and speaks to the theoretical framework that conceptualises the study in relation to Bowen family systems theory.

ADHD Medication and Drug Holidays

Multiple components are involved when treating ADHD, these include educational, medical and behavioural interventions (Ibrahim & Donyai, 2018). It is recommended that medication is effective and safe to use as a first-line treatment for the symptoms of ADHD (Charach & Fernandez, 2013). This is especially true for school-aged children and young adults who have severe symptoms and impairment (Ibrahim & Donyai, 2018; NICE, 2013). Many studies have shown that both stimulants and non-stimulant medications are most effective in mitigating ADHD symptoms and further improving the academic functioning of children who receive treatment (Hechtman et al., 2004; Wilson et al., 2006). However, there has been a debate around the side effects of ADHD medication. According to a multisite study, there is no long-term advantage of using medication beyond two years (Molina et al. 2009).

Furthermore, the presentation of short-term effects, such as insomnia and suppression of appetite, has raised legitimate concerns for families (Faraone et al., 2008). Many caregivers and children choose to discontinue treatment for various reasons. Usually, healthcare decisions are made by the caregiver when a child is younger than eighteen years old. Older youth have different attitudes and beliefs and tend to make their own decisions (Charach & Fernandez, 2013). A study by Toomey et al. (2012), found that many children often cease ADHD medication within the first year of use, due to the medication itself being ineffective, and because of psychological side effects

such as depression, irritability, mood changes, and personality changes. Studies show that there are associations between discontinuation of ADHD medication and caregiver attitudes about ADHD (Toomey et al., 2012). Caregivers frequently perceived that medication side effects influenced discontinuation of ADHD medication as well as the lack of medication effectiveness. As a result, caregivers of children who discontinued medication were more likely to report that ADHD medication was not effective (Toomey et al., 2012). Toomey et al. (2012) state that in order to ameliorate these side effects, children and caregivers should set realistic medication goals and improve the way they manage the psychological side effects.

Some caregivers tend to allow medication breaks which are mostly done during school holidays, these are commonly referred to as "drug holidays" (Dosreis et al., 2003; Howland 2009; Wilens et al., 2005). Drug holidays are purposeful discontinuation of pharmacotherapy for a set period of time (Wilens et al., 2005). Studies show that between 25-70% of families follow the school-time medication pattern (Ibrahim & Donyai 2015). There are various factors that affect the choice caregivers make to continue medication or follow the drug holiday pattern. These factors include child or adolescent academic progress, severity of the child's symptoms, the caregiver's beliefs with regards to medication, and the caregiver's ability to cope with the child's behaviour (Kinda et al., 2016). There are four identified benefits from implementing drug holidays (Ibrahim & Donyai, 2015). These benefits include managing drug tolerance, medication continuation or discontinuation, managing and preventing medication side effects, and assessing the need for medication (Ibrahim & Donyai, 2015).

Furthermore, there are unplanned factors associated with discontinuing ADHD medication, due to various child, family, and health system factors (Ji et al., 2018). As a result of the increased prevalence of ADHD there has been a corresponding increase in the cost of medication (Munasur-

Naidoo & Truter, 2019). According to Schoeman and de Klerk (2017), the healthcare costs of medical scheme beneficiaries doubled due to ADHD prevalence. However, studies focusing on the access and utilisation of ADHD medication in South Africa are limited (Munasur-Naidoo & Truter, 2019). ADHD can be costly on the quality of life of patients and their families (Schoeman & de Klerk, 2017). Additionally, unplanned medication breaks can lead to challenges for the caregivers to monitor the efficacy of the medication or the need for a dose adjustment (Adler, 2010; Ahmed & Aslani, 2013). Whether discontinuations are planned or unplanned, the symptoms associated with ADHD may return once the discontinuation is implemented (Howland, 2010).

Negative Responses from Family and Public

Children diagnosed with ADHD as a neurocognitive disorder are often judged and stigmatised by peers and those around them (Chang et al., 2021). It is common for these children to be stigmatised and judged by their own family members for their behaviour due to the symptoms associated with the behaviour (Chang et al., 2021). ADHD symptoms are frequently attributed to the afflicted children's lack of self-control or deliberate objections to instructions, and misunderstanding of ADHD increases social rejection and hostile sentiments among peers, teachers, family members, and neighbours (Paulson et al., 2005). According to Bussing et al. (2010), children that are unwilling to undergo treatment are linked to a high amount of public stigma associated with ADHD. Therefore, children with ADHD may internalise the stigma from family members and cause them to develop self-stigma, which further affects their self-esteem, and how they regulate their emotions (Kellison et al., 2010; McKeague et al., 2015).

Stigmatisation can affect treatment adherence in patients (Harpur et al., 2008; Mueller et al., 2012). Parents and caregivers often experience “associated stigma” when their children are affected by the outward judgement of family members and society (Nguyen & Hinshaw, 2020).

In a study conducted by Mcleod et al. (2007), it was found that public knowledge on ADHD was limited and that close to 80% of participants believed that ADHD was not a real disorder. This is based on a lack of knowledge or a distorted perception of ADHD and other disorders (Cheesman, 2019). It was also found that parents or caregivers who choose to use medication as a treatment method to ease ADHD symptoms also experience stigma for their choice of treatment method (Nguyen & Hinshaw, 2020).

Oftentimes parents who are particularly closely related to children with ADHD display a sense of duty to seek treatment and in return receive criticism and judgement for their decisions (Nguyen & Hinshaw, 2020). Fighting a crossfire of blame, self-criticism, and stigmatisation are obstacles parents of children with ADHD describe as a result of living with children with ADHD (Laugesen et al., 2016; Song et al., 2018). Many parents are concerned not only about how society labels, isolates, and rejects their children, but also about the impact of diagnosis on, and treatment of their children's self-esteem and future potential (Dosreis et al., 2010). The desire of parents and children to use community health services is also negatively associated with parental stigma (Koro-Ljungberg & Bussing, 2009). Globally, it is viewed as bad parenting when society witnesses a child's uncontrolled behaviour which in essence stems from ADHD symptoms (Rodrigo et al., 2011).

There is a rich diversity of cultures in the South African context (Truter et al., 2018). Intercultural differences are present in terms of the structure and frequency of ADHD-like behaviour (Meyer et al., 2004). It is imperative to note that these intercultural differences and cultural backgrounds can influence and perpetuate the stigmatisation of ADHD (Mueller et al., 2012). For instance, it has been reported that South Africans are not open to discussing or acknowledging mental disorders in general (Bosire et al., 2021). Within this context, a child's

uncontrollable behaviour can be negatively labelled by the society as “naughty” /or “uneducated”, without taking into consideration the disorder itself (Dosreis et al., 2010). This is an indication of society’s lack of knowledge around mental disorders, which ultimately affects the children and parents who directly deal with mental disorders on a daily basis (Adshead et al., 2015; Crisp et al., 2000). Therefore, stigmatisation of ADHD is influenced by one's cultural background (Mueller et al., 2012). Even though various cultures may have different perceptions and interpretations of the behaviour, they discriminate between different kinds of behaviour patterns presented by a disorder such as ADHD (Meyer et al., 2004).

Conflict and Stress Within the Family

Parents of children with ADHD face several difficulties in their parental responsibilities (Wells et al., 2000; Wiener et al., 2016). Children with ADHD experience functional impairments which persist across different domains, such as peer relationships and academic performance (Wiener et al., 2016). Mothers alone make up the majority of the samples in studies on parental stress with regard to parents of children with ADHD (Theule et al., 2013). It was established that the problematic behaviours of their children caused higher stress for parents of children with ADHD than for parents of children without ADHD (Edwards et al., 2001; Theule et al., 2013; Wells et al., 2000; Wiener et al., 2016). The relationship with their children, role limitations, social alienation, arguments with partners, feelings of guilt and ineptitude, and the relationship with their children were all sources of significant stress for mothers of children with ADHD (Theule et al., 2013; Wiener et al., 2016).

In comparison to their peers, children with ADHD are less obedient to their parents’ instructions and only comply for short periods of time and are less likely to stay focused (Wells et al., 2000). Children and adolescents with ADHD frequently experience conflict and

disharmony in their families in addition to impaired parent-child interactions. Additionally, mothers of female children with ADHD experience extremely high levels of parenting stress in the parent domain (Theule et al., 2013; Wiener et al., 2016). These mothers reported that they frequently had trouble sleeping, devoted their entire lives to raising their daughters, were socially isolated and had diseases related to stress (Theule et al., 2013; Wiener et al., 2016). Coupled with their children's behaviours, these interpersonal issues may contribute to parents feeling as though they lack the physical, financial, and emotional resources to handle the demands of parenting (Theule et al., 2013; Wiener et al., 2016). In addition to child externalising and internalising issues, mother depressive symptoms and poor marital quality are also predictors of stress in parents of ADHD-affected children (Theule et al., 2013).

Furthermore, low levels of social support and maternal ADHD symptoms are related to parenting stress in the parent domain (Theule et al. 2011). According to Wells et al. (2000), both medication and behaviour interventions may be useful in easing the strain on families caused by issues like parenting stress, maternal depression, and marital conflict.

Family As a Support System

The wellbeing of the child has an impact on overall family functioning. The family burden associated with ADHD consists of different challenges experienced by family members as a result of an individual's condition (Sikirica et al., 2015). These challenges range from the different costs involved for medication, time missed at work and intangible costs such as marital tension (Zhao et al., 2019). Therefore, children with ADHD have needs that require an approach that is multimodal (Laugesen et al., 2016). According to Carol Ho et al. (2011), parents need extra support when raising a child with ADHD. Parents have to juggle between maintaining a good family life, while learning how to manage their child's behaviour successfully (Carol Ho et

al., 2011). Therefore, parents require intensive support from family members and those close to them in order to help their child in the best possible way (Moen et al., 2011; Dennis et al., 2008). Help from family members, friends and teachers to take care of the child in different domains of the child's life is of great importance, not only to the child but to the parents as well (Finzi-Dottan et al., 2011). When family members take up roles to collect the child from school or schedule a playdate, it helps relieve time and the workload from parents (Pfiffner et al., 2007).

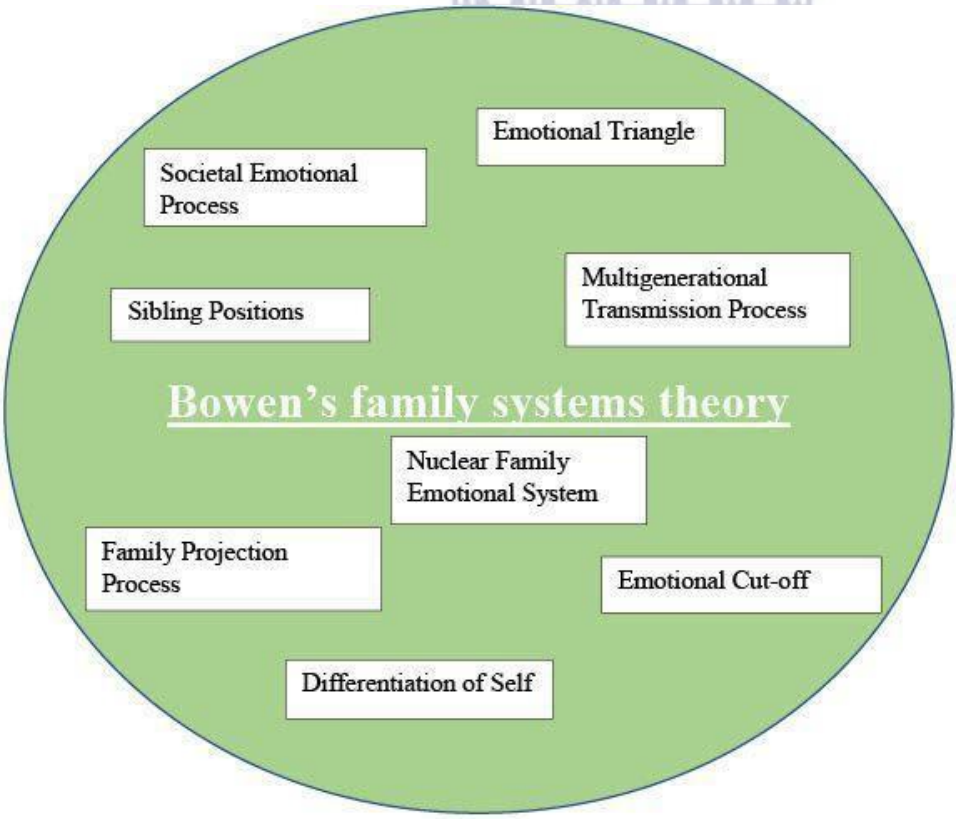
Theoretical Framework

The theoretical lens through which this study will be viewed is Bowen family systems theory. This theory sees the family as an emotional unit with strong interdependence between family members and emotional change (Bowen, 1985). Bowen family systems theory focuses on the big-picture patterns of a system rather than the narrower view of what causes difficulties for one individual, thereby allowing one to view the world through the lens of each family member (Bowen, 1978; Brown, 1999; Haefner, 2014; Wilson, 2021). According to Bowen family systems theory, individuals cannot be understood in isolation from other family members, but should be seen in the context of their family (Brown, 1999). Bowen family systems theory has been used to address cultural and gender differences within the family (Garrett-Peters et al. 2011; Riina & McHale, 2015). Bowen family systems theory has also been used as a theoretical framework in studies related to ADHD and family functioning, and ADHD and treatment (Aman, 2000; Baxter, 2013; Macaluso, 1995; Wilson, 2021).

For this particular study, Bowen family systems theory focuses on how the wellbeing of children may impact sibling behaviour, caregiving stress, and family functioning, in general. In this case, human behaviour is examined using the family system as a unit of study instead of the individual caregiver or child. Therefore, the entire family is viewed as an emotional entity with

strong connections and relationships between family members (Wilson, 2021). Cultural differences within families have also been addressed using Bowen family systems theory. South Africa is rich in diversity and has a unique culture. Therefore, this study would be instrumental to the South African context, as it will provide in depth understanding and produce interventions that are more applicable and suitable to the culture within South Africa. Dysfunction in family functioning is a result of stressors that are caused by tension which affects the emotional connection between family members. Mohammadi et al. (2012) state that a child with a medical or psychological disorder can increase stress in a family, which is particularly relevant in the context of ADHD diagnosis.

Figure 1. Bowen family systems theory.



Bowen's eight concepts are Differentiation of Self, Emotional Triangle, Nuclear Family Emotional System, Family Projection Process, Emotional Cut-off, Multigenerational Transmission Process, Sibling Positions, and Societal Emotional Process (Bowen, 1978). Differentiation of Self refers to an individual's ability to function independently by making their own decisions, while remaining emotionally attached and connected to a significant relationship system (Brown, 1999; Haefner, 2014). An individual can achieve "complete differentiation" if they have settled any emotional attachment to their family, then only can they function as an individual within the family system (Brown, 1999; Haefner, 2014). Bowen emphasises that it is impossible to attain total differentiation (Brown, 1999; Haefner, 2014). A child who presents with ADHD may grow up and decide to terminate the ADHD treatment their parents or caregivers have provided for them over the years. They may choose an alternative method that works for them or discontinue treatment completely.

Emotional Triangle refers to when a third party becomes involved. When anxiety develops in a dyad the third party's role either involves taking sides or providing a detour for the anxiety (Brown, 1999; Haefner, 2014). Apart from their mother or father, a child who presents with ADHD may seek comfort and support from their siblings, a close relative or peer in order to ease their anxiety.

Nuclear Family Emotional System refers to the impact of "undifferentiation" on the emotional functioning of a single generation family (Brown, 1999; Haefner, 2014). Bowen puts forward that relationship fusion can lead to triangling which fuels symptom formation and can manifest in one of the following three categories: conflict, illness in a spouse, and projection of a problem onto one or more children. Conflict may arise between the child who presents with ADHD and their siblings as the siblings may find their uncontrolled unmedicated behaviour disruptive.

Family Projection Process refers to how children inherit negative behaviour based on previous generation's anxiety about relationships (Brown, 1999; Haefner, 2014). The most vulnerable to inherit this behaviour or developing symptoms is a child with the least emotional separation from his/her parents (Brown, 1999; Haefner, 2014). This commonly occurs when a child anxiously responds to the tensions that rose within the parents' relationship, sequentially mistaken as a problem in the child (Brown, 1999; Haefner, 2014). This results in a detouring triangle, as the attention is shifted to the child and not the original problem between the parents (Brown, 1999; Haefner, 2014). When tension arises between parents or caregivers within a household, the child who presents with ADHD may place blame on him/herself as the reason for the disagreement or tension.

Emotional Cut-off refers to the manner in which people have control over the integration and merging of generations (Brown, 1999; Haefner, 2014). Bowen states that a "cut-off" is achieved through emotional withdrawal or physical distance (Brown, 1999; Haefner, 2014). However, the current family group can experience intense emotional pressure when Emotional Cut-offs occur resulting in no effective escape (Brown, 1999; Haefner, 2014). Furthermore, triangling comes into play as it provides a detour for family members to seek support from others for their own position in relation to the cut-off (Brown, 1999; Haefner, 2014). Caregivers and parents have the agency to stop or continue generational beliefs regarding ADHD and mental health disorders that have been passed down from previous generations.

Multigenerational Transmission Process refers to the different themes, patterns and roles within a triangle that is passed down from generation to generation, from parent to child (Brown, 1999; Haefner, 2014). Notably, each child will be impacted differently depending on the extent of triangling they have with their parents. Due to the potential hereditary nature of ADHD, caregivers

may hold their own personal experience of the diagnosis that shapes their receptivity or resistance towards the diagnosis and the preferred course of management.

Sibling Positions refers to the different roles individuals take upon themselves based on the relationships they find themselves in (Brown, 1999; Haefner, 2014). For example, the eldest child tends to take the role of leader, while the younger sibling is more content with being dependent (Brown, 1999; Haefner, 2014). However, this could vary from family to family or generation to generation. Older siblings who have younger siblings who present with ADHD may take on the role of the third parent in these households, by taking responsibility for their sibling's adherence to treatment.

Lastly, Societal Emotional Process refers to an extension of triangles beyond that of the immediate family domain (Brown, 1999; Haefner, 2014). Societal Emotional Process goes beyond the family to everyday life, which includes when individuals within a family operate at an emotional level with individuals outside of their family group (Brown, 1999; Haefner, 2014). Close family friends, peers, colleagues, teachers in the school system and support group members may act as support systems for families who have children who present with ADHD.

Chapter Summary

This chapter outlined the literature review of this study. The literature review spoke to ADHD medication and drug holidays, negative responses from family and public, conflict and stress within the family and family as a support system, as well as Bowen family systems theory which was used to conceptualise the study.

Chapter Three: Methodology

This chapter will provide an outline of the methodological approach employed in the study. It will present a brief overview of qualitative methodologies. Proceeding this, the research design, research context, participants and sampling, data collection techniques, the procedure that was followed, and data analysis methods will be discussed. Lastly, the ethical considerations will be provided.

Research Design

This study utilised a qualitative methodological framework, which provided participants with a space to voice their subjective experiences (Gerring, 2017; Moriarty, 2011). This framework presented the researcher with an in-depth understanding of challenges caregivers experience when their children are weaned from ADHD medication, and the impact of discontinuation of medication on family functioning.

An exploratory research design was used as this study aimed to explore caregivers' experiences of weaning their children from ADHD medication (Stebbins, 2001). This design was appropriate, as limited qualitative literature explores the topic within the South African context, and therefore it is important to describe and understand the phenomenon from the participants' subjective perspective, as it is a developing area in health science.

Research Context

This research was conducted within the Cape Town metropolitan area, situated within the Western Cape. The Cape Town metro alone has a population of over four million people (Lehohla, 2015). It is unknown what the specific lifetime prevalence of ADHD is in South Africa (Schoeman & Liebenberg, 2017). A study conducted by Stein et al. (2009), looked at the prevalence of mental health disorders as well as treatment access and use. Findings were classified as substance use

disorders (SUD), mood disorders and anxiety disorders, and "any other disorder", which meant that ADHD was included in the last category, with a prevalence of 30.3 per cent (Stein et al., 2009). This context was chosen as the primary context for research due to convenience, as the researcher resides in Cape Town. Participants were primarily recruited from ADHD caregiver support groups based in Cape Town, social media such as the Neurodiversity Centre monthly newsletter, as well as through snowball sampling technique. The ADHD support groups are non-profit organisations who have been assisting parents, caregivers, family members and children living with and/or affected by ADHD. The Neurodiversity Centre aims to provide support, intervention and multi-disciplinary assessment of children, adolescents and adults presenting with neurodevelopmental needs and challenges. Their purpose is to collaborate with families in order to assess the child's needs.

Participants and Sampling

A total of 10 participants were purposively selected from various suburbs in Cape Town. Selection criteria include participants as primary caregiver/s of a child that was weaned from ADHD medication. Primary caregivers were eligible to participate if their child was weaned from ADHD medication between the ages of 6 and 12 years, even if the child was now older and not currently in that specific age group. This also included caregivers who had completely discontinued medication, were in the process of discontinuation, and those who had implemented drug holidays or periods of non-medication.

The study recruited participants by means of purposive sampling, which is a non-probability sampling technique where participants are purposefully selected, based on the desired criteria (Babbie, 2013). Additionally, a snowball sampling method was employed where participants were asked to recommend a potential participant who also met the inclusion criteria

for the study (Babbie, 2013). The snowball sampling technique assisted in gaining participants, as caregivers recommended relatives and friends when asked if they knew of any additional person who fit the inclusion criteria.

Data Collection and Procedure

Upon the approval of ethical clearance from the Humanities and Social Sciences Research Ethics Committee (HSSREC) at the University of the Western Cape (Appendix 5), the participants were recruited via social media sites of ADHD support groups and awareness groups, as well as via websites of NPOs such as the Neurodiversity Centres monthly newsletter. A poster was created that was shared to the different support groups and in the Neurodiversity Centres monthly newsletter (see Appendix 4). Potential participants would either call or text the number on the poster. The researcher would proceed to introduce herself and the study. If they were interested in participating after the introduction, an information letter and consent form were forwarded to them via WhatsApp or email, depending on their preference.

At the time of the conceptualisation of the study and the commencement of data collection, South Africa had been experiencing a National State of Disaster, due to the Covid-19 pandemic, which led to the implementation of restrictions, such as the limit on social contact (Hasan & Bao, 2020; World Health Organisation, 2020). As a result, data were collected through semi-structured individual interviews which were conducted via online video platforms, including WhatsApp video call and Google Meet. These platforms are reliable, cost-effective and efficient, and allowed this research study to gain in-depth data from participants. One of the 10 participants had the option to partake in a telephonic interview, due to the online video platforms not being accessible to her. The interviews were all conducted in English. Provision would have been made in the event that

participants requested a different language. However, none of the participants requested to be interviewed in any other language besides English.

Prior to the interview, an Information Sheet (Appendix 1) and Consent Form (Appendix 2) were forwarded to the potential participants via WhatsApp or email. The Information Sheet (Appendix 1) outlined details of the research, the aims and objectives, the data collection process and how information would be disseminated and protected. The consent form (Appendix 2) provided the researcher with permission to use the information shared during the interview. Participants were informed that all information shared was confidential and would be kept private. After participants had shown interest in the study, the researcher communicated via WhatsApp to suggest a date and time for a phone call to take place. During this telephonic conversation, further details of the study were communicated. The potential participant had an opportunity to ask questions, and verbal informed consent was obtained. Participants were informed of their rights during the research process, such as having the freedom to withdraw at any time, should they wish to, with no negative consequences. When an individual agreed to participate in the study, they were asked to sign the consent form, either physically or electronically, and send it to the researcher directly. Thereafter, the researcher confirmed the date and time to conduct the interview via WhatsApp or Google Meet, and participants were provided with the relevant meeting invitation link.

Interview questions centred around the participants' experiences of weaning their children from ADHD medication. The discussion guide (Appendix 3) was composed of two sections. Section A: Participant's basic information, such as name and contact details. Section B: Open-ended questions that were formulated through literature and guided by the study's research questions. Once consent was obtained from the participants, each interview took approximately 30 to 45 minutes to complete. The sessions were audio-recorded, transcribed and stored on a

password protected computer. The researcher made brief notes during the interview. These reflective notes played a crucial role in informing the researcher's new gained knowledge and apprising the findings of the study.

Data Analysis

Thematic analysis, as developed by Braun and Clarke (2006; 2013; 2019), was used to analyse information gathered during the interviews. Thematic analysis involves acknowledging the specific themes that were identified in the data collected, and proceeding to analyse those themes. A theme, in this instance, is created by acknowledging a pattern within the participants' responses (Braun & Clarke, 2006). Firstly, the researcher familiarised herself with the data collected by transcribing the interviews, then the researcher proceeded with reading each transcript and making notes. This was followed by step two and step three, where codes were recognised and possible themes were investigated. This was a long and continuous process where reoccurring themes were coded using Atlas Ti. Software. As themes were investigated, codes shifted based on the different elements found in the data. The fourth step involved reviewing the identified themes by checking whether each theme was a true reflection of the data collected and checking for any missing themes that may have been overlooked. Step five involved naming and defining these themes based on the core information that it represented and ensuring that it was aligned to answering the research questions of the study. Step six involved producing the report where examples of extracts were utilised to explain the themes (Braun & Clarke, 2006). Atlas Ti. Software was used to extract the relevant sections to assist in explaining and interpreting the themes. Thematic analysis is valued as having the potential to produce detailed information (Braun & Clarke, 2019), which was appropriate in this qualitative study that involved in-depth

explanations of caregivers' experiences with regard to weaning their children from ADHD medication.

Reflexivity

Reflexivity refers to the act of a researcher examining the influence that their own beliefs and thoughts have on the collection and interpretation of the data (Babbie, 2013). As the lead researcher for this study, the researcher acknowledged that she may be perceived as an 'outsider' to participants, as she is a young woman, who does not have children, nor does she have first-hand experience of dealing with children diagnosed with ADHD. Therefore, certain methods, such as personal reflection, were employed regularly throughout the research process, to ensure that her bias and possible misinterpretations did not hinder the study in any way. Areas for reflection included the researcher's attitudes towards ADHD as a diagnosis, medication as a treatment choice, and the challenges of parenting and decision making in sociocultural contexts. Some of these factors are explored at the outset of the thesis, in the Foreword.

Trustworthiness

The researcher aimed to produce quality information by ensuring that all the information was relevant and unbiased within this qualitative study. Trustworthiness is characterised by four main concepts, namely credibility, dependability, transferability and confirmability (Lincolin & Guba, 1985).

Credibility, which refers to the truthfulness of the data, was achieved when the data were confirmed with participants during and after the interview (Pandey & Patnaik, 2014). This was achieved through reaffirming a participant's responses during and after the interview, which ensured that the researcher understood what the participant intended to say.

Dependability, which relies on how consistent the data remain over similar conditions (Pandey & Patnaik, 2014), was achieved through supervision and evaluation of the quality of data collection and analysis.

Confirmability refers to ensuring that the data signifies the responses given by the participants (Pandey & Patnaik, 2014). This was achieved through conducting an audit trail, by meticulously detailing the data collection, data analysis and data interpretation process. This ensured that the results of the study were a true reflection of the participants' responses and not the researcher's own biases and preconceptions.

Finally, transferability refers to findings that would be related to other groups; this was ensured by providing a detailed description of the final results, as seen in Chapter Four (Pandey & Patnaik, 2014).

Ethics

This study followed the ethics guidelines as specified by the Humanities and Social Sciences Research Ethics Committee (HSSREC) at the University of the Western Cape (UWC). Institutional permission was obtained from the organisations that assisted with the recruiting of participants. Participants were informed of their rights during the research process, such as having the freedom to withdraw at any time, should they wish to, with no negative consequences. All information collected was held private and processed by following the Protection of Personal Information Act (Staunton et al., 2020). Additionally, permission was obtained from participants to audio record the interview sessions.

Participants were informed that all information shared was confidential and will be held private. Anonymity was ensured in the reporting of findings by replacing participant names with pseudonyms. Upon completion of an interview, each participant was debriefed to ensure that she was still feeling emotionally well, contained and calm.

Fortunately, none of the participants expressed distress as a result of the research, and did not request the need for psychological services, although psychological services were available within the UWC psychology department.

Audio recordings and transcriptions were safeguarded in a secure folder on an electronic device that was password-protected, to which only the researcher and supervisors had access. All digital files and hard copy files will be discarded after five years and the 'Recycle Bin' folder will be emptied to ensure that they cannot be traced. Any hard copies of interview notes and transcriptions will be shredded and destroyed.

Chapter Summary

This chapter reported on the methodology of the study. It outlined the research design, research context, participants and sampling, data collection and procedure, and data analysis. In addition, reflexivity, trustworthiness, and ethical processes were outlined where the knowledge, information and insight gained through this research may be used to inform community-based interventions which are essential to public health provision in South Africa.

Chapter Four: Results

This chapter reports on the results and discusses the findings of this study relative to the research questions set out in Chapter One. The research findings were identified through thematic analysis, where themes were identified through the analysis of the transcripts and formulated in the research process. Table 1 summarises the demographic information of all the caregivers who participated in the study.

Participant Profile of Caregivers

All of the participants' interviews included maternal family members of children weaned from ADHD medication. The sample consisted of six biological mothers, three adoptive mothers, and one stepmother. The age of the participants ranged from 32 to 47 years old. Nine out of the 10 children were boys and one was a girl child. Eight of the participants identified as Coloured (an official term used in South Africa for population classification, denoting a person of mixed race), one identified as White, and one identified as Indian. Notably, caregivers were in different stages of the weaning process. Seven had completely discontinued medication and three were in the weaning off process.

Table 1: Summary Table of Demographic Information of Caregivers

#	Pseudonym	Age (in 2021)	Gender	Gender of child	Race	Caregiver	Marital status	Age of child	Stage of the weaning process
1.	Tamia	43	Female	Male	Coloured	Biological Mother	Parenting with partner	12	Completely discontinued medication
2.	Leah	36	Female	Female	Coloured	Biological Mother	Single	13	Completely discontinued medication
3.	Carla	46	Female	Male	Coloured	Adoptive Mother	Married	14	Currently in the weaning off process
4.	Simone	34	Female	Male	White	Step Mother	Married	14	Completely discontinued medication
5.	Portia	41	Female	Male	Indian	Adoptive Mother	Married	14	Currently in the weaning off process
6.	Nicole	47	Female	Male	Coloured	Biological Mother	Married	15	Completely discontinued medication
7.	Amy	32	Female	Male	Coloured	Biological Mother	Parenting with partner	16	Completely discontinued medication
8.	Shiela	37	Female	Male	Coloured	Biological Mother	Parenting with partner	11	Completely discontinued medication
9.	Nadia	42	Female	Male	Coloured	Adoptive Mother	Single	11	Currently in the weaning off process
10.	Erin	38	Female	Male	Coloured	Biological Mother	Married	14	Completely discontinued medication

Participant Journey

The children of the participants who make up the findings of this study were professionally diagnosed with ADHD between the ages of 4 and 7 years old. Most of the caregivers had similar experiences that lead to their child's ADHD diagnosis. Some caregivers discovered differences in their child's behaviour through simple at home activities. Nicole found that her son had difficulty learning how to ride a bike and constantly lost his balance. She proceeded to seek professional help, where an occupational therapist diagnosed him with low

muscle tone and ADHD. Felt et al. (2014) state that medication can be effective for the treatment of ADHD symptoms and the early identification and treatment of symptoms may improve longer-term social, educational and work outcomes. Majority of Ritalin users are children between the ages of 7 and 12 years old (Singh, 2005). This corresponds to the demographics of the children who make up the findings of the study. It was found that caregivers in this study gave their children two to three doses; one in the morning, one at lunchtime, and one late afternoon; this corresponds to the literature (Singh, 2005). At times, clinicians prefer to start children on short-acting Ritalin in order to have more control over dosing and to more effectively track drug effects (Coghill et al., 2013; Singh, 2005). Later, these children may be put on a long-acting form of methylphenidate such as Ritalin. Notably, most caregivers who attempted the use of medication to ease their child's symptoms, proceeded to switch between medications to find what worked best for them. Therefore, it was found that Ritalin worked for some and Concerta worked best for others.

A common experience for some caregivers was that their child has a very good memory, high intelligence quotient (IQ) but struggle to pay attention. This is in line with the literature since the diagnosis of ADHD is valid among children who report with an average to high IQ (American Psychiatric Association, 2013) as it indicates a pattern of behavioural, cognitive, functional, psychiatric and familial features that are consistent with the diagnosis (Antshel et al., 2007). Some caregivers discovered their child's ADHD symptoms and behaviours through their class teachers, who noticed it first. Carla expresses that:

> We didn't suspect anything. In Grade R. His teacher was a little bit worried about it because he couldn't sit still in class. He was hyper and he was always fidgeting with other children and stuff in class. So, she called us in and talked to us about it and she gave us... like a paper with a lot of questions, actually for a doctor, he already had a paediatrician so

we took it to the paediatrician and he took some tests and all that and he was diagnosed with ADHD.

According to Carla, the teachers reported that her child was hyperactive and fidgeting with things around him, and he would not listen to instructions. Similar to what has occurred here, Murray et al. (2007) indicate that there is usually an agreement between caregivers and teachers on the diagnosis of the child's ADHD. However, two of the 10 participants had a unique story to tell.

Both mothers mentioned that during their pregnancy they felt that their child was very active, strong and busy. One of the mothers compared her first pregnancy to her second and implied that she knew her second was going to be special due to the child's movement in her womb. Nicole states that: "Well, when he was inside me I felt that he was very strong and hard. I felt it when he was busy inside of me and growing up he was a busy little boy".

Furthermore, there were similarities in experiences from Carla and Nadia, as both caregivers had adopted their children and learnt that the child's biological mothers were engaging in drug use during their pregnancy. Carla states: "His birth mother was on the streets and using drugs and all that so you can just see that for the drugs that she used, obviously they affected the baby". In a similar response, Nadia explains: "When his mother gave birth, his mother was on drugs". Both Carla and Nadia allude to the fact that the mother's lifestyle choices during her pregnancy had resulted in a negative outcome for the child, who has been diagnosed with ADHD. Many of the caregivers had similar experiences and sought professional advice. The primary recommended course of action by professionals was to prescribe medication. This was the start of the journey for most caregivers.

Research Findings

The following three main themes were identified, as shown in Table 2. These themes were derived from the objectives of the study. The subsequent subthemes were identified based on participants' responses.

Table 2: Summary of themes and subthemes

Main Theme	Subthemes
4.4.1 Reasons for discontinuation of ADHD medication	4.4.1.1 Family judgement 4.4.1.2 Side effects of medication 4.4.1.3 Helping children reach their true potential or "true self"
4.4.2 Impact of discontinuation	4.4.2.1 Conflict and stress within the family 4.4.2.2 Negative responses of the public to the uncontrolled non-medicated behaviour
4.4.3 Management of challenges post-discontinuation	4.4.3.1. Family support system 4.4.3.2 Parental hard work

Reasons for Discontinuation of ADHD Medication

Family Judgement. Caregivers expressed their battles with family members who were medication hesitant. Amy explains that her family was hesitant due to addictive behaviours that run in the family. Therefore, fearing that the child may become addicted to the medication:

> My family was very against me putting him on meds in the first place because addiction runs in my family and they would say that I am giving him cocaine...so it was hectic so I had a lot to deal with initially.

Addictive behaviours are common in Amy's family, therefore they viewed ADHD medication as a threat and potentially did not want him to become dependent on the medication. In a similar situation, Erin explains that she too had experienced family members being medication hesitant: "I've seen many people who are so against the medication and even with family members I had so many arguments with them that I don't bring it up now because there's like this huge stigma attached to taking medication". Erin feels as though her family and others have developed a stigma against the use of medication to treat ADHD symptoms. This stigmatisation and family influence were some of the reasons that influenced the caregiver's decision to discontinue medication to treat their child's ADHD symptoms.

In addition to this, most caregivers noted that their child was stigmatised by their own family members and labelled as "naughty" and "lazy", when in fact they were showing symptoms of ADHD. Within family and cultural systems, especially Coloured households, as displayed by the demographics of this study, it is common for there to be an initial feeling of denial of ADHD as a real condition. Evidently, this can be found from findings in the study, where Amy expressed the following:

> Coming from a Coloured household they always used to say he is just naughty or he's lazy. And I thought, is there something wrong and a doctor supported me a lot and then I realised that this is all very normal [within ADHD].

Family members view ADHD as a diagnosis that is not real, therefore medication is not needed. Thus, family members are hesitant when it comes to the use of medication, as some may not view it as a means to treat ADHD symptoms but rather as a tool to discipline the child and ease the disruptive behaviour. Based on Amy's cultural background, her son's behaviour was seen as normative boy behaviour, although this was not the same feeling she experienced. With

the support of a doctor, she came to the realisation that the behaviour her son was presenting with, should not allude to him being labelled as lazy and naughty, instead his behaviour was normative for a child of his age presenting with ADHD symptoms.

Side-Effects of Medication. Seven out of the 10 caregivers had negative experiences with the medication they used to treat their child's ADHD symptoms. Evidence of this can be found within the findings of the study, as participants described the side effects and the medication their child has been prescribed. Nicole mentions that:

> He's only been on Ritalin. I have Bio Strath but it didn't work for him. At first it worked like a charm then all of a sudden it didn't last forever, then we noticed that his concentration was dropping a little bit and that he needed a higher dose and every time he needed a higher dose.

Nicole explains that her son's physiological tolerance became accustomed to the medication being used, as well as the dosage. This meant that she constantly needed to increase his dosage, however, constantly increasing the dosage did not seem to ameliorate the child's symptoms, which led to the discontinuation of medication and seeking alternative treatment methods.

Caregivers in this study typically report giving their children two to three medication doses a day; one in the morning, one at lunchtime, and one late afternoon. Simone mentions that her child also used Ritalin but later switched to Concerta because he needed a slower release:

> He was first on Ritalin. He would take it early. When he leaves early for school, he would take it at about six in the morning. About five years ago we had him reassessed again and then put him onto Concerta because he needed a slow release. Also, instead of us giving

him two Ritalin tablets like one in the morning and then one-half day, we swapped over to Concerta for the slow-release medication.

Caregivers voiced the many different side effects their children experienced. These vary from physical changes which are weight fluctuations, insomnia, restlessness, to emotional symptoms, such as anxiety, irritability, and lack of warmth. The loss of weight as a side effect of the medication is a common theme that caregivers mentioned. This is evident in Nicole's response: "Ritalin did however put a damper on his appetite...uhm worried that he wasn't gaining weight for a while. He was on 35 kilograms for a very, very long time". Nicole expressed concern and worry for her son as he was not gaining weight, a side effect of the medication. Similarly, Tamia's experience with Concerta was the same:

> It was quite a journey because the Concerta literally did help. It kept that focus in class but he became a totally different person. He would literally sometimes just sit on his bed and stare... but I think the worst part for us, was that he lost weight. He became a skeleton. I mean I have pictures of how he looked before and once we started the medication, but we still continued. We make sure that we give him all the foods that the doctors prescribed, that he must have before he has his medication. Every morning we made sure that he had structure.

Tamia experienced mixed feelings about the medication as it seems to have positive outcomes in terms of educational performance, however this was at the cost of her son's personality and freedom to express himself as a child.

In a similar experience with her child, Nadia explains that "When he has the tablets he just sits in the corner like he would just sit still like he doesn't go on like he normally would". Nadia too shares the same experience as Tamia as the medication affected her son in a manner

where he would isolate himself from his family and friends. While other caregivers' experiences were along the same spectrum. Erin sadly explains that:

> Because yet he had terrible side effects. He was extremely anxious. Everything made him nervous. He started sleeping with us again and we decided no. So, we stopped it and we didn't go back to Ritalin or anything, we just left it for a while.

Erin found that the medication heightened her child's anxiety to the point where he digressed back to sleeping in the same bed as his parents. It was moments like these for many of the caregivers that became the deciding factor to discontinue medication.

On the other hand, Shiela did not want her child on medication from the start of his diagnosis: "No I didn't want to put him on medication", Shiela proceeds to justify that: "From my point of view I just feel it will change the person he is, his personality will be different because he would be more calmer with the medication but I am used to him being all of over the place". Shiela explained that from the start of her child's diagnosis, she refused to have him on medication, although she feels that it may calm him, she is not willing to sacrifice her son's possible loss of personality (a side effect) for a calm child. Moreover, Leah explains that:

> Because when she was on the meditation it was almost like... you know a zombie, you sitting in your own kind of world and things like that and you become really… how can I say, really worried about your child in that state.

Leah says that she became worried about her daughter when she would find her alone and as if she was in a trance that only she could get herself out of. While Amy states that: "The thing is, he got all the negative side effects that you could possibly ever get, he got headaches, withdrawals from people, stomach aches where he couldn't even walk. It was really terrible.".

Amy's son experienced a handful of negative side effects as a result of the medication, one of the many side effects affected his ability to walk on some occasions.

After many attempts by some parents, they decided to discontinue the medication altogether. As seen by Tamia's response:

> We went on various forums; we went to research to see how other parents did it and how we can do it. We went completely cold turkey. It wasn't even a gradually taking him off the medication. It was literally with stopping the medication completely

Tamia therefore explained that after doing their own research and asking other parents in similar situations for advice, the experiences with the side effects of medication and constant changing between medications lead them to instant discontinuation. Furthermore, Erin stated that "Because I want him to eat, we moved him to 40 milligrams. It was also a mistake because he was like a complete zombie. Yeah, so and then we stopped medication completely for I think from January". As seen here, medication side effects are a great influencer as to why parents choose to discontinue medication.

Helping Children Reach their True Potential or "True Self". Caregivers chose to discontinue medication for various reasons, which they felt would allow their child to grow into their full potential. Leah reiterated: "What influenced me to discontinue the medication? I didn't want her to become dependent on the medication. I wanted her to show her true potential of what she really is". This caregiver chose to discontinue medication in order to help her child reach her true potential in a natural way. Additionally, this included avoiding the possibility that the child may become too dependent on the medication, as Leah puts forward that**,** "I didn't want my child to become addicted to the drug". Leah also mentions that their experience was that her child

presented a state of calmness after the discontinuation “Because she’s more calm now more... mature now, and that's without the medication”. Correspondingly, Carla expresses that:

> To tell you the truth, my husband and I don't want him to be on this stuff for the rest of his life. He must try to get used to being his own self, we want to see how he's gonna be his own self.

Carla explains that she and her husband wanted their son to develop into his own authentic self without being medication dependent. Therefore, they have chosen to wean him from the medication. Caregivers have stressed their concern around their child using medication and what was commonly highlighted was their concern and care for the child, and them reaching their full potential in life without having to be dependent or subjected to a drug.

It is common for caregivers to implement breaks from their child’s ADHD medication. These breaks commonly take place over school holidays, weekends and festive periods (Cortese et al., 2020, Ibrahim & Donyai, 2015; Kinda et al., 2016). This is commonly referred to as drug holidays (Cortese et al., 2020). Some caregivers were, at the time of the interviews, in the process of weaning their child’s ADHD medication. Carla states that “We will take him off it. We are trying today... actually we keep him off and he's giving me headache over headache. That's why I'm sitting in the car so it can be quiet here”. With relief in her voice, Simone states that “because he's off medication he is happier than when he is actually on the medication”. Carla makes the comparison and suggests that her son presents as his authentic and happy self on days that he is not on medication. Tamia explains that her son’s diagnoses has strengthened the bond she has with him:

> I think if anything it probably brought us closer to him, closer to understanding him. Closer to what his makeup is. I mean he would get...sometimes he would sit and focus on

> talking...he was into cars and puzzles. And by the time he was three years old, he could do hundred-piece puzzles and literally just sit here on the mat. And he will build those puzzles for hours. There's things that he would do that would just fascinate you because you just could not believe that a 2-year-old is able to do this or 3-year-old that's able to do this. So, we always see a lot of potential in him, so I think it's always brought us closer. And not distant from him or anything like that.

Tamia reflects on her son's diagnosis and how the different activities they did together from a young age has brought them closer and allowed her to better understand his mannerisms. She has always been amazed at how advanced he was for his age and she always believed that he had great potential.

Furthermore, Simone mentions that weaning her son off medication was the best decision for him as it brought out his personality and he was a joy to interact with:

> Well, I do feel like the discontinuation brought his personality out. It was nice for us to be able to interact like that.".

In a similar fashion, Nicole states that she feels her son has matured and has found his own independence: "And I can depend on him now that's why I constantly hammer him to bring me this, do this."

Impact of Discontinuation

Conflict and Stress Within the Family. Having a child with any neurodevelopmental disorder does not come easy for the caregivers and the functioning of the household (Maridal et al., 2021). At times, the hyperactivity of one's siblings can come across as frustrating when it occurs at unwanted times. Nicole explains their family dynamics and how the weaning off of the medication has impacted the family:

> It does frustrate the brothers, his 17-year-old brother because he does talk loud and he does weird stuff so there is some frustration. They always tell him that he must keep quiet or that he is talking too much. In that sense definitely, I wouldn't say it disturbs the family but we got to know him in that way.

Nicole's son becomes talkative and hyperactive when he is not on medication and his behaviour tends to frustrate his brothers, especially his older brother. However, for the most part they have become accustomed to this behaviour.

While Nadia explained that in her experience the family had a difficult time in trying to understand her son's behaviour: "They can't really handle him...he's busy, he's up and down, up and down...".

On the other hand, Shiela expresses that her son and his siblings tend to argue a lot since they are very much different and this would create some tension in the family:

> Well, it is disruptive for any family because, you are not dealing with a normal child because before him I had another son that is 15 years old and that was... they are nothing alike but okay no children are alike but he was very different from him. So, it comes to a point where him and his baby brother will argue a lot about things because he is very difficult to understand, he is a very uhm... in touch with his emotions, he is not scared to

say that you are hurting my feelings and I feel that you this and that, he is that type of child.

Shiela expresses that she experienced different challenges when raising her children as they are all different individuals. However, it seems there is always tension between her son and his baby brother and this affects the family dynamics. Carla goes on to explain that she is quite stressed when her son is not on medication and how it affects the family dynamics: I'm stressed out when he is not on medication. Believe me, as I told you earlier, I have a headache already. That's why I told him now I'm gonna be on the phone. Its work related…He's a very busy baby. You can trust me, but otherwise he stresses us out.

Although he is currently in the weaning process (at the time of the interview), Carla seems to feel anxious when her son is not on medication due to his hyperactive tendencies. Moreover, Portia explains her experience with her child being off medication and how it influences the family dynamics: “He becomes a nightmare to be around... To the point where I just tell him to please just shut up and go to your room and then he starts kicking and screaming...”. Haydicky et al. (2015) confirm that children with ADHD tend to experience emotional and behavioural difficulties, which often contribute towards stress and conflict in their family relationships, which commonly occurred in the lives of those caregivers who have been interviewed.

Negative Responses of the Public to the Uncontrolled Non-Medicated Behaviour. Caregivers experienced medication stigma from different aspects in their lives, these included stigmatisation from family, close friends and their children's peers. Outsiders tend to label children with ADHD as busy, lazy or naughty. Tamia says that: “People would just think this

child is busy or naughty, whatever the case might be ". However, what they failed to understand was that what they were experiencing was a child who presented with ADHD symptoms.

Carla explains that: “Like this year, at the beginning, he was actually bullied by a boy in his class, but he immediately came to tell us”. Carla expressed how her son was bullied due to his diagnosis by one of his classmates. Unfortunately, children who have unique differences tend to become easy targets for their classmates (Arseneault, 2018). However, the fact that he was able to share this information with his mother highlights the bond he shares with his mother.

Nicole shares that they have overcome many obstacles and she becomes emotional when her child is judged for his disorder:

> His overcoming a lot, I'm overcoming a lot with him but the battles were real, the battles were hard, we always cry because our child is always blamed or labelled, it's not been a nice position to be in as a mother. I wouldn't trust anyone with him because they wouldn't understand him.

Nicole expressed concern for her child; she fears how he is always labelled by others based on his disorder. Similarly, Nadia expressed that her child is also judged and labelled by close friends and family: “And they would say they don't want to be rude but don't bring Tyler* again with”. The participant expresses the stigma she faced as being a caregiver of a child with ADHD. This would often leave them uninvited to social events and excluded from family gatherings, due to family and family friends not understanding her child’s behaviour and perceiving it as disruptive. Both Nadia and Nicole worry about their child's social exclusion due to their disorder and this has influenced their decisions when it came to medication usage. Many caregivers felt that they and their children were isolated because of their children’s behaviour.

This complicates caregivers' decision to discontinue their child's ADHD medication, as the child would then not be an easy target for stigmatisation from people in general.

Management of Challenges Post-Discontinuation

Family Support System. Most caregivers were fortunate enough to receive additional support from their spouses, household and extended family when weaning their children from ADHD medication. This support came in many forms such as emotional support and physical support, for example, helping out around the house and with regard to the child's needs. Nicole states that:

> Once the teacher got on board with me and discovered who he is and how to teach him. So, the important person was the teacher but also my husband, because with these types of children, it takes a lot of people to raise and it takes a lot people to be a supporter, and he needs a supportive structure because you can't do it on your own and Matthew* is still a mild case of ADHD, I have seen worse. So, my support structure was mainly myself, my husband and teachers, and lots of friends.

Nicole emphasises that she had a good support structure which consisted of her husband, teachers and friends. Furthermore, she mentions that having a good relationship and understanding with her son's teacher was important because it allowed for a healthy teaching environment for her son during the weaning process. In this case, the teacher was the child's support system at school, ensuring a suitable learning and working environment for the child.

Similar to Nicole, Simone too relied on the help of the teachers and the additional staff at her son's school, as well as her husband and family:

> So, we actually landed up putting him in at Helpbay* School. He was there with children with special needs, they have these psychologists and there's quite a lot of support teachers at the school, because they are based on helping the children with ADHD and ADD. So, we had support from them and also obviously our family as well. Thankfully, my husband has been through it and relates to it more. You know he'd often chat to me about what the signs and symptoms are and how to deal with certain things.

Simone and Nicole express that a strong support system helped them through the weaning process, especially when the child and parents needed the support in the home and school context. In addition, they explain that a supportive class teacher that is accepting and understanding of a non-medicated child with an ADHD diagnosis is crucial in the child's academic environment. Furthermore, Shiela explains that her support system is her sisters: "My support system is my sisters. With him, it's not parents alone raising him, it's a village. He must be watched closely with the random stuff he does". Similarly, Tamia states that she had a very strong support structure which was made up of her partner and family who helped her with the day-to-day activities and managing roles. Tamia explains that:

> Between myself and my partner there was always somebody at home that sat down with him, helped him with his homework, but he was literally failing… I think I come from a very supportive family, I come from a family of teachers as well. And, um, I think that, and even my own sister she has... she is a social care manager so she works with... uhm she's got patients that are autistic, and she had quite a lot of knowledge, so I had a lot of really strong support structure.

Tamia emphasises how open her family was to understanding and accepting her son during the weaning process. She was fortunate enough to have family members who have

experience with working with children who have been diagnosed with neurodevelopmental disorders, and could offer her a helping hand when needed. Furthermore, Leah mentions that her aunt and doctor made up her support system. She states: “I thank my aunt Rosie* for also helping me through the times and then I also had another doctor, Doctor Williams*”. Leah's support system consisted of a close family member and their family doctor who was always willing to assist when she needed support. Like the previously mentioned participants, Carla explains that her husband and those who knew and understood her child’s diagnosis were supportive towards her. She says: “Yes, yes, yes. My husband yes... and everybody who knows about his condition and, where he comes from and the background of it.”.

Portia explains that her husband has been her support system and they have managed to work together to ensure the smooth sailing of the household: “I have a very hands- on husband, very supportive... So, we both take on different roles at different times... We are both really hands-on parents; I receive a lot of support from my husband”. She adds that her family has also played a big role in their lives because she is able to depend on her brother and mother:

> Look, uh... one of the good things is that I come from a very united family, so reliance from my mom and reliance on my brother. My friends, I have a very good support structure, I do a lot of activism work and the ladies within that activism group have become my sisters.

Social support is one of the main resources for parenting children with ADHD and managing child behaviour (Finzi-Dottan et al., 2011). Cohen (2004), defines social support as an interpersonal transaction that involves social, informational and emotional help, which has been evident in the responses from the caregivers in this study. Most caregivers reported similar

responses with regard to their parenting style, which stayed the same after the discontinuation of their child's ADHD medication.

Parental Hard Work. The relationship between a mother or primary caregiver and child is a very special bond that is shared between the two (Fegran et al., 2008). The relationship between the mother and child has surfaced multiple times in the findings from this study. On a lighter and successful note, Amy states that her relationship with her son has become easier after the discontinuation of medication:

> I must say that I think it has been easier because of the adolescence age like I can take him anywhere and he just behaves, he sits down and he was just there… but now he just started to get out of control a little bit but I am sure if he was on the meds, according to how he was feeling, our relationship would have been a lot rockier. It's almost like when he is off the meds he is more reasonable...like I could speak to him and reason with him, but when he is on the meds, it's like he is feeling this intense pain all the time and I was disrespected and it was actually horrible.

Amy feels she is able to reason with her son, and they have a better understanding. She further explains that she fears that if he was on medication, their relationship would not have been as mature as it is now. On the other hand, Shiela states:

> Well with me, all my children are the same with me, the one or the other. There is no difference; the bond is the same like mother and child. It's not like I love him more or care for him more. I love them the same but obviously I need to watch him more.

Shiela does not favour one child over the other but she does feel she needs to monitor her son more than her other children. Shiela feels that it is her duty to fight for her child's needs and stand up for him, since he is not able to do so for himself.

When weaning their children from ADHD medication, the caregivers sought alternative treatment methods in order to treat their child's ADHD symptoms. Caregivers explored other measures of treatment such as physical activity and therapy. Amy mentions that:

> So that year he went to extreme functioning training and he went to a therapist for two weeks. So, we really had to put in the skills to get him where we wanted him to get off of the medication, so we changed his diet, we changed everything just to get him on track again.

Amy states that they changed their child's routine in terms of his physical activity and diet. Similar to Amy, Tamia too attempted a change in routine by allowing her son to partake in sporting activities:

> We started an exercise regime…luckily, I live close by to the sports field and you could go every evening where he could go run his heart's content. We make sure that he exercises daily, will make sure that he is involved in sports at school and in a lot of activities.

Furthermore, Amy described the battle the family experienced in getting her child off the medication at first and once he was off the medication, they found that it took support from everyone in the family to help him achieve many positive outcomes:

> I think we were more grateful in a way because it affected us more by him being on [the medication] and his dad would say leave it, so there was a constant battle of what will we do, and surprising to all of us repeated it again. There actually have been positive

> outcomes and it has been a lot of work from us and the family to actually get him to pass and to get him to succeed and what I noticed is that he is more social and he is socialising and he's got more friends and he's not in his own world anymore and to me that is a major surprise.

After discontinuing medication and implementing alternative treatment methods, Amy was surprised by her son's ability to socialise and engage with peers. Although the use of alternative treatment methods requires more work and patience from herself and the family, she is pleased with the positive outcomes. Erin mentions that she allows her child to have medication breaks on weekends and holidays: "There is no medication on the weekends and nothing on the holidays. He is totally fine because he just carried on with his life and stuff. The main thing is concentrating in school." Similarly, Tamia implements the medication break to allow her child to gain healthy weight again:

"Then when we get to school holidays, the doctor will take him off the Concerta. And the doctor would then say okay, give him a break for a couple of weeks, let him pick up weight and then we'll see how things go".

Simone also mentions that she too allows the drug holiday in order for her son to embrace life as a child: "So when it came to weekends, I said he needs a break. You know, during holidays and all of that he needs a break from the medication. He needed that break away from this and be a normal kid". Ibrahim and Donyai (2015) state that parents consider drug holidays for different reasons. These can include managing drug tolerance, to test if medication is still needed and to manage the different side effects caused by the medication. As seen by the caregivers' responses, they have all implemented drug holidays for different reasons. These

reasons correlate with the statement by Ibrahim and Donyai (2015) as Tamia mentions she used the drug holiday period to allow her son to manage the side effects caused by the medication.

Chapter Summary

This chapter examined the data collected through the interviews employed for the study. Through the use of Atlas Ti. Software, the researcher has analysed and coded the results collected. The results of this chapter will be further interpreted in the following chapter in order to address the objectives of the study. In the subsequent chapter, the researcher will report on a discussion of the findings which emerged from the interviews conducted with the caregivers of children who were weaned from medication relating to their ADHD diagnosis.

Chapter Five: Discussion

This chapter provides a detailed analysis and interpretation of the experiences of caregivers who have discontinued their child's ADHD medication, this will be discussed within the framework of Bowens theory. Specific focus was placed on the caregivers' reasoning for discontinuation, the impact of discontinuation and caregivers' experiences after discontinuation and how they managed these perceived challenges. Seven sub- themes were identified: family judgement; side-effects of medication; helping children reach their true potential or 'true self; conflict and stress within the family; negative responses of the public to the uncontrolled non-medicated behaviour; family support system and parental hard work. The sub-themes will be discussed to provide an extensive description of caregivers' experiences of weaning their children from ADHD medication.

Reasons for Discontinuation of ADHD Medication

The first of the main themes identified speaks to the first objective of the study which sought to explore the reasons behind caregivers' experience to discontinue ADHD medication. Each sub-theme will be explored and discussed.

Family Judgement. Family judgement was one of the themes that influenced caregivers to discontinue their child's ADHD medication. It was found that family members of caregivers were hesitant of the medication prescribed to their children, which caused caregivers to battle with their decision to continue or discontinue their child's medication. According to Amy, addictive behaviour is prevalent in her family and this was the reasoning behind the family's hesitancy. The family viewed this as detrimental to the child's potential and a possible factor for the child's dependency on the medication. A study done by Leitch et al. (2019) explored the experience of stress in parents of children with ADHD and reported significant distress experienced by parents as a result of the difficulty of living with family and societal judgements

about their child's diagnosis, medication use and behaviours. Parents reported feeling isolated by the public as they did not understand ADHD, its consequences, or the value of medication (Leitch et al., 2019). Parents reported encountering individuals who were very vocal and harsh in their criticisms around ADHD as a mental disorder and claimed that the parent was overmedicating their children, and passing judgement on the parent's behaviour (Leitch et al., 2019).

Multigenerational Transmission Process is one of the eight concepts that speaks to Bowen family systems theory. This concept describes how different roles, themes and patterns in a triangle are passed down from parent to child, from generation to generation through projection (Bowen, 1978; Haefner, 2014). The theory states that when one is able to pay close attention to family patterns that have been passed down over time, it helps family members create a barrier to the situation they are faced with and observe the manner in which they transfer anxiety over generations (Bowen, 1978; Haefner, 2014). Therefore, when dealing with presenting symptoms, such as addictive behaviours being prevalent in the family, the mother of the child is able to observe the stigma, labelling and anxiety from her parents and extended family that are attached to her child's disorder and the use of medication that follows. She is able to break the generational cycle of the stigma and anxiety associated with medication use that may lead to addictive behaviour for her child. She therefore becomes an active player in preventing interactions that repeat themselves. In this study, it seems like the stigma and anxiety around the medication is difficult to shake, and that it does impact the caregivers' decisions around medication use.

An additional theme that emerged from the findings was the stigmatisation against children from their own family members due to their parents' decision for the use of medication

to treat their ADHD symptoms. Parents often experience intense feelings of scrutiny and stigma from professionals and the wider community (Leitch et al., 2019). As previously mentioned, the stigmatisation against parents for the use of medication to treat their child's ADHD can be seen through the lens of the Multigenerational Transmission Process. Parents have implemented an intervention that helps the family member, which in this case is the child, to get sufficient distance from the struggles with the symptoms they are experiencing. The broader family members are placing judgement on the type of intervention pursued by parents and have affected the emotional functioning of the family unit which links to the family emotional system presented by Bowen's theory (Bowen, 1978; Haefner, 2014). The broader family members then exert anxiety on parents for their intervention methods through stigmatisation, which ultimately leads to the parents' decision to discontinue medication usage.

Culturally, children who displayed behaviour that presented as ADHD symptoms were labelled as "naughty" and "lazy", as previously mentioned in Chapter Four. This labelling of the child can have a negative effect on the child's psychological development (Law, 2007; Thomson, 2012). Family members avoided caregivers and their children to the point where they were uninvited to family events as their children were seen as disruptive to the occasion. This stigmatisation against the child's behaviour as a result of their neurological disorder can be understood through symptoms in a child which is linked to the family emotional system (Bowen, 1978; Haefner, 2014). Furthermore, it may affect their emotional behaviour and lead to them developing behavioural or emotional problems (Bowen, 1978; Haefner, 2014).

Side Effects of Medication. The side effects mentioned by the participants were core influences to caregivers' decision to discontinue medication, as noted in other studies (Charach & Fernandez, 2013; Toomey et al., 2012). Weight fluctuation was one of the side effects listed by caregivers. Zachor et al. (2006) confirm that children diagnosed with ADHD experienced significant weight loss within the first few months of treatment with psychostimulants. Caregivers noted that they would engage in drug holidays in order to allow their child to gain healthy weight, as the medication caused a significant amount of weight loss. Weight loss is deemed worrisome to caregivers as young, growing minds are in need of good nutrition in order to be healthy and have good mental health.

Induced irritability, anxiety, insomnia and emotional instability are the most common side effects of Ritalin, where irritability and weight loss were the most frequent (Kim et al., 2020). Caregivers confirmed that their children's unusual sleeping patterns and mood swings impacted the family household. Commonly, caregivers noted that their child who presented with ADHD symptoms would frequently quarrel with older siblings. These included emotional outbursts and older siblings viewing the younger sibling (who is diagnosed with ADHD) as annoying and disruptive. Interestingly, two of the common side effects of Ritalin; irritability and emotional lability (Kim et al., 2020), are also common symptoms that the children in this study had experienced. One of the participants in the study reported that they discontinued their child's ADHD medication due to the child experiencing some withdrawal symptoms, such as fatigue. These findings are supported by Ibrahim and Donyai (2018), who determined that withdrawal effects are associated with the abrupt stopping of stimulant medication. As a result, parents are reluctant to cease medication or initiate drug holidays without a professional opinion.

Helping Children Reach their True Potential or "True Self". Caregivers were concerned about their child not being able to reach their full potential while being on medication. They believed that the medication would delay the child's development. Similarly, in a study conducted by Singh (2005), parents feared that Ritalin would hinder the child's growth and true personality. Kutsyuruba et al. (2015) state that ADHD can have a significant impact on a child's academic performance, social interactions, family life, and emotional wellbeing. Generally, ADHD affects not only the patient but also their immediate family (Cadman et al., 2012). While treatments may help to reduce ADHD symptoms, parents are concerned about the extent to which unmet needs persist, despite current treatment options and the level of care that children require (Sikirica et al., 2015). In this study, the uncertainty influenced their decision to discontinue medication. In addition, caregivers feared that their child would become dependent on the medication for the rest of their lives. Therefore, they felt it was necessary to wean the child off the medication before they developed dependency. Notably, it was found that the child's true personality surfaced when they were not on medication, thus being their authentic and happy self.

Caregivers highlighted that the decision to discontinue medication was made in the best interest of the child and their future development. With that being said, caregivers placed emphasis on the need for independence. Parents do not want their child's growth to be obstructed by the medication, thus linking this to Bowen's concept of differentiation of self (Bowen, 1978; Haefner, 2014). Differentiation of self in relation to the discontinuation of medication speaks to the child's autonomy (Bowen, 1978; Haefner, 2014). Parents mentioned that they have made this decision in the best interest of their children and want their child to function autonomously by making self-directed decisions, while remaining emotionally connected to the intensity of a

significant relationship system (Bowen, 1978; Haefner, 2014). Therefore, if a child is not on medication, they are able to make autonomous decisions on their own without needing additional assistance or being dependent on medication. Furthermore, if the child is not on medication, they will be able to exist independently from their families, while functioning as an individual within the family unit (Bowen, 1978; Haefner, 2014). Whereas if they are on medication, they may not develop this level of independence. Thus, the continuation of medication may hinder their children developing their true self.

Impact of Discontinuation

The second main theme identified speaks to the second objective of the study which sought to explore the impact of the discontinuation on family functioning. Each of the three sub-themes will be carefully elaborated below.

Conflict and Stress Within the Family. In the case of parent-child relationships, the child's environment and context influence the child's characteristics and behaviour. Consequently, the child's characteristics and behaviour can influence both the parent and the environment in which the different interactions occur (Holden, 2019). Considering Bowen family systems theory and viewing the current study through the lens of each family member, the children who make up the findings of this study cannot be viewed and understood in isolation, instead they should be seen in the context of their family, both the extended family and those in the household. Bowen family systems theory focuses on how the wellbeing of children may impact sibling behaviour and caregiving stress. Haydicky et al. (2015) confirm that children with ADHD tend to experience emotional and behavioural difficulties, which often contribute towards stress and conflict in their family relationships, which has been a common occurrence in the findings of this study. Tension in the household as a result of sibling conflict was a common

occurrence in the findings of this study. This was a result of the younger siblings being weaned from ADHD medication and while caregivers were testing alternative methods for the child. As previously mentioned, the hyperactive behaviour of children came across as frustrating to older siblings which caused conflict between children and required caregivers to be mediators in these situations, especially mothers.

According to Bowen's theory, more specifically sibling positions speak to the different roles individuals embody within relationships (Bowen, 1978; Haefner, 2014). Bowen states that the eldest child is more likely to take responsibility as opposed to the younger siblings who allow others to decide for them and take on the “follow the leader” role (Bowen, 1978; Haefner, 2014). In this case, the child with ADHD develops behavioural difficulties. When considering the theory, one would expect older siblings to be more understanding and supportive of their younger siblings, but instead in this study it was found that they become frustrated with their younger sibling who have ADHD which results in conflict in the household (Bowen, 1978; Haefner, 2014).

Negative responses of the public to the uncontrolled non-medicated behaviour. It was found that caregivers and their children were stigmatised for the child's non- medicated behaviour. Linked to the previously mentioned theme of family judgement, the stigmatisation around a child’s non-medicated behaviour can be viewed through the lens of the Multigenerational Transmission Process (Bowen, 1978; Haefner, 2014). Parents have chosen to discontinue their child's ADHD medication, and as a result, it is normal for symptoms related to the disorder to reappear. The recurrence of symptoms has also resulted in the stigmatisation of the child's behaviour (Leitch et al., 2019). The judgement and stigma from the broader

community of the child's behaviour may not only affect the emotional functioning of the child but also of the family unit (Bowen, 1978; Haefner, 2014; Leitch et al., 2019).

Studies have shown that caregivers of children diagnosed with ADHD often experienced stigma (Bussing & Mehta, 2013; Broady et al., 2017; Chang et al., 2021; Dosreis et al; Lin & Tsang, 2020). Many caregivers felt that they and their children were isolated due to their child's behaviour as a result of the symptoms associated with ADHD. However, despite most caregivers' experiences of stigma related to their child's ADHD, many used medications to help manage their child's ADHD symptoms with the hope that it would allow their child to fit into the environment around them (Chang et al., 2021; Dosreis et al., 2010; Lin & Tsang, 2020).

Caregivers in this study consulted medical professionals who diagnosed their child and prescribed psychostimulants as a treatment. Caregivers entrusted that the medication would ease the child's symptoms and allow them to fit into the environment around them (Chang et al., 2021; Dosreis et al., 2010; Lin & Tsang, 2020). However, as a result of the side effects mentioned and other contributing factors, caregivers chose to discontinue, which led to the re-occurrence of ADHD symptoms displayed by the child. Children and caregivers were judged both for their decision to discontinue medication and the child's presented behaviour, therefore this stigma is a challenge for both the parents and the child, based on their decision to discontinue medication, as parents fear their child will be judged for their uncontrolled behaviour. Van den Ban et al. (2010) found that the discontinuation of ADHD medication is fairly high within the first year of initiating treatment.

Management of Challenges Post-Discontinuation

The last main theme identified speaks to the third and fourth objectives of the study which aimed to explore the caregivers' experiences after discontinuation and the management of

these perceived challenges after discontinuation.

Family Support System. As discussed in the sub-theme above, most caregivers received additional support from their spouses, household and extended family when weaning their children from ADHD medication. As per Bowen family systems theory, the wellbeing of children may impact the family's functioning (Bowen, 1978; Haefner, 2014). During this time, family members took up different roles to provide relief, support and encouragement to the caregivers (Firmin & Phillips, 2009; Kendall & Shelton, 2003). This support came in many forms, such as emotional support and physical support, for example, helping out around the house and with regard to the child's needs (Firmin & Phillips, 2009; Kendall & Shelton, 2003). Caregivers commonly feel heard and connected when sharing their experiences with others, as this process validates their own experiences and challenges (Leitch et al., 2019). It was found that a healthy and understanding relationship with the school teacher allows for a healthy teaching environment for the child. Moreover, teachers who are informed of the caregiver's processes and reasoning for discontinuation are able to assist caregivers by providing feedback on the child's behaviour in class and presenting constructive recommendations to caregivers which would make the process of discontinuation smoother for all involved (Brinkman et al., 2012). This support from those directly involved in the child's life is essential. Social support is one of the main resources for parenting children with ADHD and managing child behaviour (Finzi-Dottan et al., 2011).

In addition, the family as a whole stepped in to offer support in many forms. Bowen family systems theory speaks to how the wellbeing of children may impact on family functioning. During the trial and error phases embarked by caregivers to find an alternative method or routine that worked for them, family members offered support. This included offering

their time to engage in extracurricular activities with the child, taking some of the responsibility from the caregiver, to prevent caregivers from becoming overwhelmed during the process. Studies found that genetic and neurological factors play an important role when diagnosing a child with ADHD, as ADHD is two to eight times more common in an individual who has a first- degree relative who presents with the disorder (Antshel et al., 2007; Felt et al., 2014). Therefore, Simone's husband who has been diagnosed with ADHD as a child, was able to support his wife and help her understand their son's behaviour as he too was diagnosed with ADHD as a child.

Parental Hard Work. Mothers are usually the key informant in surveys and interviews collecting data on their children (Finzi-Dottan et al., 2011; Wilson, 2021). Mothers also wear many hats when it comes to their relation with their children (Finzi-Dottan et al., 2011; Whalen et al., 2011). It was established that mothers tend to be mediators, carers, defenders and nurturers (Corcoran et al., 2017; Whalen et al., 2011). With these roles come a great deal of responsibility and hard work, particularly for mothers. According to Bhide et al. (2019), parenting warmth and a lower parenting anger were related to an increase in the child's social behaviour, responsibility and self-control, as displayed by the parents in this study. When children are bullied by peers, their mothers come to their rescue to defend them and fight their fight for them (Modesto-Lowe et al., 2008; Riany et al., 2021). Mothers would restore peace between younger and older siblings when quarrels occur (Modesto-Lowe et al., 2008; Riany et al., 2021). Furthermore, in this study mothers were the decision makers regarding the discontinuation of the child's medication and actively sought alternative methods. Throughout this trial-and-error process, mothers supported their children and endured the journey with the child until a new normal routine was established, which required strength and courage (Honkasilta et al., 2015).

As per Bowen family systems theory, caregiving stress emerged through the findings of the study. Mothers endured countless moments of stress when taking responsibility for the many roles they play in their children's lives. A mother experiences stress and anxiety when she has to constantly play mediator to resolve conflict between siblings. As seen in the experiences of mothers in this study, mothers in particular are more sensitive to the pain of others as a result of their experience of raising a child with ADHD (Corcoran et al., 2017; Finzi-Dottan et al., 2011). Therefore, they are perceived as tough and more authoritative when it comes to standing up for their child (Finzi-Dottan et al., 2011).

In this study, caregivers explored alternative treatment methods that were successful, then went ahead with discontinuing medication. Notably, many studies suggest the possible benefits of exercise in alleviating ADHD functional outcomes (Den Heijer et al., 2017; Medina et al., 2010; Vysniauske et al., 2020). Therefore, the methods employed by Amy and Tamia coincide with what has been investigated. It was found that moderate to intense physical activity significantly improves functional outcomes for children with ADHD (Vysniauske et al., 2020). Thus, exercise interventions are relatively easy to implement and follow and it has little to no side effects (Den Heijer et al., 2017). It is also much more affordable in comparison to medication (Den Heijer et al., 2017). Although parental commitment and involvement in the maintenance of exercise is important (Den Heijer et al., 2017; Vysniauske et al., 2020).

Chapter Summary

This chapter reported on the findings of the study which has been discussed in Chapter Four. It was found that caregivers discontinued their child's ADHD medication for various reasons. Family Projection Process, Emotional Cut-off, Multigenerational Transmission Process, Sibling Positions, and Societal Emotional Process of Bowen family systems theory were relevant

concepts from Bowen's theory that helped place this study into context. It also assisted in the understanding of caregivers' subjective experiences of weaning their children from ADHD medication. On the other hand, Differentiation of Self, Nuclear Family and Emotional System were not relevant to this study as it is more applicable to the child's subjective experiences with treatment and did not necessarily provide a clear understanding of caregivers' subjective experiences. In the following chapter, the limitations, recommendations and conclusion of the study will be reported on.

Chapter Six: Limitations, Recommendations and Conclusion

This chapter reports on the limitations and recommendations, and provides a conclusion for the study. The limitations report on characteristics of the study that impacted or influenced the interpretation of the research. The recommendations propose areas for future research, areas for intervention and provide policy and practice suggestions, and the conclusion provides an overall summation of the dissertation.

Study Limitations

As with any study, there were limitations to this study design. Firstly, only mothers of children were interviewed in this study. Thus, father figures and their experiences were not included in the findings of the study. Therefore, the emerging themes may be more reflective of mothers' than fathers' experiences. Mothers and fathers of children with ADHD may have different or similar experiences of parenting a child with ADHD. Thus, future studies should elucidate whether mothers and fathers of children with ADHD have different experiences when weaning their child from ADHD medication.

Another limitation may include a different representation of the age bracket of children who make up the findings of the study. Children younger than 18 years old do not have the autonomy to discontinue their ADHD medication; only their parents are able to make this decision for them. Therefore, future studies should explore if parents may discontinue their child's ADHD medication for different or similar reasons as compared to adults who choose to discontinue their ADHD medication. Furthermore, specific issues may occur when parenting younger children or older teenagers with ADHD that were not captured in this study.

An additional limitation is that the study was only conducted in English. Although provisions were made in the event that participants requested to be interviewed in Afrikaans or

isiXhosa, none of the participants requested it. Conducting the research in the participants' native language would have allowed the participants to speak more freely and openly about their experiences. Furthermore, participants may not have understood the questions in English and answered according to their perception and understanding of what was being asked of them.

Recommendations for Future Research

In terms of the limitations noted above, it is recommended that future studies increase the sample size of the study, as this would allow for a distribution of participants that includes fathers in the study and generalisation of the findings of the study. Future research may also explore and investigate alternative methods that caregivers use to treat ADHD, as opposed to traditional pharmacological interventions. This would provide parents who are hesitant to employ pharmacological interventions, with trusted alternative methods that would provide their child with a better quality of life. Future research may focus on exploring methods that would ease the influence ADHD has on patients and their caregivers; this would allow for a better quality of life for both the child and the caregiver. Additionally, healthcare professionals could provide this new knowledge and information about alternative methods, to parents who are medication hesitant after they have trialled traditional pharmacological interventions. Future research may also explore research that focus on teachers' perspectives, and compare teachers and parental perspectives as both are actively involved in the child's life. In addition, it is suggested that the children's experience themselves should be investigated.

Recommendations Based on the Findings of the Study

This research contributes to the awareness and understanding of the influence of the discontinuation of ADHD medication on family functioning; the experiences caregivers encounter after the discontinuation of ADHD medication; and the strategies caregivers use to manage the child's difficulties after the discontinuation of ADHD medication. The knowledge,

information and insight gained through this research may be used to inform community-based interventions which are essential to public health provision in South Africa. Whereby, it will assist with psychoeducation on a larger scale, for example implementing mental health education programmes that can take place in schools and clinics. These programmes and interventions could aim to include educating children and parents/caregivers. The information and insight gained from this study may also inform existing interventions in South Africa and make provision for better or improved referrals for parents/caregivers.

Going forward, there are ways to assist parents with the weaning process, as it pertains to the findings in this study. Finding support from other parents and learning about what worked and what did not work within their family can assist parents who are experiencing similar challenges. Some parents found that placing their child in extra mural sporting and art activities helped them ease excessive energy. In addition to this, consulting with other healthcare professionals such as a dietitian to set up a ‘clean’ eating plan for the child as parents mentioned that a good diet helps their child's day-to-day lifestyle. The implementation of drug holidays helped parents monitor their child's symptoms when medication use is needed and when to allow their child a break from medication as some parents may not discontinue medication completely but only use medication for the purpose of the child's schooling career. Lastly, parents need multidisciplinary support and supervision from the health service and personnel in schools, both in their parenting and in their decision making and follow-up sessions, and focusing on the entire family is essential as early interventions may help the family. The understanding from a teachers perspective and their input in the process, should also be considered.

Conclusion

This study was aimed at exploring and understanding the experiences of caregivers of children being weaned from ADHD medication, with the goal of informing future interventions

and to inform caregivers experiencing parenting stigma around ADHD medication. The findings of this study suggest that caregivers tend to discontinue their child's ADHD medication due to the negative results and experiences associated with the medication trials. Furthermore, all caregivers had one thing in common, which was that discontinuing the medication was in the best interest of the child, and finding an alternative method that would best suit the child, even if it meant more roles, work and responsibilities for the caregivers. Notably, each child is unique, and each family must determine what works best for them and their child through trial and error as caregivers experimented with various medications and dosages to find what works best for their child.

In conclusion, parenting a child with ADHD can be a complex task that challenges the very nature of traditional parenting. This study confirms current literature in that caregivers implement drug holidays for their children to allow the child relief from various side effects caused by the medication. This study highlights and brings attention to the different subjective experiences' caregivers encounter within their respective households, through the use of traditional pharmacological interventions to treat their child's ADHD symptoms. The disconnect between current literature and this study, are the alternative treatment methods employed by caregivers in order to treat and ease their child's ADHD symptoms. This highlights that traditional pharmacological interventions are not the sole intervention for the treatment of ADHD symptoms. However, caregivers have trialled different treatment methods and have used a combination of what is suitable and in the best interest of their child. In this study, it was established that the roles mothers play when parenting a child with ADHD is inextricably complex, contributing to high demands and strain on the individual and the family system. Therefore, this observation can be linked to motivation for supporting family systems, particularly mothers within these family systems.

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Appendices

Appendix 1: Information Sheet

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-9592825, Fax: 27 21-9593515

E-mail: 3640323@myuwc.ac.za

03 May 2021

INFORMATION SHEET

Project Title: Caregivers' experiences of weaning their children from ADHD medication.

What is this study about?

This is a research project being conducted by Casey Botha, a Masters in Research Psychology student under the supervision of Dr. Leigh Tucker (Supervisor) and Prof. Kelvin Mwaba (Co-supervisor) at the University of the Western Cape. We are inviting you to participate in this research project because your participation may provide me with a better understanding regarding parents' knowledge and understanding of weaning their children from ADHD medication. The purpose of this research project is understanding parents' first-hand experience of the discontinuation of ADHD medication.

What will I be asked to do if I agree to participate?

You will be asked to participate in an individual semi-structured online video (Zoom/ Google Meet) interview to provide information about your experiences of weaning your children from

ADHD medication. The aim is to gain an understanding of your knowledge and experiences of weaning your child from ADHD medication.

Would my participation in this study be kept confidential?

The researcher undertakes to protect your identity and the nature of your contribution. To ensure your anonymity, pseudonyms will be utilised in order to protect the participants identities and no one will know what you have shared during the interview. Only the researchers involved in the research study will have access to information for data collection and analysis purposes. To ensure your confidentiality, all data will be safeguarded in a secure folder that is password protected for at least five years, to which only the researcher and supervisor/s will have access. All of the participants are encouraged to maintain confidentiality. Should a report or article be written about this research project, your identity will be protected.

All of the data will be stored on a password-protected computer. You have the right to withdraw from the study at any time without any negative consequences. I will do my best to reduce risks (if there are any) and act promptly to assist you if you experience any discomfort, psychological harm or otherwise during the process of your participation in this study. Your participation will be greatly appreciated.

What are the risks of this research?

There may be some risks from participating in this research study. All human interactions and talking about yourself or others carry some amount of risks. I will nevertheless reduce such risks and act promptly to assist you if any discomfort or psychological harm is experienced during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

A benefit of your participation could contribute to the awareness and understanding of ADHD medication and the experiences associated with the discontinuation of medication, that aids in bettering the quality of life of an individual with ADHD. The knowledge, information and insight gained through this research may be used to inform community-based interventions which are essential to public health provision in South Africa. I hope that, in the future, other people might benefit from this study through improved understanding of parents' experiences of weaning their children from ADHD medication.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part. If you decide to participate in this research, you may stop participating at any time throughout the process. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify

What if I have questions?

This research is being conducted by *Casey Botha at the Department of Psychology* at the University of the Western Cape. If you have any questions about the research study itself, please *Dr. Leigh Tuckerat:021-959 2819 / ltucker@uwc.ac.za or myself at: 3640323@myuwc.ac.za.*Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department:

Prof. Anita Padmanabhanunni

Head of Department: Psychology

University of the Western Cape

Private Bag X17

Bellville 7535

apadmana@uwc.ac.za

Dean of the Faculty of Community and Health Sciences:

Prof Anthea Rhoda

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Human and Social Sciences Research Ethics Committee

(HSSREC) Ethics Reference: HS21/5/22

Human and Social Sciences Research Ethics Committee (HSSREC)

research-ethics@uwc.ac.za

021 959 4111

Appendix 2: Consent Form

UNIVERSITY OF THE WESTERN CAPE

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CONSENT FORM

Title of Research Project: **"*Caregivers' experiences of weaning their children from ADHD medication.*"**

The study has been described to me in a language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

For this research project an audio recording will be made of you, which will ensure that transferability and credibility is maintained throughout the research study. Audio recordings will be kept in a safe area at all times. After the transcription of the data the audio recordings will be deleted.

____I agree to be audio-taped during my participation in this study.

____I do not agree to be audio-taped during my participation in this study

Participant's name…….

Participant's signature…….

Date……

Appendix 3 Interview Guide

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
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E-mail: 3640323@myuwc.ac.za

Section A: participant information

We are aware of the sensitivity of the following questions. This information will allow us to gather information about our participants, and also to collect important information. Your responses will remain anonymous so no one is able to know who provided the information. Thank you for your participation!

Mother/Father of child:	
Contact details:	
Age of Parent:	
Age of Child:	
Marital Status:	

Section B: interview guide

1. Tell me about your experience that led to your child's ADHD diagnosis

- How long ago was this?
- Who diagnosed him/her?

- Is there a family history of any other diagnosis such as ADHD?

2. Please tell me about the medication used to treat your child's ADHD?

- In your experience, how did this ease the symptoms for the child?

3. Describe your experience of discontinuing the medication, whether for a period of time or completely?

   - What factors influenced this discontinuation?

   - How has this impacted the family?

   - Tell me how it impacted other siblings or their relationship with other siblings?

   - Tell me how it impacted your relationship with your son/daughter?

   - Tell me about your personal experience regarding the discontinuations?

4. Tell me about your experiences (good and bad) after the child was weaned from the medication

- How did you cope/manage with this?

- Tell me how this impacted your relationship with your son/daughter

5. Tell me how has the discontinuation changed the way you parent

- How did you cope/manage with this?

6. In your experience, tell me how the discontinuation altered or changed the family functioning/environment?

- How did you cope/manage with this?

Appendix 4: Poster

UNIVERSITY of the WESTERN CAPE

Are you a Caregiver/Parent of a child who discontinued ADHD medication for A PERIOD OF TIME?
Is the Child between the ages of 6 and 12?

I would love to hear your experiences!

I am a Masters in Research Psychology student conducting research for my thesis, under the supervision of Dr. Leigh Adams Tucker (Supervisor) and Prof. Kelvin Mwaba (Co-supervisor) at UWC. We are inviting you to participate in this research project because your participation may provide me with a better understanding regarding caregivers' knowledge and understanding of weaning their children from ADHD medication.

- You will be asked to participate in an individual semi-structured online video (Zoom/Google Meet) interview to provide information about your experiences of weaning your children from ADHD medication.
- The researcher will ensure that your participation in this study is kept confidential at all times.

Please contact:
Casey Botha: 074 050 9111
3640323@myuwc.ac.za
OR
Dr. Leigh Tucker: 021-959 2819
(Research supervisor)
ltucker@uwc.ac.za

Appendix 5: Research ethics clearance certificate

UNIVERSITY of the WESTERN CAPE

60 YEARS of hope, action & knowledge

15 July 2021

Ms CB Botha
Psychology
Faculty of Community and Health Sciences

HSSREC Reference Number:	HS21/5/22
Project Title:	Caregivers experiences of weaning their children from ADHD medication.
Approval Period:	14 July 2021 – 14 July 2024

I hereby certify that the Humanities and Social Science Research Ethics Committee of the University of the Western Cape approved the methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report by 30 November each year for the duration of the project.

The permission to conduct the study must be submitted to HSSREC for record keeping purposes.

The Committee must be informed of any serious adverse events and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

Director: Research Development
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NHREC Registration Number: HSSREC-130416-049