



**Black Parents' and Caregivers' Perceptions and Decision-Making  
Regarding an Attention Deficit Hyperactivity Disorder Diagnosis:  
Implications for Intervention Pursuits.**

By

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A thesis submitted in fulfilment of the requirement for the Doctor of Philosophy  
Degree in Psychology in the Faculty of Humanities, University of the  
Witwatersrand, Johannesburg.


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### **Declaration**

I declare that this thesis is my own work. The assistance I received was only for supervision and guidance purposes. It is submitted in fulfilment of the Doctor of Philosophy in Psychology requirement in the faculty of Humanities at the University of Witwatersrand, Johannesburg. It has not been previously submitted, in its entirety or part, for any degree or examination at any other university.

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**Signature:** 

**Date:** 08 May 2024

## **Dedication**

*To all parents and caregivers of children with ADHD:*

*Know that you are not alone in your journey. Your dedication and love for your children inspire us all. Keep shining a light on their unique strengths and talents and continue to advocate for their needs. Together, we can break down the barriers of misunderstanding and build a world where all children are valued and supported.*

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### **Abstract**

Despite the increase of attention deficit hyperactivity disorder (ADHD) prevalence in South Africa, many Black parents and caregivers have been observed to struggle with accepting an ADHD diagnosis for their child. Various influences impact parental and caregivers' ADHD perceptions, hence influencing their decision-making regarding intervention pursuits and preferences for their child diagnosed with the disorder. This study aimed to examine the perspectives of Black parents and caregivers regarding ADHD diagnosis for their children. The study also aimed to understand the significance of this diagnosis for parents and caregivers, their decision-making process, and their preferences and willingness toward different intervention options. The theoretical framework encompassed a discussion of Bronfenbrenner's bioecological systems theory to understand, within the model of the multi-dimensional structure, different levels of influence that shape Black parents' and caregivers' perceptions regarding an ADHD diagnosis for their child and the implications on intervention decision-making and preferences. The study utilized an explorative and qualitative Interpretative Phenomenological Analysis (IPA) approach, focusing on the participants' subjective experiences. Twenty-one Black parents and caregivers of four to 17-year-old children with a confirmed ADHD diagnosis were recruited from the Gauteng region in South Africa through non-probability purposive sampling. Data was collected through semi-structured face-to-face, telephonic, and online individual interviews and focus groups. Interviews and focus group discussions were audio-recorded, manually transcribed, and analyzed by the researcher. The findings highlighted a lack of ADHD awareness and knowledge among the participants. It emerged from the findings that many participants had not initially perceived their children's ADHD-related behaviors as impairing; however, they had perception shifts through exposure to ADHD. The findings revealed that participants

experienced varying adverse psychological responses to their children's ADHD diagnoses. However, nearly all the participants displayed receptiveness to the diagnoses. Participants' understanding of the etiology and nature of ADHD for their children was shaped by several influences: 'culture,' 'awareness and knowledge,' 'religious and spiritual beliefs,' 'stigma,' 'the role of school,' and 'sources of support,' which shaped various beliefs on the management of the disorder. The study revealed that the school played a significant role in the identification of ADHD-type behaviors in children. Yet, many participants perceived that many mainstream schools were neither conducive nor accommodating of children with the disorder. Participants formed positive and negative meanings from experiences arising from their children's behaviors and diagnoses. The meanings contributed to decisions to seek interventions for their children. A noteworthy finding from the study was the unreserved willingness displayed by participants to pursue ADHD interventions for their children, with many employing a multi-approach to ADHD management, including pharmaceutical interventions. However, the study highlighted key hindrances to intervention compliance and adherence, namely, 'lack of awareness and limited knowledge,' 'parental perceptions' about recommended interventions, and 'limited resources.'

**Keywords:** *Attention deficit hyperactivity disorder (ADHD); parents' and caregivers' perceptions; parenting & child discipline; intervention pursuits; Black African cultural influences; interpretative phenomenological analysis (IPA).*

### **Abbreviations and Acronyms**

ADHD	Attention Deficit Hyperactivity Disorder
APA	American Psychiatry Association
CBT	Cognitive Behavior Therapy
IPA	Interpretative Phenomenological Analysis
MTA	Multimodal Treatment Algorithm
NICE	National Institute for Health and Care Excellence
NIMH	National Institute of Mental Health
DBE	Department of Basic Education
ODD	Oppositional Defiant Disorder

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## CHAPTER 1: INTRODUCTION

### Background

Attention Deficit Hyperactivity Disorder (ADHD) is regarded as one of the most prevalent childhood disorders, affecting about 3% - 10% of children internationally (Bussing et al., 2016). According to Ayano et al. (2020), the ADHD incidence rates in Africa are estimated to be 7,4% among school children, falling within the global trends. In South Africa, it is estimated that ADHD affects 8% - 10% of children (Schellack et al., 2019). However, it is essential to note that information on ADHD prevalence rates may vary depending on the contextual and cultural behavioral interpretation of different geographic places. ADHD's defining feature "is a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development" (American Psychiatric Association [APA], 2013, p. 61). According to Schipper et al. (2015), the effects of ADHD symptoms are linked to considerable impairment in various aspects of one's life, such as academic, social, psychomotor, and emotional functioning. This implies that if left untreated, ADHD can adversely affect an individual's functioning.

Different influences shape parental and caregivers' subjective perceptions regarding the etiology and nature of ADHD diagnoses for their children. Those perceptions form acceptance, rejection, and tolerance attitudes, which subsequently inform decision-making processes regarding intervention choices. However, a brief consideration of the general human perceptions of mental disorders might lay background on parental and caregivers' subjective perceptions, considering that ADHD is a mental disorder. In developed countries, mental disorders are mostly "predicated on a model that focuses on individual intrapsychic experience or individual pathology" (Tribe, 2005, p.8). Angermeyer et al. (2020) also claim that developed countries link the cause of mental disorders to individual pathology. Furthermore, psychosocial factors also tend to be associated with the etiology of mental

disorders. As a result, people from developed countries are most likely to be open to a mental disorder diagnosis and its professional interventions.

On the other hand, traditional cultural beliefs, spiritual and religious convictions, age, and educational levels influence perceptions of mental disorders in developing countries. Tibebe and Tesfay (2015) claim that supernatural forces are primarily attributed to mental disorders in developing countries. In a study in Nepal conducted by Mandal et al. (2019) with 500 participants of three different religions, 77% of the 378 Hindu participants, 86,5% of the 89 Islamic participants, and 72,7% of the 33 Buddhist participants perceived mental disorders to be associated with a god. Many in developing countries connect mental disorders to evil spirits, magic, and witchcraft, as seen in a study by Bouhleb et al. (2013) in a mental health hospital in Tunis. However, some religious people claim that mental disorders result from sin (Angermeyer et al., 2020). These religious people argue that any deliberate disregard for God's or Allah's law produces destructive conduct in individuals, as revealed by a study conducted among Tunisians, whose population is 98% of the Muslim faith (Angermeyer et al., 2020). Chikomo (2011) also claims that some people in African countries link mental disorders to intentional disobedience of God's law.

Individuals' educational levels in developing countries may also influence their perceptions of mental disorders. For example, Abera et al. (2015) assert that illiterate people or those with low academic levels are more likely to accept supernatural powers as an explanatory cause for mental disorders than people with high educational levels. Additionally, they further assert that the younger generation has a more positive perspective on mental disorders than the older generation (Abera et al., 2015). This positive perspective could be due to the younger generation's more significant chances of educational exposure than the much older generation in developing countries. Regarding childhood mental

disorders, the above factors would shape parental perceptions concerning their child's diagnosis (Abera et al., 2015).

Particularly concerning mental disorders that primarily affect children's behavior, many Black parents and caregivers in South Africa (Kedimetse, 2017) and other minority ethnic groups in America (Alvarado & Modesto-Lowe, 2017) believe childhood behavioral challenges are part of normal development that children will outgrow. This perception leads to some parents and caregivers rejecting mental disorder diagnoses, especially ADHD, depression, or anxiety, for their children (Mandal et al., 2019). Hence, most Black children are less likely to receive mental health interventions because of their parents' and caregivers' perceptions and intervention-seeking decision-making processes.

It can be argued that the perceptions of mental disorders mentioned above shape people's decision-making regarding intervention options. Those with a medical or psychological perception of the etiology of mental disorders are likely to seek mental health professional help (Ghosh et al., 2016). Conversely, those who reject a mental disorder diagnosis and attribute its symptoms to supernatural sources are likely to turn to religion or traditional cultural intervention options for their mental health challenges (Abera et al., 2015).

Based on findings on the general human perceptions of mental disorders, including childhood mental disorders, and the influence of those perceptions on intervention decision-making, this study sought to explore what subjective attributes within the South African context influence Black parents' and caregivers' perceptions of ADHD diagnoses for their children. Moreover, as a researcher, I wondered how those perceptions influence parental decision-making regarding intervention pursuits for their children with ADHD.

## **Rationale**

Based on the literature search for this study, it was noticed that there is a dearth of research on Black parents' and caregivers' perceptions and decision-making regarding an ADHD diagnosis for their children and the implication of those for intervention pursuits and preferences within the South African context. Therefore, due to this dearth of research in South Africa, this study sought to fill that knowledge gap. In addition, parents and caregivers are gatekeepers to ADHD intervention options for their children. Thus, their feelings, thoughts, opinions, and belief systems that shape their decision-making are equally essential and should be considered when ADHD diagnoses are made and intervention options are recommended.

Furthermore, the Black South African population does not share similar demographic and cultural characteristics with the Black population from other countries. Hence, research findings (Evans, 2019) on this subject conducted outside South Africa cannot be generalized to the South African Black population. Therefore, to wholly understand the full implications of the influence of parental and caregivers' perceptions and decision-making regarding an ADHD diagnosis for their children among the Black people in South Africa and to extend ADHD knowledge, candid exploration of this issue needed to be undertaken.

Alvarado and Modesto-Lowe (2017) claim that parents' and caregivers' perceptions of ADHD may significantly influence the willingness to pursue available intervention options. The National Institute of Mental Health (NIMH, 2011) in the United States of America highlights various ADHD intervention options, including pharmacological, non-pharmacological, and multimodal interventions combining pharmacological and non-pharmacological treatment. Morgan et al. (2013) suggest that one of the reasons for parental reluctance to pursue intervention options for an ADHD diagnosis for their children is the negative beliefs and attitudes about mental health. They further assert that parental "knowledge about ADHD and their cultural attitudes about behaviors" influence intervention

pursuits (Morgan et al., 2013, p. 172). Therefore, the parental belief systems must be considered to understand the parents' and caregivers' perceptions and decision-making attached to seeking help for their children with ADHD.

Keddiemetse (2017), a child psychiatrist based in South Africa, claims that most Black parents have a misapprehension that ADHD does not impact Black children. As a result, she reveals that most Black parents struggle to accept an ADHD diagnosis for their children. Furthermore, she alleges that most Black parents she has encountered in her profession claim ADHD to be simply a behavioral problem that children will undoubtedly outgrow. This observation seems to concur with a longitudinal, mixed-methods study conducted by Bussing et al. (2012), which noted that many African American parents reject an ADHD diagnosis and treatment options.

It could be that parental perceptions of an ADHD diagnosis for their children make it difficult for them to seek help. Corkum et al. (2015) validate the claim when they argue that parents' knowledge of ADHD influences their perceptions of the nature of the disorder and willingness to pursue and adhere to recommended interventions. Notably, an individual's perception of something may depend on different influences. Many influences, such as culture, religious and spiritual beliefs, gender, age, socioeconomic status, awareness and knowledge, level of education, and stigma, shape perception and decision-making.

Although most Black parents and caregivers have been observed to struggle to accept an ADHD diagnosis and recommended intervention options for their children, as previously mentioned, Corkum et al. (2015) point out that an intervention can change these perceptions. On that note, findings from this study could be directed to ADHD awareness to clear misapprehensions for Black parents and caregivers who struggle to accept ADHD diagnoses, thus increasing access to intervention options for children with ADHD and reducing the severe effects associated with the disorder.

Furthermore, this study's findings can inform healthcare practitioners to consider Black parents' and caregivers' perceptions when making ADHD diagnoses for their children. Sensitivity to various influences that shape Black parents' and caregivers' perceptions regarding an ADHD diagnosis for their children will allow for collaborative decision-making between parents and healthcare practitioners on intervention pursuits. Coletti et al. (2012) assert that such joint, effective communication is related to increased parental ADHD intervention acceptability and adherence, thus benefitting children with ADHD. Therefore, the children need interventions to manage the symptoms of the disorder.

### **Aims of the Study**

The following aims guided the research study:

1. To explore Black parents' and caregivers' perceptions of the nature and causes of ADHD.
2. To explore Black parents' and caregivers' perceptions of an ADHD diagnosis for their children.
3. To understand factors that influence Black parents' and caregivers' perceptions of an ADHD diagnosis for their children.
4. To explore the meaning creation of an ADHD diagnosis and how it impacts Black parents' and caregivers' decision-making on the willingness to pursue various intervention options and preferences.

### **Research Questions**

The following research questions guided the study:

1. What are Black parents' and caregivers' perceptions of the nature and causes of ADHD?
2. What are Black parents' and caregivers' perceptions of an ADHD diagnosis for their children?

3. What factors influence Black parents' and caregivers' perceptions of an ADHD diagnosis for their children?
4. What meanings do Black parents and caregivers attach to an ADHD diagnosis for their children, and how do those meanings influence their decision to pursue intervention options?
5. Which ADHD intervention options, if pursued, do Black parents and caregivers prefer based on their perceptions and decision-making regarding an ADHD diagnosis for their children?

### **Outline of the Thesis**

This study explores Black parents' and caregivers' perceptions and decision-making regarding ADHD diagnosis and the implications of those perceptions on intervention pursuits. This thesis consists of 10 chapters as follows:

Chapter 1 introduces the study by outlining the background, rationale, aims, and research questions.

Chapter 2 presents a review of relevant literature for this study. The historical background of ADHD, diagnosis, etiological perspectives, and intervention options are explored within the existing body of knowledge. Additionally, the study examines different factors that influence the perceptions of parents and caregivers towards ADHD and how these factors impact decision-making on diagnosis acceptance, intervention preferences, and adherence. The text also highlights the gaps in the existing literature related to the topic under investigation.

Chapter 3 provides an in-depth analysis of the theoretical framework that was utilized to conduct the study. Furthermore, the reasoning behind selecting this particular theoretical framework is also elaborated upon.

Chapter 4 presents the methodology used in the study. It includes a discussion of the research paradigm, qualitative research design using interpretative phenomenological analysis (IPA), sample description, sampling strategy, data collection methods, ethical considerations, and data analysis. The reflexivity section is also provided in the chapter.

In Chapters 5-9, the study findings are thoughtfully presented and analyzed. The findings showing significant connections are thoughtfully grouped within a single chapter for a comprehensive discussion. The discussion of these findings carefully integrates the perspectives of the literature review and the study's theoretical framework to address the research questions at hand.

Chapter 10 concludes the study, providing an overview of findings, strengths, limitations, and recommendations for practice and future research.

## CHAPTER 2: LITERATURE REVIEW

As indicated in the previous chapter, this study focuses on exploring Black parents' and caregivers' perceptions and decision-making regarding an ADHD diagnosis for their children and the implications on intervention pursuits and preferences within the South African context. This chapter reviews literature related to the study, focusing on the critical issues and deliberations in the existing literature relevant to the research questions. I begin by exploring ADHD's historical background because it lays the foundation for understanding the disorder and its development. Debates on ADHD etiology, intervention, and over-diagnosis beliefs are presented in the chapter because they are core influencing factors that shape parental and caregivers' perceptions regarding an ADHD diagnosis and intervention pursuits and preferences. Finally, the chapter reviews the literature on factors that shape parents' and caregivers' perceptions of an ADHD diagnosis for their children and meanings attached to those perceptions as they are pertinent to decision-making regarding ADHD diagnosis acceptance or rejection, willingness to seek interventions, intervention preferences, and adherence.

### **ADHD Historical Background**

ADHD is not a recent phenomenon. In 1775, Melkior Adam Weikard, a German physician, described ADHD symptoms of inattention and distractibility, attributing the cause to environmental and neurological factors (Barkley & Peters, 2012; Mash & Wolfe, 2016). In 1798, a Scottish physician, Alexander Crichton, claimed inattention and fidgetiness caused mental restlessness, attributing these ADHD symptoms to birth and random disease (Crichton, 1798). Heinrich Hoffman, a German neurologist, described ADHD symptoms in his 1845 poem about 'Fidgety Phil' who displayed hyperactivity-impulsivity and inattention (Wolraich et al., 2019). In 1902, George Still, a British physician, believed that ADHD symptoms were caused by defective moral control (Still, 1902).

Between 1917 and 1926, another perspective on the etiology of ADHD symptoms emerged. The symptoms were associated with the encephalitis lethargica epidemic and influenza outbreak, ascribing them and multiple behavioral difficulties to infections, birth trauma, head injury, and exposure to toxins (Mash & Wolfe, 2016). Later, descriptions such as minimal brain damage and minimal brain dysfunction were used to describe children with ADHD symptoms (Clements, 1996; Mash & Wolfe, 2016).

ADHD was first included in the second edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-II) in 1968 under the hyperkinetic reaction of childhood (APA, 1968). In the DSM-III edition, the condition was labeled attention deficit disorder (ADD) with or without hyperactivity (APA, 1980), highlighting a noteworthy difference in the subtypes of ADHD. The ADD label was changed to attention deficit hyperactivity disorder (ADHD) in the DSM-IV (APA, 1994) and subsequently, its revised text version DSM-IV-TR where an ADHD diagnosis was confirmed if the symptoms were present by the age of 7 years and persistent for at least six months in at least two settings (Sadock et al., 2015).

### **Nature and Diagnosis of ADHD**

The current DSM-V classifies ADHD under three subtypes, namely, predominately inattention, predominately hyperactivity-impulsivity, and combined type (APA, 2013). These ADHD features should manifest in a persistent developmentally disabling manner for at least six months, be observed in two or more settings, and be present by the age of 12 years (APA, 2013). Generally, the core symptoms of ADHD are identified mainly by teachers and substantiated by parents and caregivers (APA, 2013). A professional such as a psychologist or a medical professional confirms the diagnosis (Ahmann et al., 2017). ADHD interventions are subsequently recommended and commence after consultation with parents and caregivers on preferred options. However, an ADHD diagnosis can create a challenge when parents and

caregivers do not accept the diagnosis or the recommended intervention options. Several influences that shape parental and caregivers' perceptions of an ADHD diagnosis for their child and the decision-making regarding suggested interventions might create this challenge.

### **Comorbidity**

According to Mash and Wolfe (2016), 80% of children diagnosed with ADHD have a comorbid psychological spectrum of behavioral, emotional, social, and academic disorders. These ADHD comorbid disorders include conduct disorder, oppositional defiant disorder, anxiety disorders, disruptive mood dysregulation disorder, major depressive disorder, specific learning disorder, and motor disorder (APA, 2013). These comorbid disorders are prevalent in individuals with ADHD compared to those without (Wall, 2017) and influence the disorder's developmental course (Masi & Gignac, 2015).

### **Over-diagnosis of ADHD**

ADHD over-diagnosis is becoming an increasing concern (Pozzi-Monzo, 2012). Several reasons may lead to ADHD over-diagnosis, fueling confusion about an already controversial disorder. Some critics of ADHD diagnoses argue that there is an increase in pathologizing acceptable and normal behavior to make profits for pharmaceutical companies (Bowden, 2013; McClure, 2013). Furthermore, Honkasilta (2016) alleges that an ADHD diagnosis is chiefly based on the subjective perceptions of professionals and caregivers regarding social norms. Thus, it is alleged that many ADHD diagnoses are made out of the socio-cultural context of the children.

Often, ADHD symptoms overlap with some psychiatric disorders (APA, 2013). For example, a child may present with inattention unrelated to ADHD but frustration, reduced concentration, and restricted ability due to a specific learning disability (APA, 2013). Alternatively, the inattention could be caused by major depressive disorder, characterized by a decreased ability to think and focus on tasks (APA, 2013). Therefore, to make an accurate

ADHD diagnosis and avoid over-diagnosis, it is imperative to differentiate ADHD from other disorders with similar characteristics.

According to Pozzi-Monzo (2012), ADHD over-diagnosis may also result from the parents', caregivers', and teachers' response to the child, parental anxiety, intolerance and annoyance, and some teachers' exasperation regarding children's behavior. Pozzi-Monzo (2012) further claims that the use of ADHD medication often brings relief to parents and teachers because the medication has a calmative effect on the child, making one wonder who benefits from the ADHD diagnosis and medical treatment. Misinformation, pressure from some parents, caregivers, and teachers, shortage of resources, and overburdened health practitioners have led to the over-diagnosis of ADHD (Pozzi-Monzo, 2012). This brings to question the accuracy of the ADHD diagnosis, which adds to its controversy.

### **ADHD Etiology Perspectives**

Even though ADHD is one of the most commonly researched subjects, its etiology is still largely debated. Gargiulo and Bouck (2019) claim that ADHD is a disability plagued by misconstructions and misunderstandings, while Ford-Jones (2015) considers its nature a controversy. This suggests that despite the vast literature on the disorder, there are still differing opinions on the etiology of ADHD. Some view ADHD etiology from a biomedical perspective, while others see it from an environmental perspective. In addition, others use the psychosocial lens to explain the etiology of ADHD. However, some attribute the existence of ADHD to multiple etiologies, i.e., biomedical, environmental, and psychosocial influences that are in complex interaction with each other. These varying etiological explanations of ADHD largely contribute to different views of the disorder and its management.

Those who view ADHD from a biomedical perspective assert that the disorder is biological and predominately 75% genetic due to the intricate interplay of "neuroanatomical and neurochemical systems evidenced by data from twin and adoption family genetic studies,

dopamine transport studies, neuroimaging studies, and neurotransmitter data” (Sadock et al., 2015, p. 1175). This leads to a belief that ADHD is a heritable neurological condition caused by an imbalance of neurochemicals, although the exact cause of this imbalance is unknown.

Despite the dominance of the biomedical ADHD etiological perspective (Sadock et al., 2015), the approach does not come without criticism. Some experts argue that the biomedical perspective gives an inaccurate suggestion that there is a single cause and solution to ADHD (Batstra et al., 2014). The criticism suggests that advocates of the biomedical perspective of ADHD are most likely to settle for pharmacological interventions and disregard other etiological risk factors and interventions. This is seen as a narrow way of understanding ADHD’s causes, development, and interventions.

Other critics of the biomedical explanation of ADHD declare that there are no scientific, measurable biological indicators or objective measures to determine the presence or lack of a pathology that triggers ADHD symptoms (Efron, 2015; Gambrill, 2014; Thapar et al., 2013). Instead, it is alleged that diagnosis mainly lies in cognitive evaluations based on the subjective opinions of health experts (Gambrill, 2014). Therefore, such critics argue that ascribing ADHD as a neurological disorder or illness is scientifically false as it lacks empirical validation. Perhaps this could be one of the reasons some question and reject the legitimacy of an ADHD diagnosis.

Environmental stressors have also been associated with the etiology of ADHD, although the mechanism of their ADHD causation is unclear (Polańska et al., 2012). Stressors include prenatal exposure to nicotine, alcohol, and drugs, low birth weight, and oxygen deprivation during birth. Diets such as sugar, food preservatives, and colorants (Barlow & Durand, 2016) and exposure to lead poisoning (Donzelli et al., 2019) are also attributed to ADHD etiology. However, there is conflicting information on diet and lead toxins’ causation of ADHD. The contribution of sugar (Del-Ponte et al., 2019; Mash & Wolfe, 2016) and lead poisoning

(Mash & Wolfe, 2016) to ADHD etiology is alleged to be nonexistent. In addition, Killen et al. (2013) argue that ADHD prevalence is similar in countries with or without lead toxins, thereby dismissing any effect of lead poisoning on ADHD etiology. Furthermore, Sadock et al. (2015) declare that carefully controlled studies have shown no evidence that diet, including sugar, causes ADHD symptoms. The belief that diets, especially sugar, are the cause of ADHD largely influences how some parents and caregivers perceive an ADHD diagnosis for their child and the decision-making on intervention pursuits.

In addition to the above-mentioned etiological views of ADHD, some psychosocial factors are also contemplated to cause ADHD in children (Kennedy et al., 2016; Pozzi-Monzo, 2012). These psychosocial influences include maternal psychiatric disorders, poor parenting, abuse, poverty, malnutrition (Sagiv et al., 2013), family dysfunction and conflicts (Barlow & Durand, 2016), and institutional deprivation (Kennedy et al., 2016). However, Thapar et al. (2012) dispute the claim, citing insufficient evidence except for severe institutional deprivation. Severe childhood deprivation leads to inattentive and overactive symptoms of ADHD, as evidenced by a study on Romanian orphans adopted by parents living in the United Kingdom (Kreppner et al., 2010). These other psychosocial factors only exacerbate the ADHD symptoms in a predisposed individual (Thapar et al., 2012). Thus, there seems to be conflicting information on the effect of psychosocial factors on the etiology of ADHD. Such conflict will likely confuse parents and caregivers of children diagnosed with the disorder.

Despite the biomedical, environmental, or psychosocial etiological explanations of ADHD, the cause of the disorder cannot be reduced to a singular explanation (Thapar et al., 2012). Therefore, it can be said that the cause of ADHD and its development is a result of the interplay of multi-risk factors affecting children who are genetically and inherently

predisposed, i.e., biomedically, to the disorder and is exacerbated by environmental and psychosocial risk influences.

Given the above review, what can be understood is that the debate on the etiology of ADHD has no conclusive consensus. The cause of ADHD is unknown, and its conflicting etiological theories create uncertainties for some people regarding its existence and validity. These differing etiological theories have resulted in various ADHD interventions and preferences.

### **ADHD Interventions**

ADHD is considered to have no cure. However, there are a number of interventions that are offered to manage the disorder to improve the quality of life for children with ADHD. The intervention options include pharmacological interventions, which are medical therapies; non-pharmacological interventions, which are non-medicinal; and multimodal interventions, which combine treatments from both pharmacological and non-pharmacological therapies (NIMH, 2011).

#### ***Pharmacological Interventions***

Medication has been found to be the most effective intervention method to manage the symptoms of ADHD (Sadock et al., 2015). ADHD medication therapy is classified under two groups: the stimulant and the non-stimulant.

Stimulants are the primary medicinal intervention for ADHD (Sadock et al., 2015). The approved medicinal stimulants in the treatment of ADHD are methylphenidate, dexamethylphenidate, dextroamphetamine, lisdexamfetamine, and the combined dextroamphetamine/amphetamine salts (Sadock et al., 2015). The methylphenidate is a dopamine and acts on the neurotransmitters in the central nervous system (Briars & Todd, 2016). ADHD medicinal stimulants are argued to have 65% - 80% efficacy in managing the

disorder (Pelsser et al., 2017). This means children who take stimulants to manage ADHD symptoms show improvement in their academic, emotional, and social functioning.

Despite the effectiveness of stimulant medications in managing ADHD symptoms, unfavorable side effects have been reported. The most common reported side effects include but are not limited to headaches, decreased appetite, weight loss, slight growth suppression, insomnia, stomachaches, irritability, hyperactivity due to rebound effects, and increased blood pressure and pulse. However, a medical practitioner can effectively monitor these side effects, making the medicinal stimulants safe to use (Sadock et al., 2015). It is important to note that stimulant medications are contraindicated for children with ADHD who have tics, anxiety, epilepsy, and glaucoma.

Although a stimulant named methylphenidate (Ritalin) has a calming effect in managing ADHD symptoms for a diagnosed person when appropriately used, it has been reported that some people abuse it for recreational purposes (Sadock et al., 2015). This raises concerns that diagnosed individuals who use methylphenidate according to prescription to treat ADHD symptoms could get addicted to it, especially considering that individuals with ADHD have to use it long-term to benefit from its effectiveness, as discontinuation of use brings back the ADHD symptoms. On the contrary, research has shown no addictive effects of ADHD stimulant medication if used according to the medical practitioner's prescription (Sadock et al., 2015).

Non-stimulant medicinal interventions are also used to treat ADHD (Sadock et al., 2015). The U.S. Food and Drug Administration (FDA) non-stimulant-approved medications include Strattera, Apyay, and Intuiv (Sadock et al., 2015). Although the non-stimulants offer the same benefits as the stimulant ADHD medications, they take longer, about 4-6 weeks, to be fully effective. Individuals taking non-stimulant ADHD medications also need to be closely monitored for side effects such as headaches, drowsiness, fatigue, stomachaches, and

increased pulse (Sadock et al., 2015). Non-stimulant ADHD medication is believed to be safe to use on ADHD children with concurrent mood, anxiety, and tic disorders.

### ***Non-Pharmacological Interventions***

Some ADHD non-pharmacological interventions have proven effective in managing ADHD symptoms (Hodgson et al., 2014).

**Behavioral Intervention.** ADHD behavioral interventions at home and school involve a number of approaches. There is the behavior modification approach that focuses on altering antecedent events and preventing undesirable behavior before it happens, such as setting rules, creating structure and routine, and constant praise (Kern et al., 2015). Another behavior modification approach uses consequences whereby reinforcement such as rewards or punishment is employed to motivate or discourage positive and negative behavior (Hodgson et al., 2014). Positive reinforcement includes praise and rewards, while negative consequences such as time-outs, verbal reprimands, and withdrawal privileges are used to discourage undesirable behavior. Although this behavioral intervention shows partial improvement in managing ADHD symptoms, the approach is only practical as long as the parents, caregivers, and teachers maintain external control and consistency in positive and negative behavior management (DuPaul et al., 2011). This suggests that the rewards should be meaningful to the child to serve as an incentive for behavior change.

Lastly, another ADHD behavior intervention is the cognitive-behavior approach through cognitive behavior therapy (CBT), which focuses on using strategies aimed at cognitive processes to enhance self-regulatory processes (Flores & Parra, 2014). The objective is to motivate the child to use effective and appropriate techniques to solve problems and respond to their environment.

**Academic Intervention.** ADHD adversely affects a child's academic functioning (Martins & Burns, 2014); hence, interventions must extend to the school setting. The teachers

are encouraged to set structure, routine, and consistency for learners with ADHD to help them manage their academic environment (DuPaul et al., 2011). Attainable goals and objectives for these learners are recommended. Rules and instructions should be clear and realistic. The teacher should also use reinforcement to motivate positive behavior and discourage undesirable behavior. Learners with ADHD will likely have poor grades and may require additional academic support (Kern et al., 2015). The academic support may be visual activities to capture their focus, extra time to complete tasks, and instant feedback. It is advised that the learner with ADHD should sit near the teacher's desk to allow easier monitoring of the learner's unpredictable behavior. Some children with ADHD thrive better academically in settings where they obtain specialized academic attention, such as in remedial and special needs schools. The teacher must collaborate with the parents to complement home-based ADHD interventions for consistency. Working in collaboration is demanding, and a break in the routine might disrupt the child's progress.

**Group Intervention.** Children with ADHD tend to have poor social skills due to their aggressiveness, impulsivity that results in intrusiveness, and difficulties interpreting other people's intentions (DuPaul et al., 2011). Hence, they often struggle to make and maintain friendships and are often rejected by peers, affecting their self-esteem. Therefore, group therapy intervention assists children with ADHD to "refine social skills and increase self-esteem" (Sadock et al., 2015, p. 1178). This is achieved by assisting them in following instructions, giving attention to a specific task or scenario, and waiting their turn when interacting with others. However, some argue that despite group therapy intervention positively impacting behavior during the sessions, there is a lack of application in real-life settings (DuPaul et al., 2011).

**Parent Training.** Families, especially parents and caregivers of children with ADHD, may require assistance in dealing with an ADHD child. Their coping strategies might

become maladaptive due to the demands caused by caring for a child with ADHD (Barlow & Durand, 2016). Thus, parental training aims to promote compliance with socially acceptable behavior from their children with ADHD while discouraging negative, undesirable, and disruptive behavior (Barlow & Durand, 2016; Mash & Wolfe, 2016). Additionally, parent training aims to assist parents with skills that will reinforce academic behavior (Sadock et al., 2015). Parents are encouraged to collaborate with school-based support to maintain consistency in behavior management at home and school for children with ADHD.

**Dietary Interventions.** The ADHD dietary interventions are classified into two groups. One focuses on eliminating food components believed to cause or aggravate ADHD symptoms, while the other aims to increase food components claimed to alleviate the symptoms (Sonuga-Barke et al., 2013). Some condiments, specific food stabilizers, and unnatural food colorings are believed to cause and worsen ADHD symptoms; hence, their removal from the diet helps prevent and manage ADHD in children (Feingold, 1977). Sugar is another food substance debated mainly as a cause of hyperactivity in children, with some researchers claiming that its elimination from the diet decreases hyperactivity (Azadbakht & Esmailzadeh, 2012; Park et al., 2012). However, Del-Ponte et al. (2019) argue that there is no substantial evidence supporting that sugar is a cause of ADHD.

Another view is that the lack of certain nutrients like minerals, amino acids, fatty acids, and vitamin D contributes to the development of ADHD. Increasing these helps decrease ADHD symptoms (Dehbokri et al., 2019). However, research shows little evidence that ADHD symptoms decrease due to dietary interventions (Sadock et al., 2015). It appears as if further extensive research still needs to be done to investigate the impact of diet on ADHD intervention.

### ***Multimodal Interventions***

The National Resource Center (2011) in the United States of America states that ADHD multimodal treatment is the use of pharmacological ADHD interventions in conjunction with non-pharmacological ones. In this intervention approach, medication, behavioral modification at home and school, and parental training through psychoeducation are used together to manage ADHD symptoms in children (Mautone et al., 2011). Research on the multimodal ADHD intervention revealed that the approach was equally effective as the medication intervention, resulting in reduced ADHD stimulant medication dosage (Multimodal Treatment Algorithm [MTA] Cooperative Group, 1999). Additionally, positive outcomes on the overall functioning of children with ADHD were reported (MTA Cooperative Group, 1999). Nonetheless, the multimodal intervention requires a collaboration of various professionals with the parents and caregivers to manage ADHD symptoms in children.

### **Factors Influencing Perceptions of ADHD: Impact on Intervention Decision-Making**

#### ***Culture***

Culture greatly influences people's perceptions regarding the etiology of mental illness and decision-making on intervention pursuits (Angermeyer et al., 2020). Culture can be viewed as a way of living influenced by a particular group's beliefs, attitudes, principles, feelings, and behaviors (Vasuthevan & Mthembu, 2016). In that regard, culture influences decision-making as it relies on the values and beliefs of the person making the decision (Dabić et al., 2015). However, culture is a complex fluid phenomenon influenced by different factors (Azuma, 2019). Consequently, an individual may create their unique culture defined by an overlap of assimilated cultures, religious beliefs, experience, geographic context, education, and socioeconomic strata. Hence, Azuma (2019) emphasizes that culture should also be viewed from an individual approach rather than a collective stance because it motivates perception, behavior, and decision-making. It can be argued that culture is a

principal determining factor in parental perceptions, acceptance, or rejection of their children's mental health diagnoses, including ADHD and the recommended intervention options. Thus, the concept of shared culture versus unique culture was explored in the study.

ADHD is diagnosed based on the child's manifestation of specific behavior using the DSM-V criteria. However, cultural disparities in behavioral interpretation may lead to different meanings in classifying normal and abnormal behavior, as validated by Wallach-Kildemoes et al. (2015). Thus, parents and caregivers who perceive the child's behavior as problematic will readily accept the ADHD diagnosis for their child and probably comply with the recommended interventions to manage the disorder. On the other hand, parents and caregivers who do not regard their child's behavior as problematic will most likely reject an ADHD diagnosis and the recommended interventions.

Evidence highlights that most Black American parents and caregivers regard ADHD-type symptoms as normal developmental behavior that children will abandon as they grow (Olaniyan et al., 2007). Likewise, in South Africa, Kediemetse (2017) shares similar observations of most Black parents and caregivers rejecting an ADHD diagnosis for their child and attributing the disorder's symptoms to a developmental phase that children will outgrow. This suggests that some people within the Black population seemingly do not perceive hyperactivity, impulsivity, distractibility, and inattention as pathological. As a result, some Black parents and caregivers are likely to reject their child's ADHD diagnosis, by so doing, denying the child diagnosed with ADHD interventions that could alleviate the disorder's symptoms.

Critics of the biomedical ADHD etiological explanation seem to validate the ADHD mentioned above perception of some Black parents and caregivers. They argue that there is an upsurge in the categorization of mental disorders, which has led to increased medicating of normal and acceptable childhood behavior (Bowden, 2013; McClure, 2013). They claim that

pharmaceutical companies profit by conveniently labeling ADHD diagnoses. As a result, these pharmaceutical companies may view some behaviors acceptable in certain cultures as pathological. Nonetheless, it could be possible that some Black children diagnosed with ADHD often go untreated due to their parents' and caregivers' perceptions despite the likelihood of benefiting from ADHD interventions.

Black parents and caregivers who are worried about their child's ADHD-type behavior yet reject the diagnosis might adopt a more authoritarian parenting approach (Jones et al., 2010). They could perceive the problematic ADHD behavior to be caused by a lack of discipline. Culturally, Black parents and caregivers are expected to be able to manage their child's behavior. Failure to do so may be interpreted as permissiveness. Furthermore, medicating or seeking behavior therapy for their child's problematic behavior could be considered culturally inappropriate and poor parenting.

Taking cognizance that the South African official languages include nine Black population languages, one could not presume that all the nine Black population groups represented by each language strictly share the same cultural beliefs because they are of the same racial group. Therefore, it was envisaged that this study might reveal any cultural disparities in parental and caregivers' perceptions and decision-making regarding their child's ADHD diagnosis within the Black racial groups in South Africa.

### ***Religious and Spiritual Beliefs***

Due to a paucity of literature on the impact of religious and spiritual beliefs on Black parents' and caregivers' perceptions and decision-making regarding an ADHD diagnosis for their child, the focus was given to the influence of spiritual and religious beliefs on perceptions of mental disorders in general. The purpose was to inform speculation on how Black parents' and caregivers' religious and spiritual beliefs may influence their perceptions and decision-making about their child's ADHD, given that ADHD is a mental disorder.

Religious and spiritual beliefs play a significant role in African lives, with most believing in the existence of supernatural powers from different sources, such as God, ancestral spirits, evil spirits, and witchcraft (Asare & Danquah, 2017). Furthermore, some Black people have embraced Christianity yet still cling to traditional ancestral worship. According to Chukwunke (2012), religious and spiritual belief systems hugely influence every aspect of the Black population's lives. Thus, Africans' religious and spiritual beliefs shape their worldview, perceptions, and decision-making, consequently informing how they perceive mental health issues.

Some studies indicate that a majority of Africans with sufficient scientific knowledge of diseases may integrate religious and spiritual beliefs when addressing illnesses (Asare & Danquah, 2017). This claim is consistent with the South African findings by Van Rensburg et al. (1992). Their study of the first-year Medunsa students revealed that two-thirds were firmly grounded in the notion that supernatural powers, witchcraft, and evil spirits exist and have the power to cause diseases. This reveals the level of influence that religious and spiritual beliefs have on shaping people's perspectives about health matters despite their educational attainments.

According to Asare and Danquah (2017), most Africans attribute mental illness to supernatural powers. In addition, Angermeyer et al. (2020) state that some religious explanations of mental challenges are attributed to God's anger due to people's sins, thereby turning to prayers and religious rituals for interventions. Some Africans believe that witchcraft and evil spirits or ancestors cause mental illnesses, even in children (Abera et al., 2015). Such would seek interventions from African traditional healers, ancestors, or churches.

The consideration of the significance of religious and spiritual belief systems is essential in the management of ADHD in children. Some recommended interventions might

go against people's beliefs, as shown by a study in India where 40% of the people declined CBT as an intervention option, claiming it was against their religious beliefs (Rathod et al., 2017). Literature has revealed that people with parapsychological explanations of mental disorders prefer spiritual, religious, or traditional rituals for intervention (Choudhry et al., 2016).

Relating the above observations to this study, it was assumed that most Black parents and caregivers who do not conform to the Western etiological understanding of mental disorders and their mainstream psychological interventions may reject their child's ADHD diagnosis. They may seek interventions from prayers, faith healers, and traditional cultural healers in an attempt to alleviate the problematic ADHD symptoms in their children (Abera et al., 2015).

In certain cultures, among the South African Black population, rituals are performed to introduce a child to its ancestors (Muvore, 2009). It is believed that if these rituals are not performed, the child will have a troubled life and unbecoming behavior. Therefore, it can be assumed that some of the children's ADHD symptoms and its comorbid oppositional disorder may be attributed to the ancestral punishment if the birth rituals for those children were ignored. In such cases, an ADHD diagnosis for the child is likely to be rejected, and traditional rituals are performed instead to manage the child's behavior.

Awareness of Black parents' and caregivers' religious and spiritual practices will enable professionals to be sensitive when diagnosing and recommending intervention options for children with ADHD within the South African context.

### ***Stigma***

Stigma is considered one of the prevailing influences that shape negative perceptions of mental disorders globally (Lien et al., 2019). Literature reveals that stigma associated with mental disorders has a significant role in shaping parental and caregivers' understanding and

decision-making regarding an ADHD diagnosis for their child (Laugesen et al., 2016; Ohan et al., 2013). Many parents reject an ADHD diagnosis due to fear of social rejection and the labeling of their children. Research reveals that the general population holds parents and caregivers liable for their child's ADHD (Ahmed et al., 2013). Consequently, parents fear the stigma of being judged as bad parents due to their child's ADHD diagnosis. This declaration is consistent with findings where Taiwan (Chang et al., 2020) and African American (Evans, 2019) parents and caregivers fear the blame of incompetent parenting due to their child's ADHD-type behavior. As such, the parents decline any ADHD interventions that might help manage their child's ADHD symptoms (Gulliver et al., 2010).

In a traditional Black family setup, children are expected to portray strict obedience to parental rule (Alvarado & Modesto-Lowe, 2017). This usually proves to be a challenge for children with ADHD as their symptoms might be regarded as defiance of parental instruction. As a result, their parents may be deemed incompetent. Thus, the stigma of being negatively perceived as inadequate and incompetent parents influences some to reject the ADHD diagnosis for their child. For this reason, some Black parents and caregivers may resort to stricter discipline to manage their child's ADHD behavior (Jones et al., 2010). Conversely, some parents welcome the ADHD diagnosis and its interventions because the diagnosis brings relief and validation of their parenting skills, helping them avert blame for their child's challenging behavior (Ghosh et al., 2016).

Some parents may feel stigmatized for medicating their children instead of using parenting skills to manage their children's ADHD behavior (Bussing et al., 2012). Hence, they may discontinue the use of ADHD medication. However, dosReis et al. (2010) claim that many continue to medicate their children because they regard the benefits to exceed the stigma hurdles. This reveals that stigma towards medication is not always an influencer of other ADHD intervention preferences for parents and caregivers.

This study was informative in understanding the idiosyncratic motivators influencing parental and caregivers' intervention preferences to guide health practitioners when making ADHD recommendations for Black children in South Africa.

### *Awareness and Knowledge*

Awareness and knowledge about ADHD form parental subjective beliefs on the nature of the disorder, informing decision-making towards intervention seeking and preference for their child with ADHD. Visser et al. (2015) findings show that the degree of ADHD awareness and knowledge varies according to ethnicity. This suggests that people of different population groups may have different understanding and intervention preferences regarding the disorder. Alvarado and Modesto-Lowe (2017) claim that African American parents and other minority populations in America may have little awareness and knowledge of ADHD compared to their White counterparts. Possibly, this is due to different interpretations of childhood behavior amongst these groups. Alvarado and Modesto-Lowe (2017) state that most parents of children with ADHD from minority groups assume the child will outgrow the ADHD symptoms, as found by Kediemetse (2017) regarding most Black parents and caregivers of children with ADHD in South Africa.

In addition, some parents express concerns about drug addiction and other side effects of ADHD medication (Nafees et al., 2014). However, these side effects can be effectively managed by consulting a physician. Sadock et al. (2015) argue that claims that ADHD medication causes drug addictions are false, yet due to misinformation and lack of knowledge, many parents reject or discontinue medication for their children without consultation with health professionals.

With vast and contradicting information about ADHD coming from experts, family, and media, parents are prone to be exposed to misconceptions, which could lead to uncertainty about their child's ADHD diagnosis, non-compliance to interventions, and

misguided interventions (DuPaul et al., 2014). Sage et al. (2018) indicate that most parents of children with ADHD use media platforms, especially the Internet, to acquire knowledge about the disorder and its intervention courses. However, due to conflicting Internet information regarding the disorder, many parents are skeptical about the existence of ADHD.

Moreover, the media can perpetuate sugar and dietary ADHD etiological beliefs (Bussing et al., 2012), misconceptions about the addictive nature of ADHD medications, and exaggerate medication side effects (Wang et al., 2016). These misconceptions may lead to rejecting the diagnosis and professional treatment options. They may also lead to flawed intervention pursuits of managing ADHD and non-compliance to interventions, thereby depriving the children with ADHD of an opportunity to manage their functioning to the optimal.

Nevertheless, the Internet as an information source might provide a support platform for parents of children with ADHD, where they can exchange information and experiences (Sciutto, 2015). When used correctly, the support platform increases awareness and knowledge about ADHD.

Sciutto (2015) points out that despite some parents of children with ADHD using the media to seek information on the disorder, many more continue to consult professional health practitioners, psychologists, and school counselors. By consulting experts on the disorder, parents increase their knowledge about ADHD and its interventions, thus increasing their willingness to accept the ADHD diagnosis and the suggested professional interventions (Bussing et al., 2012; Sciutto, 2015).

The literature consulted above highlights that awareness and knowledge of ADHD shape parental beliefs about the disorder. Those beliefs are associated with intervention preferences for their child diagnosed with ADHD. However, within the South African context, there was a gap in the literature regarding Black parents' and caregivers' ADHD

awareness and knowledge that inform their understanding of the nature and causes of the disorder and the influence on the willingness to pursue interventions. This study sought to fill in that gap in knowledge of ADHD.

### ***Socioeconomic Status***

Parental low socioeconomic status has been associated with a remarkably low understanding of ADHD and its intervention courses (Ghosh et al., 2016). The claim suggests that misconceptions about ADHD are likely to be higher among parents and caregivers from low socioeconomic strata. Bussing et al. (2003) affirm this claim when they reveal that parents from low socioeconomic groups seemingly prefer to refer to their child's behavior as simply problematic instead of acknowledging the diagnostic identifier of ADHD. Many attribute their child's ADHD behavior to sugar consumption, thus rejecting ADHD as a mental disorder (Bussing et al., 2003). Therefore, some parents and caregivers from low socioeconomic status are most likely to refuse pharmacological and behavioral modification and the multimodal intervention recommendations, opting for dietary changes or stricter parenting instead.

The above assumption corresponds with findings by Bussing et al. (2007), who indicate that African American parents from a disadvantaged background are less prone to accept that ADHD symptoms can be treated by pharmacological means. For those who do pursue professional interventions, research indicates a lack of adherence and compliance (Ghosh et al., 2016). On the other hand, research shows that parents from higher socioeconomic strata tend to accept an ADHD diagnosis for their child as a medical condition and embrace pharmacological interventions (Ghosh et al., 2016).

However, Olfson et al. (2003) speculate that lower acceptance of pharmacological interventions for children with ADHD by African American parents and caregivers is probably due to cultural influences rather than low socioeconomic status. Rathod et al. (2017)

affirm the speculation when highlighting that economic reasons do not entirely influence the preference for alternative interventions to contemporary professional ones for mental disorders. They allege that cultural beliefs, instead, also influence the choice of interventions for mental disorders. Still, Pearson (2015) maintains that low socioeconomic status presents financial challenges that may hinder access to healthcare services for individuals among economically deprived populations. This emphasizes that those from disadvantaged backgrounds have decreased access to healthcare services compared to their counterparts.

Literature on the role of socioeconomic status on parental perceptions and decision-making regarding ADHD interventions was obtained from international studies; this study focused on the issue from a South African Black population context, thereby filling the knowledge-specific gap.

### ***Level of Education***

Research by Paidipati et al. (2017) indicates that individuals with higher educational levels tend to have a more positive understanding of mental disorders compared to people with lower educational levels. It is alleged that higher educational achievement is associated with greater exposure to information and an increased understanding of ADHD (Paidipati et al., 2017; Partridge et al., 2012). As a result, parents who are more educated are likely to welcome pharmacological interventions. In other words, parents and caregivers with higher educational levels may have fewer misconceptions regarding ADHD and its intervention options.

On the other hand, parents and caregivers with lower educational levels are most likely to have a negative understanding of an ADHD diagnosis for their child (Chang et al., 2020). Such negative understanding is seemingly associated with misconceptions regarding ADHD etiology and its interventions.

Findings by Abera et al. (2015) are consistent with the claim above, whereby the researchers state that in a study exploring the causes of mental illnesses in children, 81.8% of 532 participants attributed the causes to curses and 73.9% indicated sin as religious causes of mental illnesses. The researchers claim these beliefs were more prevalent among the parents who were illiterate and less educated than their counterparts who were more educated (Abera et al., 2015). Consequently, such parents and caregivers are most likely to pursue misdirected interventions for their child diagnosed with ADHD.

Due to contradictory explanations of ADHD etiology and its treatment courses, parents and caregivers of a child with the disorder may feel unsure and overwhelmed by the diagnosis. As such, those with little education may become passive recipients of professional opinions, causing them to accept the ADHD diagnosis for their child and the suggested interventions without question. This is because parents and caregivers with lower educational levels might regard healthcare professionals as experts (Dillion, 2011).

A dearth of literature regarding the influence of educational level on Black parents' understanding of an ADHD diagnosis for their child and willingness to pursue interventions within the South African context was noted. As such, this study aimed to add to the body of knowledge about ADHD. Thus, informing professionals and service providers to acknowledge the influence of parental education level when diagnosing Black children with ADHD as it shapes the intervention decision-making.

### ***Parental/Caregivers' Gender and Age***

Early research suggests that parents have different perceptions regarding an ADHD diagnosis for their child based on biological characteristics. Chen et al. (2008) claim that mothers are most likely to accept a biomedical explanation of ADHD. On the other hand, fathers tend to attribute the child's ADHD behavior to intentional disobedience by the child (Hoza et al., 2000). The probable reason for most mothers' acceptance of the biomedical

approach to the disorder may be that female parents of a child diagnosed with ADHD tend to reach out and interact with other parents whose children have a similar disorder, unlike male parents (Ohan et al., 2013). Possibly, this increases their awareness and knowledge of ADHD; hence, they are receptive to the biomedical etiology of the disorder. Literature shows that people with increased awareness and knowledge of ADHD favor biomedical ADHD etiology (Bussing et al., 2012; Sciutto, 2015).

Given the above differing parental ADHD etiological beliefs, one would expect the mothers to prefer pharmacological interventions and the fathers to favor behavioral modification therapy. Literature reveals that those with a biomedical ADHD perspective often pursue pharmacological interventions, while those with psychological ADHD etiological explanations often favor psychological interventions (Ghosh et al., 2016). However, interestingly, one study reveals that most mothers choose behavioral modification while fathers are more inclined toward medication for ADHD intervention for their children (Meadows, 2016). Thus, their ADHD etiological beliefs appear to contradict the expected intervention preference.

Perhaps the above conflicting parental ADHD etiology beliefs and the preferred interventions are due to the following explanation. The mothers and female caregivers are often expected to assume the child-rearing role in the family (Chang et al., 2017). This suggests that if a child's behavior does not meet societal expectations, the mother is criticized for failing to uphold that role. As such, mothers and female caregivers often are blamed for their child's ADHD behavior. Chang et al. (2017) support this argument when revealing that mothers are constantly held responsible for their child's ADHD behavior, unlike fathers. This could lead to some mothers and female caregivers experiencing stigma due to societal perception of their failure to manage their child's difficult behavior. It could also be possible that this perceived negative judgment may fuel the mothers' rejections of medical

interventions because of the stigma associated with using pharmacological interventions to manage ADHD symptoms in children (Dempster et al., 2013).

Concerning parental age, some researchers claim that the younger generation tends to have more positive views regarding mental disorders than the older generation (Abera et al., 2015). Therefore, following this understanding, younger parents and caregivers tend to have a positive perspective toward an ADHD diagnosis for their child compared to their older counterparts. It may be assumed that the older generation might still be upholding traditional cultural values that influence their perceptions of mental disorders. In contrast, younger parents and caregivers might be influenced by education, which brings more knowledge and awareness of mental disorders. Furthermore, acculturation may cause the younger generation to adopt some of the cultural values of the modern societies they live in; hence, they are open-minded to mental disorders, including ADHD. It is, therefore, imperative to consider parental and caregivers' age when diagnosing children with ADHD, as it could potentially influence their perception of ADHD and its management.

### **Summary**

Based on the reviewed literature, it is clear that ADHD is a complex disorder whose etiological explanation is largely debated. This gives rise to different intervention options based on individuals' understanding of the etiology of ADHD. Furthermore, it can be concluded from the literature that the debates surrounding the disorder and its diagnostic criteria cause some parents and caregivers to struggle with accepting an ADHD diagnosis for their children. This leads parents and caregivers to reject the diagnosis and recommended intervention options. Existing literature also highlights that parental and caregivers' perceptions of ADHD diagnosis for their children may be influenced by several factors such as culture, religious and spiritual beliefs, gender, age, socioeconomic status, awareness and knowledge, level of education, and stigma. Those perceptions ultimately inform Black

parents and caregivers' decision-making about ADHD intervention preferences for their children.

### CHAPTER 3: THEORETICAL FRAMEWORK

Urie Bronfenbrenner's bioecological systems theory was employed as the lens for exploration for this study. This theory offered a multi-dimensional structure model (Elliot & Davis, 2018) for understanding different levels of influence that may shape Black parents and caregivers' perceptions regarding an ADHD diagnosis for their child and the implications on intervention decision-making and preferences. The bioecological systems theory consists of different interdependent structures that work with the active participation of the individual, influencing each other in the development of that individual (Bronfenbrenner, 1986). It was assumed that influences that shape Black parents' and caregivers' understanding and intervention decision-making regarding an ADHD diagnosis for their child are embedded in these bioecological structures, as would be outlined later in the section; hence, the suitability of this theoretical model for this study.

#### **Models of Urie Bronfenbrenner's Theory**

Bronfenbrenner's bioecological systems theory emerged from his ecological theory, which was the theorist's original perspective on understanding an individual's development (Rosa & Tudge, 2013). It is essential to highlight that Bronfenbrenner's theory of human development has undergone three evolution phases since its inception (Rosa & Tudge, 2013).

##### ***Phase 1: Ecological Model***

The first phase of the theory (1973-1979) was named the ecological model, and it focuses on the fit between the individual and the ecological context in which they exist (Bronfenbrenner, 1975). Bronfenbrenner regarded the environment as consisting of structures interconnected at four ecological levels: the microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1975). The microsystem is where the individual exists and

lives and has direct bi-directional engagement with their ecological contexts such as immediate family and home, school, work, and neighborhood (Bronfenbrenner, 1977).

The mesosystem consists of interactions between the structures of the microsystems in which the developing individual actively engages (Bronfenbrenner, 1977). The exosystem comprises social structures in which the developing individual does not actively participate, yet they affect the individual's immediate ecological setting (Bronfenbrenner, 1977). These include extended family, friends, health care services, mass media, and public services. According to Rosa and Tudge (2013), the exosystem level is important because it is where political role-players create societal policies, including health policies, that affect an individual. The last level of Bronfenbrenner's ecological theory is the macrosystem, consisting of ideologies, customs, norms, values, and attitudes of the societal culture in which the individual exists. The macrosystem also contains the socioeconomic status of a society. The influence of the macrosystem level flows through the interactions of all other levels.

### ***Phase 2: Bioecological Model***

The second phase of Bronfenbrenner's ecological theory (1980-1993) saw the incorporation of an individual's biological attributes, such as gender and age, interacting with the ecological context in human development (Eriksson et al., 2018; Rosa & Tudge, 2013). This acknowledgment of the influence of an individual's biological characteristics in their development led to the renaming of the model to the bioecological theory of human development (Rosa & Tudge, 2013). Furthermore, the chronosystem level was added to the framework (Eriksson et al., 2018). This additional level acknowledged the influence of changes over time on how the individual relates to their environment in the development course.

### ***Phase 3: Process-Person-Context-Time Model***

The third and final phase of Bronfenbrenner's theory (1993-2006) led to the emergence of the process-person-context-time (PPCT) model, emphasizing the proximal processes currently termed the "engines of development" (Bronfenbrenner & Evans, 2000, p. 118). The proximal process component is the interplay between the individual and the immediate settings that influence that individual's development (Bronfenbrenner & Morris, 1998). The person component focuses on the individual's biological attributes that influence the process; the context is the influence of the four ecological levels on the proximal processes that lead to development; and the time component refers to the chronosystem as identified in the bioecological system (Bronfenbrenner & Morris, 1998).

### ***Preferred Model for this Study***

Noting the evolutionary phases of the original Bronfenbrenner's theory, the researchers must explicitly clarify the model they will employ to guard against theoretical confusion (Eriksson et al., 2018; Rosa & Tudge, 2013). It is important to note that the earlier models of the theory are still helpful, valuable, and acceptable in research when used within a relevant context despite the theorist admitting to the latest model (PPCT) as the most appropriate (Bronfenbrenner & Evans, 2000).

Although Bronfenbrenner's ecological model acknowledges that a person's mental health requires to be explored using a multi-layered approach, it gives more attention to contextual or environmental influences, undermining the role of the individual's biological characteristics such as gender and age in the developmental course (Rosa & Tudge, 2013). On the other hand, critics of the PPCT model for use in public mental health highlight that the model puts more emphasis on "proximal processes and the immediate environment, lacks a clear focus on how social, economic and cultural environment that people are exposed to influence mental health" (Eriksson et al., 2018, p. 431). This suggests that the PPCT model

gives less attention to the social influences of mental health and is more suited for individual interventions than being applied to public health care interventions.

Considering the limitations mentioned above of the other two models of Bronfenbrenner's human development theory, the bioecological systems model of the theory was applied to this study. This is because the model considers the "intrapersonal, physical [biological], organizational and cultural" (Eriksson et al., 2018, p.430) influences that may shape a Black parent and caregiver's perceptions and decision-making regarding an ADHD diagnosis and interventions for their child. Thus, this model encompasses and enables me to explore the research topic within a larger context.

### **Applying the Bioecological Systems Theory to the Study**

#### ***Microsystemic Level***

Based on the bioecological systems theory, an individual's biological characteristics, such as gender, age, and temperament, which lie within the microsystem level, play a role in an individual's understanding of a given matter. Reviewed literature reveals that the younger generation seems to be more open-minded toward mental disorders compared to the older generation (Abera et al., 2015). It was, therefore, presumed that the younger Black parents and caregivers within the South African context might be more receptive to an ADHD diagnosis for their child. According to Chen et al. (2008), most females have a biomedical perspective of ADHD etiology. In contrast, Hoza et al. (2000) allege that most Black males tend to have a psychosocial perspective, attributing their child's ADHD symptoms to defiance and disobedience. Thus, gender, as a biological attribute of an individual, shapes parental perceptions of ADHD in their child.

In addition, a parent who considers ADHD to be caused by poor parenting might experience low self-esteem due to the self-stigma associated with their child's ADHD diagnosis, causing such an individual to reject the diagnosis and its recommended

interventions. Therefore, an individual's characteristics, which fall within the microsystemic level, influence perceptions and behavior. It was from this view that Black parents' and caregivers' characteristics were explored concerning their perceptions and decision-making regarding an ADHD diagnosis and intervention pursuits for their child.

Furthermore, Bronfenbrenner (1989) states that interpersonal relations an individual has within the microsystem with their immediate family and workmates contribute to that individual's development. Accordingly, parental perceptions and decision-making regarding a mental disorder diagnosis and interventions for their child may be embedded in the opinions of their immediate family and workmates (Bussing et al., 2015). For this reason, parents and caregivers may have a positive perspective about an ADHD diagnosis for their child based on immediate family members' and workmates' experiences and support. This makes it easier for parents and caregivers to seek intervention for their child diagnosed with ADHD. Conversely, they may develop stigma toward the disorder's diagnosis and its interventions due to negative opinions from those at their microsystem level, thereby hindering them from seeking effective interventions for their child with ADHD.

### ***Mesosystemic Level***

As the mesosystem is the interactions and connections of the microsystems (Bronfenbrenner, 1977), the school, particularly the teacher, may influence the parental perceptions of their child's ADHD behaviors. The teachers are key players in identifying most ADHD-type behaviors in children (APA, 2013). Therefore, the approach that the teachers employ to interpret and discuss the child's behavior may prompt the parents to either accept or reject the suggestion that the child may have ADHD. How a child is perceived at home and school may differ based on the home and school culture.

Hence, the school relating in a mesosystemic manner with the home, i.e., parents and caregivers, should be aware of the child's home culture to interpret the child's behavior in

context. This is particularly important in the South African setting where some Black children attend schools with predominantly White culture and teachers. Keeping in mind that the school can be a vital resource for ADHD assistance through the services of its school-based educational psychologist, a lack of awareness of differing behavior interpretations may lead to lower utilization of this service among children whose parents and caregivers perceive their child's behavior as misconstrued. Therefore, the mesosystem provides the structure to explore interactions between the school and the home regarding a child's behaviors and how those interactions shape the parental understanding of their child's behavior.

### *Exosystemic Level*

Within the exosystemic level, the interaction between the parents and the professional healthcare service providers can influence the parental understanding of ADHD and its interventions. Parents and caregivers tend to respond positively to shared decision-making with health practitioners (Coletti et al., 2012). Therefore, there is a likelihood of increased medication adherence in children whose parents and caregivers have such a relationship with the health practitioners (Coletti et al., 2012). Thus, effective communication between parents and caregivers, who are gatekeepers of their children's health decisions, and the healthcare service providers may increase parental acceptance of their child's ADHD diagnosis and intervention course.

Parents' and caregivers' beliefs of ADHD and its interventions can be informed by knowledge and awareness of the disorder. However, it is noteworthy to be mindful that although some sources of knowledge and awareness may provide accurate and valuable information about ADHD, some may fuel misconceptions and misinformation about the disorder, leading to futile intervention pursuits (DuPaul et al., 2014). The media, a component of the exosystem, often presents sensationalized information about ADHD, thereby increasing misconceptions in the public. For instance, it may exaggerate the ADHD

etiology to poor parenting or sugar consumption and the effects of pharmacological interventions, causing parents to be ambivalent towards such interventions. Bussing et al. (2012) attest to this, indicating that the media portrays the use of ADHD medication as harming children and an effort to control their behavior chemically. As a result, distorted reporting may cause many parents and caregivers to reject an ADHD diagnosis and intervention courses. Thereby denying children diagnosed with ADHD an opportunity for interventions that will assist them in effectively managing the symptoms of the disorder.

Other sources of knowledge and awareness for parents and caregivers of children with ADHD within the exosystem level are friends and extended family, often used as a reference for validation for decision-making (Feinstein et al., 2009). The relationship between parents and caregivers with extended family is particularly relevant for this study because of the emphasis on Black families. According to Feinstein et al. (2009), the extended family has an impact on Black families because it influences the lives of their kin. An extended family may negatively perceive a child with ADHD as disobedient. As such, when some parents accept an ADHD diagnosis for their child and pursue interventions, they may be judged as avoiding parental responsibility to control their child's behavior. Consequently, parents and caregivers may suffer stigma, which negatively affects their perceptions of their child's diagnosis.

### ***Macrosystemic Level***

The macrosystem is the society's overall cultural norms, beliefs, and values (Bronfenbrenner, 1977). According to Dabić et al. (2015), culture determines people's way of life and their decision-making processes. Thus, parental perceptions and decision-making regarding their child's ADHD diagnosis are likewise immersed in the cultural context in which they live. Important to note is that some parents from the South African Black population seemingly accept their children's freedom of expression and verve (Kedimetse, 2017). Therefore, when diagnosing a Black child with ADHD, attention should be given to

cultural context when interpreting behavior. This is important because symptoms of ADHD, such as hyperactivity and impulsivity, may be regarded as normal childhood behavior in some Black cultures. Thus, culture influences meaning creation. This suggests that some Black parents and caregivers are likely to reject the validity of an ADHD diagnosis and its interventions for their child based on their cultural interpretation of childhood behavior.

Some parents within the African culture attribute childhood mental disorders to supernatural powers (Abera et al., 2015). Given that ADHD is a childhood mental disorder, there is a possibility that some Black parents and caregivers may perceive their children's ADHD symptoms as caused by supernatural powers. Such thinking may influence their decision-making regarding ADHD interventions. Instead of pursuing professional interventions, parents who believe in supernatural causes of mental disorders may seek culturally approved interventions such as traditional or spiritual healing. Thus, the macrosystemic influence of societal ideologies, such as religious beliefs and culture, has a significant role in parental perceptions of childhood mental disorders.

Another component of the macrosystem is the socioeconomic dynamics of the society in which an individual belongs (Bronfenbrenner, 1977). Societal financial resources available in the broader community constitute the context in which parents and caregivers of children diagnosed with ADHD function. Therefore, if these parents and caregivers belong to socioeconomically deprived communities, there is a likelihood of limited educational attainment as well as exposure to ADHD (Ghosh et al., 2016). Consequently, ADHD misconceptions may be higher among parents and caregivers of low socioeconomic strata.

Additionally, socioeconomically deprived communities often experience inequalities in health service provisions. Limited access to healthcare services may result in poor ADHD management for some families from low-income groups as they may be economically struggling to access places with adequate services for their needs (Pearson & Meadan, 2018).

This is a reality for a majority of Black families living in low-income areas within the South African context. Therefore, parents' and caregivers' income status, educational achievement, resources, and services availability due to financial and geographic access are socioeconomic status features incorporated within the macrosystem, influencing parental perceptions of ADHD and its intervention preference and management (Paidipati et al., 2017).

### ***Chronosystemic Level***

The last level in the bioecological systems theory is the chronosystem, which considers the influence of changes over time in relation to an individual's interactions with the environment and the influence on the individual's development (Eriksson et al., 2018). In the context of this study, the chronosystem was employed to explore the influence of acculturation on Black parents and caregivers' perceptions and decision-making regarding an ADHD diagnosis for their child. Acculturation is the "culture learning process experienced by individuals who are exposed to a new culture or ethnic group" (Organista et al., 2010, p. 128).

Acculturation happens gradually over time through exposure to a different culture from one's own. This study regarded acculturation as the interplay between the macrosystemic culture component and the chronosystem. Being aware of the significant number of Black families that now live and work with and among other racial societies in South Africa, the influence of different cultures on each other cannot be ignored. As such, it could be possible that over time, some Black parents and caregivers intermingling with different cultures might perceive and interpret their child's ADHD diagnosis based on different cultural beliefs they have been exposed to and probably adopted. Hence, this study considered demographic influences to explore the impact of personal culture when interpreting and discussing its findings.

### **Summary**

This chapter presented Bronfenbrenner's bioecological systems theory as a theoretical foundation for understanding factors that influence Black parents' and caregivers' subjective perceptions and decision-making regarding an ADHD diagnosis for their children and the willingness to pursue offered interventions. In the chapter, I began by discussing the evolution of Bronfenbrenner's ecological theory, which resulted in the emergence of three models of his theory. After that, I explained the suitability of the chosen bioecological model of the theory for this study by explicitly revealing how factors that shape Black parents' and caregivers' ADHD perceptions within the South African context are embedded in the bioecological structures of the theory. Simultaneously, I explicated how those perceptions impact parental and caregivers' decision-making regarding intervention pursuits and preferences. The next chapter focuses on discussing the methodology employed in this study.

## CHAPTER 4: METHODOLOGY

The previous chapter presented the theoretical framework for understanding the study. This chapter begins by explaining a research paradigm and its different dimensions. Four commonly used research paradigms, positivism, postpositivism, critical theory, and interpretivism, are briefly discussed. Next, the justification for using interpretivism as the paradigm to inform the methodology for this qualitative study is outlined. According to Creswell (2014), research methodology is a systematized and structured way of navigating the research process, while Yin (2016) attests that it focuses on addressing the research questions. Therefore, a detailed description of the sample, sampling strategy, methods of data collection, ethical considerations, and data analysis are explicitly outlined in this chapter.

### **Research Paradigm**

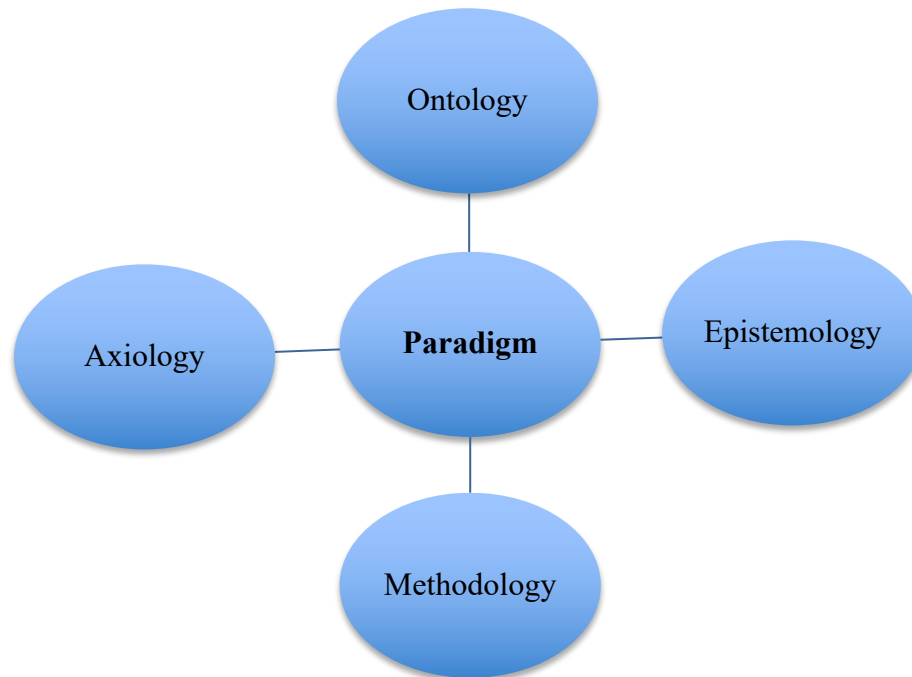
In order to understand the philosophical bedrock of the methodology for this study, it is important to discuss the research paradigm in which the study is embedded. A research paradigm is a belief system about the world that guides a researcher's approach to exploring or investigating a chosen study and interpreting its results (Guba & Lincoln, 1994; Kivunja & Kuyini, 2017). Therefore, a research paradigm guides the directions in which research is conducted. Different research paradigms assume distinctive methods of defining reality.

As shown in Figure 1, a paradigm consists of four dimensions: ontology, epistemology, methodology, and axiology (Lincoln & Guba, 1985). Ontology concerns the researcher's philosophical "assumptions about reality, how it exists, and what can be known about it" (Rehman & Alharthi, 2016, p.51). Thus, ontology focuses on an individual's beliefs about reality. The epistemology dimension of a paradigm refers to "how we come to know something; how we know the truth, or reality" (Kivunja & Kuyini, 2017, p. 27). Epistemology relates to the study of knowledge, how it is obtained, and how truth can be

arrived at. According to Guba and Lincoln (1994), epistemology defines the relationship between the researcher and the truth.

The methodology dimension of a research paradigm refers to structured processes the researcher engages to produce data that will contribute to knowledge regarding the study under exploration or investigation (Kivunja & Kuyini, 2017). Therefore, methodology considers research design, participant selection, tools and techniques for data collection, and data analysis techniques to understand the study being undertaken. It should be noted that the researchers' ontological and epistemological stance influences the methodological approach they will employ in conducting research.

The last dimension in a research paradigm is axiology, which deals with value issues and ethical considerations (Brown & Dueñas, 2020; Lincoln & Guba, 1985). At the beginning of the research journey, during the conceptualization of the research proposal, researchers need to reflect on why and how the research would be valuable and the ethical considerations to be taken into account during the research process. The level of its trustworthiness also measures the value of any qualitative research. In this research, the value of the study was discussed under the Rationale section in Chapter 1, explaining the importance of why the study was undertaken. Furthermore, the study's trustworthiness will be outlined in this chapter, explicitly displaying the quality of the study. Ethical considerations pertain to well-thought-out research practices that allow one to conduct research in ethically acceptable ways, as discussed in the Ethical Consideration section of this chapter.

**Figure 1:***Dimensions of a Research Paradigm****Commonly used Paradigms in Research***

Every research project should be within a paradigm based on the researcher's philosophical assumptions about reality. However, Brown and Dueñas (2020) argue that a paradigm serves no purpose if it “only exists in the mind of the researcher and is not clearly communicated” (p.549). Therefore, clearly highlighting one's paradigmatic stance in research is important.

Based on the individual's inclination about the worldview, some researchers are rooted in the traditional positivist paradigm, which ontologically assumes that reality exists without the influence of humans (Brown & Dueñas, 2020). Positivists frame their philosophical perspectives in realism, whereby a reality is believed to exist context-free without the influence of social constructions. Epistemologically, positivists consider knowledge objective and acquired through scientific measures that eliminate or minimize the

researcher's influence (Guba & Lincoln, 1994). Consequently, proponents of the positivist paradigm adopt a quantitative inquiry in their methodology, focusing on subjecting hypotheses to empirical experiments by manipulating variables (Guba & Lincoln, 1994). According to Lincoln et al. (2011), the positivists' axiological stance is that the researcher's values are excluded from the study to arrive at the study's empirical findings.

However, in disagreement with the positivists' strict empirical quantification of data, a modified version of positivism called the postpositivist paradigm emerged. This approach acknowledged that although reality "can never be fully understood; but at best, only approximated" (Kivunja & Kuyini, 2017, p.32). As such, the postpositivist approach accommodates qualitative research methods in social science to understand meanings attached to human behavior (Guba & Lincoln, 1994). Notably, postpositivists do not aim to reject positivism in research altogether. Instead, they seek to complement it with the mixed-methods approach (Panhwar et al., 2017). The mixed-methods approach uses both quantitative and qualitative techniques in the research process.

The critical theory paradigm, also known as the transformative paradigm, views reality from the historical realism lens (Rehman & Alharthi, 2016). Critical theorists believe in subjective multiple realities that are historically constituted, and they focus on "oppression and unequal power relationships in society" (Okesina, 2020, p.61). In critical theory, a transactional subjective epistemology is upheld, and knowledge is viewed as empowering and used to question and transform the status quo (Aliyu et al., 2015). The goal of critical theory is to bring transformation by encouraging critical awareness of political and social issues. Critical theorists are inclined toward action research, critical ethnography, and critical discourse analysis in their methodology using mainly qualitative data collection tools such as individual interviews and focus groups, ideological reviews, journals, and open-ended questionnaires (Brown & Dueñas, 2020). Particularly, critical theorists value a collaborative

standpoint with the research participants whereby participants are encouraged to be actively involved in the stages of the research process to empower marginalized groups. The axiological approach in the critical paradigm focuses on considering cultural norms (Kivunja & Kuyini, 2017).

Another paradigm commonly used in research is interpretivism. Proponents of the interpretive paradigm focus on inductively exploring and understanding the subjective nature of reality (Okesina, 2020). Interpretivism postulates that a phenomenon under study is best explored and understood when the researcher actively interacts with the individuals experiencing the phenomenon. Accordingly, reality is viewed as constructed meanings that individuals attach to their lives. Hence, the interpretive paradigm is also known as the constructivist paradigm (Kivunja & Kuyini, 2017; Rehman & Alharthi, 2016).

Ontologically, interpretive researchers take a relativist stance, believing that realities have multiple socially constructed meanings (Rehman & Alharthi, 2016). Thus, realities are created based on the meanings people ascribe to their experiences. Interpretivists discard the notion of discoverable realities. The interpretive paradigm assumes a subjectivist epistemological dimension, claiming that realities are created through contextually based meanings drawn from the interactive engagement between the researcher and the participants (Nguyen, 2019). Aliyu et al. (2015) assert that interpretivism aims to study different occurrences to understand people's behavior.

The researchers rooted in interpretivism engage in research from a naturalist methodology perspective using qualitative inquiry techniques such as semi-structured, open-ended individual interviews and focus group discussions, participant observations, textual and visual analysis, reflective sessions, and discourse analysis (Kivunja & Kuyini, 2017; Nguyen, 2019). Such methods of data collection used in qualitative research allow for the phenomenon to be explored within context, giving rich, in-depth data. Regarding axiology in

interpretivism, Nguyen (2019) states that “a balanced axiology believes that the values of a researcher will be reflected in the balanced reports of the research findings” (p.6). Being cognizant of the intertwined relationship between the interpretive researchers and the participants, the researcher’s values and beliefs may influence the data analysis process and the research findings. Therefore, it is imperative for interpretive researchers to engage in the reflexivity process to bracket their beliefs, values, and experiences that might influence the reporting of the research findings (Smith et al., 2009).

Consequently, Guba and Lincoln (1994) proposed that interpretivism researchers engage in the process of trustworthiness to validate the authenticity of research findings. They claim that trustworthiness involves credibility, transferability, dependability, and confirmability of research findings to qualify one’s study as acceptable. Interpretive research findings that fail to meet the trustworthiness requirements are unlikely to add value to the body of knowledge in the area in which the study is conducted.

This study sought to explore Black parents’ and caregivers’ perceptions and decision-making regarding an ADHD diagnosis for their children and the implications of those on intervention pursuits. The characteristics of the study required an in-depth exploration of the individual subjective experiences of the participants and how those shaped the participants’ realities. Therefore, this study used the interpretive paradigm as its framework. This was so because interpretivism aligned well with the nature of this study. Furthermore, Kivunja and Kuyini (2017) posit that contextual influences must be considered in interpretive systematic inquiry. Similarly, this study’s exploration considered diverse influences such as culture, religious and spiritual beliefs, gender, age, socioeconomic status, awareness and knowledge, level of education, and stigma in the literature review.

### **Research Design and Framework**

Due to a need for an inquiry that gives subjective, in-depth, rich participant data, the study was qualitative (Bhati et al., 2014; Creswell, 2013). The qualitative inquiry was thus in harmony with the aims of this study. This qualitative study was explored using an Interpretative Phenomenological Analysis (IPA) approach to understand and interpret the meanings that participants attach to their everyday experiences (Tomkins, 2017). Thus, the meaning created by Black parents and caregivers of ADHD diagnoses for their children shaped by various influences was explored. Furthermore, willingness towards preferred intervention options based on the meaning creations carried by each participant was also explored.

The IPA approach is built on the foundations of phenomenology, hermeneutics, and idiography (Noon, 2017). Phenomenologists seek to attain an individual's inner perspective through thoughts, feelings, and memories to access the individual's lived experience (Noon, 2018). However, IPA focuses on "an explicit commitment to person-in-environment and not just phenomenon-as-experienced" (Quest, 2014, p.43). Hence, I focused on the context-dependent perceptions of participants shaped by different influences. Acknowledging that several influences may shape perception, I explored the possibility that no single reality underlay the research problem. Instead, different individuals may have formed different realities relevant to the problem by attaching meanings shaped by their perceptions of an ADHD diagnosis for their children.

Hermeneutics is considered the art of interpretation (Smith et al., 2009). However, IPA is seen as double hermeneutics "whereby the researcher is trying to make sense of the participant trying to make sense of what is happening to them" (Smith, 2011, p.10). Therefore, IPA enabled me to interpret and make sense of the participants' lived experiences and perceptions regarding a diagnosis of ADHD for their children and how those determine decision-making regarding different intervention pursuits.

Finally, Moses and Knutsen (2012) state that idiography focuses on how individuals understand their lived experiences about a context-based phenomenon. Joeg and Othman (2016) emphasize the IPA's idiographic commitment to subjective experiences. Therefore, IPA is idiographic in that it aims to understand each participant's story through a deep, individualized analysis of every thought, belief, and behavior rather than a generalized one.

IPA allowed me to gain in-depth, rich data on different factors influencing Black parents' and caregivers' perceptions and decision-making regarding an ADHD diagnosis for their children and revealed how those influence their willingness to pursue different intervention options.

### **Critique of IPA**

IPA qualitative research employs language as a tool by which participants share their experiences (Creswell, 2013). However, this becomes a challenge when the participants do not have the language abilities to articulate their subjective experiences. In addition, participants may be reluctant to divulge sensitive experiences. To overcome this challenge, the researcher must create an empathetic and safe interview environment conducive to the participants sharing their experiences.

Another drawback of the IPA approach is that in-depth meanings depend on the researcher's ability to interpret and make sense of the obtained data. This might be a challenge for novice researchers. However, this challenge can be overcome by following IPA research guidelines set by Smith et al. (2009).

Finally, small samples in IPA research bring to question the transferability of findings (Charlick et al., 2016). Nonetheless, working with participants' detailed subjective context-based lived experiences allows the researcher to obtain rich insights into their reality (Alase, 2017). Such insights can inform policy and practice, especially in understanding different factors shaping Black parents' and caregivers' perceptions of an ADHD diagnosis for their

children and the influence those perceptions have on the decision-making regarding various intervention pursuits.

### **Sampling and Sample Size**

A non-probability, purposive sampling procedure was employed in the study. Purposive sampling allows the researcher to select participants who provide rich and valuable information about the studied phenomenon (Etikan et al., 2016). In-depth, rich data was gained by purposively selecting Black parents and caregivers who met the set criteria. Snowballing was employed whereby the participants invited other people who met the sampling criteria to participate in the study (Naderifar et al., 2017).

I proposed to use a maximum variation sampling strategy based on the set criteria to explore different perspectives about the phenomenon being studied (Creswell, 2012). Therefore, an attempt was made to include diversity in the characteristics of culture within the Black population, religious and spiritual beliefs, gender, age, socioeconomic status, level of education, and careers in the sample. This was done to highlight factors that influence perceptions of ADHD among the participants and the impact on the decision-making towards intervention pursuits and preferences.

Participants were recruited from several identified sites chosen to “best help [me] understand the central phenomenon” (Creswell, 2012, p.206). One site was a mental health organization where I completed my internship program. I sought permission from the organization’s director to advertise my study invitation flyer for sampling recruitment purposes. This organization was considered because it is located in the center of Johannesburg and provides services to people of diverse contextual backgrounds. Any potential participants who were personally known to me or who in the past had consulted with me in my capacity as an intern educational psychologist were to be excluded from the study to avoid bias and conflict of interest.

Additionally, I requested permission from pediatricians, psychologists, and psychiatrists from private practices in the Gauteng area to facilitate the advertising of my study invitation flyer to potential participants interested in volunteering in the study. Furthermore, I approached the administrators of various parent groups on Facebook for permission to post the study invitation flyer on the groups for study sampling purposes. Finally, I requested my friends and family to circulate the call for participants. The different sampling sites were chosen to enhance broader demographic characteristics, including socioeconomic status, cultural and religious backgrounds, gender, age, and level of education. These demographic features of the sample were assumed to influence perception and decision-making. Sampling was delimited to the Gauteng area for geographic proximity for the participants who would have preferred face-to-face interviews.

Although there is no specific answer to the sample size in qualitative research, most researchers agree that IPA studies have relatively small sample sizes to keep their idiographic nature (Creswell, 2014). Additionally, Alase (2017) asserts that IPA studies usually have sample sizes of 2-25 participants. Therefore, I regarded a sample size of 21 participants as appropriate to explore different influences that shape Black parents' and caregivers' perceptions and decision-making regarding an ADHD diagnosis for their child. It was anticipated that the chosen sample size provided adequate diversity in the demographic attributions of the sample to explore their influence on parental perceptions. Breen (2007) supports the claim when highlighting that where individual attributions are anticipated to impact findings, the sample size can range between 20-24 participants.

### ***Inclusion Criteria***

Participants for this study were Black parents and caregivers of a child between the ages of 4 and 17 years with a confirmed ADHD diagnosis. Broadening recruitment to this age range was intended to have a sample most likely affected by ADHD. ADHD "symptoms are

difficult to distinguish from highly variable normative behaviors before the age of 4 years” (APA, 2013, p. 62). Therefore, the sample did not consider parents with children under four years old. According to the Children’s Act 38 of 2005, a child is regarded as an adult at the age of 18 years. Hence, the study’s top end of the age range was set at 17 years old. In addition, this age range of 4-17 years old revealed how a child’s age at the time of diagnosis influences parental perceptions of ADHD.

The children of the participants were either receiving some form of ADHD intervention to manage their diagnosis or not to reveal the influences that motivate parental decision-making on intervention pursuits. The participants were over 18 years old, able to read and express themselves in English, and resided within the Gauteng province. Furthermore, eligibility for inclusion in the study required a willingness to provide written informed consent for participation, audio recording of the individual interview, and video recording of the focus group.

### ***Exclusion Criteria***

Black parents and caregivers who did not have a child with a confirmed ADHD diagnosis were excluded from the study. This was to avoid hypothetical cases in the study as they ran the risk of providing limited information on the research topic. Jiang et al. (2014) confirm that parental opinions towards treating a hypothetical child are different compared to opinions for their child. Black parents and caregivers of children between the ages of 4-17 who lived beyond the Gauteng geographic parameters were excluded from the study for practical reasons to accommodate participants who preferred face-to-face interviews.

### **Recruitment and Procedure**

Before beginning the data collection process, I obtained approval for my study from the Human Research Ethics Committee at the University of the Witwatersrand. I received permission from the gatekeepers at the selected sampling sites to advertise the study. Once

permission was granted, I gave the sampling sites an invitation flyer to circulate the study. Interested volunteers were asked to contact me via 'SMS,' call back, or email using the contact information provided in the flyer. I then contacted potential participants via email or phone to introduce myself, explain the study's aims and nature, and assess their willingness and eligibility to participate. Eligible volunteers were sent participant information sheets via email, WhatsApp, or in person. Interviews were scheduled at a time and date that worked for the interested and eligible participants.

The face-to-face interviews, through mutual agreement between the participants and me, were conducted in Johannesburg at venues and environments that were safe and convenient for the participants. The venues used were either at the participant's home (living rooms), work office, or church office (see Appendix L), on participants' requests. The participants were already familiar with these spaces, which made them feel safe. The rooms used for the interviews were kept closed and out of bounds to other people, ensuring privacy. These venues were also convenient for the participants since they did not have to incur any traveling costs and time. Instead, I, the researcher, drove to the venues to meet the participants. As the participants felt comfortable sharing their experiences in these familiar and safe venues, they responded more openly. In keeping with the South African COVID-19 pandemic safety regulations, all the COVID-19 safety guidelines were followed during data collection. On the day of the interviews, all participants were given further clarity on the study to ensure they understood their rights. All participants were asked for their written informed consent to participate in the study. All participants were requested to complete a short 5-minute demographic information sheet before the interviews.

### ***The Participants***

The research involved 21 Black participants, comprising 16 females and five males. The participants were identified chronologically as P1-P21 according to the order of their

availability for the interviews. The ages of the participants' children diagnosed with ADHD ranged from 5 years old to 15 years old. All the participants, except for P5 and P12, were the biological parents of the children they represented. P5 and P12 were the formal primary caregivers of their sisters' children and considered them as their own. Each participant in the study had only one child with a confirmed ADHD diagnosis, except for P6 and P8, who had two children diagnosed with the disorder. However, P6's case was different as she had a 14-year-old son who was the target child for the study and a 19-year-old child who also had an ADHD diagnosis but did not qualify for the study due to the age limit. Nonetheless, P6's account was still considered to have been informed by her experience with her 19-year-old child's diagnosis.

Out of the 21 participants, all but one took part in individual interviews, with 11 of those 20 agreeing to join one of the two focus groups in the study. The remaining participant could not participate due to illness but joined a focus group. In total, 12 participants were included in the focus groups, each consisting of one male participant and five female participants.

It is important to consider the contextual factors influencing participants' narratives, including demographic factors shaping their interpretation of lived experiences. To this end, Table 1 presents the participants' demographic characteristics and other relevant information. It is worth noting that, in addition to the information provided in Table 1, all participants except P12 identified as Christians. However, three participants, P2, P5, and P13, indicated that although they were Christians, they were not actively practicing Christianity. Participant P12, on the other hand, indicated that he did not adhere to any religious affiliation. The participants' demographic attributes and other relevant information enable the reader to understand each participant's subjective lived experiences within context.

**Table 1:***Demographic & Other Summary Information*

<b>Participant (P)</b>	<b>Gender &amp; Age</b>	<b>Ethnicity &amp; Marital Status</b>	<b>Highest Level of Education (&amp; Career)</b>	<b>Income Range</b>	<b>Age of Child at interview &amp; Gender</b>	<b>Participant's relationship to child</b>	<b>Diagnosis: Acceptance (√) Rejection (X)</b>	<b>Intervention</b>
<b>P1</b>	Female: 41	Zulu: Married	Diploma in Nursing <i>(Registered Nurse)</i>	R20 000 – R30 000	7 years - Female	Mother	√	<i>Past Intervention:</i> -Risperdal (for a month) <i>Currently on:</i> -Occupational Therapy -Play Therapy -Speech Therapy - In the process of moving the child to a remedial school
<b>P2</b>	Male: 43	Zulu: Married	Diploma <i>(Vehicle Examiner)</i>	R10 000 – R15 000	14 years - Male	Father	X	Herbal Supplements
<b>P3</b>	Female: 31	Zulu: Single	Diploma in Business Management <i>(Mobile Network Provider Senior Consultant)</i>	R10 000 - R15 000	9 years - Female	Mother	√	-Dietary Intervention -Herbal Intervention -Teacher Support
<b>P4</b>	Female: 39	Zulu: Single	Diploma <i>(Sales Manager of prominent leading hotels)</i>	Undisclosed	13 years- Male	Mother	√	<i>Past Intervention:</i> -Concerta -Edu-block classes (before Covid 19 lockdown) -Swimming (before Covid 19 lockdown) <i>Currently on:</i> -Mentat -Omega 3 and supplements

-Dietary changes to healthy diet.  
- Home schooling

<b>P5</b>	Male: 38	Zulu: Married	Honours Degree (Employee of a leading rail, port & pipeline company)	R40 000 – R50 000	11 years- Female	Uncle (Primary Caregiver)	√	<p><i>Past Intervention:</i> -Religious and traditional intervention -Dietary intervention -Cannabis oil (CBD)</p> <p><i>Currently on:</i> - Prescribed medication by a psychiatrist. -Play therapy -special needs school</p>
<b>P6</b> (Has a 19- year-old son with ADHD)	Female: 47	Xhosa: Married	Unspecified (Employed- unspecified)	Above R60 000	14 years- Male	Mother	√	<p><i>Past Intervention:</i> -ADDvance supplements -Dietary Intervention -Concerta (for 5 years)</p> <p><i>Currently on:</i> -Ritalin (for the past 3 years) -Attempt on healthy diet</p>
<b>P7</b>	Female: 42	Zulu: Married	Certificate (Employed- unspecified)	R0 – R5 000	11 years- Female	Mother	√	<p>-Contramyl - Currently on Ritalin</p>
<b>P8</b>	Female: 38	Venda: Married	B.Sc. Degree in Agriculture (Dep. of Agriculture)	R30 000 – R40 000	9 years- Female.  6 years - Male	Mother	√	<p><b><i>Girl:</i></b> <i>Past Intervention:</i> -Prophets -Diet -Supplements</p> <p><i>Currently on:</i> -Medication (Neucon) -Speech Therapy -Occupational Therapy - In the process of moving the child to a remedial school</p> <p><b><i>Boy:</i></b> -Medication (Inir &amp; Risperdal) -Speech Therapy</p>

-Occupational Therapy

<b>P9</b>	Female: 47	Sotho: Married	Unspecified (Unemployed)	Undisclosed	7 years - Female	Mother	√	-Medication -Dietary Intervention (reducing too much sugar intake)
<b>P10</b>	Female: 26	Pedi: Married	College qualification (Unemployed)	R20 000 – R30 000	6 years - Female	Mother	√	<i>Past Intervention:</i> -Ritalin (for a month) <i>Currently on</i> -Neucon
<b>P11</b>	Female: 39	Tsonga: Divorced	Matric (Unemployed)	R0 – R5 000	13 years - Female	Mother	√	-Concerta
<b>P12</b>	Male: 54	Tswana: Single	Master's degree (Systems Analyst)	Above R60 000	8 years – Male	Uncle (Primary Caregiver)	√	<i>Currently on:</i> -Ritalin & Risperdal (on and off basis) -Sports and other physical activities -Diet (sometimes)
<b>P13</b>	Female: 33	Venda: Single	Matric (Unemployed)	R0 – R5 000	11 years - Male	Mother	√	-Risperdal -Ritalin - Two other medications (participant cannot recall the names)
<b>P14</b>	Female: 30	Tswana: Married	Diploma in Nursing (Registered Nurse)	R30 000 – R40 000	7 years - Female	Mother	√	<i>Past Intervention:</i> -Contramyl (for a month). <i>Currently on:</i> -Neucon - Speech Therapy - Occupational Therapy - Attends remedial school
<b>P15</b>	Female: 47	Zulu: Married	Degree in Business Practice (Early Childhood)	R20 000 – R30 000	8 years – Male	Mother	√	-Ritalin -Occupational Therapy -Play therapy -Cultural Ritual

			<i>Development Practitioner)</i>					-Special needs school
<b>P16</b>	Male: 45	Zulu: Single	Diploma in Arts (Dancing)  <i>(Unspecified)</i>	R40 000 – R50 000	9 years - Female	Father	√	-Dietary intervention -Yoga -Music therapy
<b>P17</b>	Female: 43	Zulu: Single	Diploma in Financial Management  <i>(Senior Bookkeeper)</i>	R20 000 – R30 000	5 years - Male	Mother	X	-Ritalin -Speech Therapy -Waiting for placement in a special needs school
<b>P18</b>	Female: 38	Tswana: Single	Honours in Agriculture  <i>(Production Scientist)</i>	R50 000 – R60 000	9 years- Female	Mother	√	-Ritalin
<b>P19</b>	Male: 43	Ndebele: Married	Matric  <i>(Restaurant Manager)</i>	R15 000 – R20 000	8 years- Male	Father	√	-Behavioral support from parents
<b>P20</b>	Female: 44	Ndebele: Married	Degree in Occupational Therapy <i>(Occupational Therapist)</i>	R40 000 – R50 000	15 years- Male	Mother	√	-Ritalin
<b>P21</b>	Female: 37	Sotho: Single	Matric <i>(Unemployed)</i>	R0 – R5 000	13 years- Male	Mother	√	<i>Past Intervention:</i> -Epilim <i>Currently on:</i> -Ritalin - Risperdal

## **Method of Data Collection**

Keeping the goal of obtaining in-depth insight into Black parents' and caregivers' perceptions about ADHD and the impact on decision-making regarding pursuing different intervention options, semi-structured face-to-face, online, and telephonic individual in-depth interviews were conducted with each participant, depending on what worked best for each participant. The semi-structured individual interviews ranged from 15 minutes and 48 seconds to one hour and 15 minutes long. From the above-mentioned interview range, it should be noted that only one interview was 15 minutes and 48 seconds. The participant's hurried responses prompted the cause for such a short interview, as she had indicated before the interview that she was a busy individual. Nonetheless, the data collected from the participant during the individual interview was insightful. The participant gently declined the request for her participation in the focus group.

Semi-structured interviews allow the participants to express their views in their own words, prioritizing their perspectives (Denzin & Lincoln, 2017). They also allow the researcher to make meanings and understand the participants' culture and the level of misconceptions the participants may hold (Seidman, 1991). Given that the degree of the richness of detail in responses often relies on the participant's expressiveness (Hyman & Sierra, 2016), probing and clarity-seeking techniques were used when necessary to get rich data from participants.

Face-to-face interviews provide researchers with valuable social cues that aid in interpreting non-verbal communication from participants. However, it is important to note that researchers should be aware that their presence can impact how participants respond (Oltmann, 2016). While virtual interviews over the phone or online offer the convenience of being conducted from anywhere, they do not offer the same social cues. I developed an interview schedule for the individual semi-structured interviews based on the research

questions for the study to address the research topic. The interview schedule contained open-ended questions to avoid leading the participants into responding in a specific way.

In addition to the individual semi-structured in-depth interviews, two online focus group discussions about two hours long each were conducted. According to Doody et al. (2013), focus group sessions during data collection should only run up to two hours. Focus groups are small groups of about six-12 people purposively chosen to discuss a specific topic to uncover their subjective experiences, beliefs, and perceptions in a moderated setting (Then et al., 2014). All the members of the focus groups were the same participants who participated in the individual interviews except for one, as highlighted earlier. The participant selection and the size of each focus group depended on the number of participants from the individual interviews willing to partake in the focus groups. Belzile and Öberg (2012) assert that the focus groups allow the participants to compare and share their views and concerns, as listening to others may make them aware of issues they might not have considered.

Harrison et al. (2015) emphasize the importance of avoiding focus group dynamics that may inhibit members from freely sharing their subjective experiences and beliefs. As such, I ensured all participants had an equal opportunity to engage in the discussion. This included gently encouraging reserved participants to join when more outspoken members overshadowed them. To maintain consistency between the focus groups, I created an interview schedule and generated questions based on the research topic and questions.

Semi-structured individual interviews and focus group discussions were used together for the methodological data triangulation. Methodological triangulation employs multiple methods to assess a problem (Gorissen et al., 2013). It allows the researcher to cross-reference data findings against each other for clarification, verification, validation, and reduction of researcher bias (Horne & Horgan, 2012).

I designed a short demographic information-collecting sheet to gather the participants' information, such as age, gender, home language, marital status, ethnicity, level of education, religion, and career, to provide context when idiographically analyzing participants. No interviews were conducted on the same day; all were conducted on separate days. The details regarding the duration of each individual interview, the mode of communication employed, and where each interview was conducted are presented in Appendix L.

### **Role of the Researcher**

In qualitative IPA research, the researcher's role is to serve as the primary data-gathering tool (Scherzer, 2015). By providing a safe space and through exploration, the researcher engages with the participants to elicit detailed subjective responses to the research topic. The researcher has to analyze, interpret, and make sense of the subjective lived experiences of the participants (Alase, 2017). As the researcher uses self to give meaning to the participants' subjective lived experiences, the researcher must engage in reflexivity and bracketing (Creswell, 2013) throughout the research process to filter out their preconceptions, beliefs, and experiential knowledge on the research topic that might 'contaminate' the data. For this study, I moderated the focus groups, which allowed me to guard against and monitor sensitive matters that might often occur due to group dynamics (Sim & Waterfield, 2019). As the moderator, I also monitored the focus groups to ensure that participants did not discuss irrelevant issues that did not contribute to the study (Then et al., 2014).

### **Piloting**

Two pilot studies were conducted after compiling the semi-structured individual and focus group interview schedules and obtaining approval from the Human Research Ethics Committee of the University of the Witwatersrand. The first focused on the individual face-to-face semi-structured interview instrument, piloted on two participants. The second pilot

study focused on the same two participants and used the focus group instrument. The pilot studies aimed to assess the feasibility of the data collection instruments, techniques, and methods (Doody & Doody, 2015) and identify any ethical or practical challenges that could hinder the main study. Participants in the pilot studies were selected using the same criteria as those in the main study, and ethical guidelines were strictly followed throughout the piloting phase.

### **Data Analysis**

For this qualitative research, IPA data analysis was used. IPA utilizes a series of steps Smith et al. (2009) outlined. The sequence of the steps was as follows:

#### ***Step 1: Reading and Re-reading***

I was immersed in the raw data in each transcript and recordings from the semi-structured individual interviews and the focus groups to absorb the data. Free associations were made, and descriptive comments of face-value impressions of the participants' narratives (Gee, 2011) were noted using a color code.

#### ***Step 2: Initial Noting***

Through a careful and methodical exploration of the text, I inquisitively focused on "examining semantic content and language" (Smith et al., 2009, p. 82) used by the participants to note the meaning creations of key issues the participants raised. Comments on those meaning creations were noted in a different color code.

#### ***Step 3: Identifying 'Emergent' Themes***

I re-read the text, focusing on completed notes in color codes. The emergent themes that flagged something noteworthy about each section of the text were chronologically identified (Smith et al., 2009) and written in another color code. The themes integrated the participants' original words with my interpretations.

#### ***Step 4: Searching for Connections Across the Emergent Themes***

Themes were scrutinized with an interpretative focus, and similar themes were clustered duly using “abstraction, polarization, contextualization, numeration, and function” until data saturation (Smith et al., 2009, pp. 96-98). Immaterial themes not central to the study were disregarded (Willig, 2013).

#### ***Step 5: Moving to the Next Case***

I moved to the next participant’s transcript by repeating the steps above. Each participant’s transcript was analyzed with an open mind to maintain the idiographic nature of the study. I bracketed themes from the previous transcripts to do a fair and exhaustive analysis of each transcript.

#### ***Step 6: Searching for Patterns Across Cases and Grouping Master Themes***

I searched for shared patterns and trends of themes and individualistic unique instances across cases.

#### ***Step 7: Write-up of Findings***

This final stage of the data analysis is where theme interpretations are deepened by validating them with participant quotations (Smith et al., 2009). Explication of findings was further undertaken with literature in the discussion chapter.

IPA’s idiographic nature warrants that the themes remain personalized to individual narratives (Jeog & Othman, 2016). Thus, this method of data analysis uncovered the fine-drawn, intimate, and nuanced accounts of the factors that shape Black parents’ and caregivers’ perceptions and decision-making concerning a diagnosis of ADHD for their children and the impact thereof on the intervention pursuits and preferences. Furthermore, Bush et al. (2016) assert that IPA acknowledges using subjective experience as scientific data; hence, it was a suitable analysis method for this research.

While individual and focus group interviews were used for data collection, themes representing the study findings were derived from the individual interviews. No new data

emerged from the focus group discussions. Therefore, excerpts from the focus groups were used to substantiate findings from the individual interviews, enhancing the study's trustworthiness. Love et al. (2021) support using focus groups to authenticate and strengthen individual narratives in an IPA approach. Although data findings conveyed convergences in the participants' narratives, equal attention was given to divergences. Focusing on convergences and divergences in the participants' narratives enhances the hermeneutic gestalt characteristics of the IPA approach (Nizza et al., 2021), accomplished by interpreting a participant's unique experience to the group's shared experience. It is essential to retain the idiosyncratic experiences of individual participants to avoid eclipsing an individual's subjective lived experience in favor of the shared group experience.

Following the presentation of each superordinate theme, a discussion section based on each theme is presented. Thus, the coherent flow of the study was maintained, given the overwhelming data collected from a relatively large pool of participants. The discussion section of each superordinate theme focused on addressing the study's research questions through the bioecological systems theory lens employed in the study. This was done by integrating discussants from the reviewed literature into the study, highlighting the study's value in the ADHD body of knowledge.

It is important to remind the reader that the findings from the analyzed data are presented in five chapters, namely, Chapter 5: Receiving the Diagnosis and Understanding ADHD; Chapter 6: Role of the School and Sources of Support; Chapter 7: Factors Influencing Perceptions of ADHD; Chapter 8: Implications of the Child's Behavior: The Significance Attributed to the Diagnosis; Chapter 9 Decision-Making on Intervention Pursuits.

### **Summary of Superordinate Themes**

Based on my interpretive analysis of the participants' transcribed narratives, I identified seven superordinate themes, each with related subordinate themes. These are outlined in Table 2.

**Table 2:***Superordinate and Subordinate Themes*

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Receiving the diagnosis	Child's behavior prior to diagnosis Own diagnosis reaction Do I accept or reject the diagnosis?
Understanding ADHD	Perception of cause Conceptions about the nature of ADHD Beliefs about the management of symptoms
Role of the school	Positive impact of the school Negative impact of the school
Sources of support	Positive support experience Negative support experience
Factors influencing perceptions of ADHD	Culture Stigma Awareness and Knowledge Religious and Spiritual beliefs
Implications of the child's behavior: the significance attributed to the diagnosis	Negative implications of the child's behavior Positive implications of the child's behavior
Decision-making on intervention pursuits	Reasons for intervention pursuits Motivations for chosen interventions Perceptions about ADHD medications Hindrances to intervention pursuits

Given the iterative nature of IPA, participants' narratives were interpreted in a part-whole dance approach. In this manner, I endeavored to explore and understand the themes by analyzing a part in relation to a whole and a whole to a part. This was achieved by interpreting parts of the participants' accounts of their lived experiences of the phenomenon to the whole interpretation I understood the participant gave to the phenomenon. Supporting this stance, Nizza et al. (2021) state that to get deeper meanings of the participants' accounts, the researcher should pay attention to "both what is going on in the immediate quote and also

thinking of it in the context of the wider transcript” (p. 375). Thus maintaining the part-whole dynamic and the hermeneutic circle attributes of IPA.

### **Ethical Considerations**

Ethical considerations are viewed as the foundation of the researchers’ conduct in the research process to protect the participants’ dignity (Abrar & Sidik, 2019). This implies that from the onset, all researchers must ensure that their conduct does not infringe on the participants’ rights to be treated with dignity and respect and protected from harm (Abrar & Sidik, 2019). Before data collection, I sought a clearance certificate from the Human Ethics Committee of the University of Witwatersrand to protect and preserve the rights of the participants. According to Akaranga and Makau (2016), all participants should be honestly given all the information about their involvement in the study, the risks, and the benefits involved, if there are any. This allows the participants to make informed consent regarding their participation in the study. Therefore, I explicitly explained the nature and purpose of the study to the participants and obtained their written informed consent before they participated in the study.

Haines (2017) highlights the principle of research participation without coercion. Accordingly, all participants were informed that participation was voluntary, that they had the right to withdraw from the study at any time, and that they could not answer any questions they did not wish to. I informed the participants of the opportunity to provide additional information and validation if necessary.

Although participants’ identifying information was removed during data collection and pseudonyms were used in an attempt to preserve anonymity (Saunders et al., 2015), the participants were informed that confidentiality and anonymity were not guaranteed due to the public nature of the focus group interviews. However, the focus groups were conducted

online via the Zoom platform, and the participants were requested not to turn on their videos and to use pseudonyms on login. This was to minimize the risk of identification.

I emphasized the issue of confidentiality and requested the focus group members not to share the information discussed in the group outside the group. Confidentiality of the collected data was guaranteed by informing the participants and the sampling sites that I and my supervisors would hold the data in the strictest confidence. To preserve anonymity, the participants' and sampling sites' identifying information was not disclosed in the study's results or final report. Participants were informed that research feedback would be made available upon request.

Taking cognizance that the research topic might have been sensitive, I arranged free counseling for participants who might have been negatively impacted and experienced emotional upset during data collection. This was done to avoid any emotional harm to the participants during the research study. The South African COVID-19 pandemic safety regulations were followed to ensure the safety of the participants in an attempt to avoid any physical health harm to participants during the study. The participants were treated with respect and dignity throughout the study.

### **Trustworthiness**

Different methods were employed to assess the quality of this study to justify its trustworthiness. I used reflexivity throughout the study by bracketing my beliefs, preconceptions, and past experiences that might have influenced the participants during the interviews and the data analysis process. In addition, I noted down my responses to the participants, their stories, and interactions in the focus groups. Reflexivity requires intentional self-awareness of the researcher's decisions that might influence the study's findings (Smith et al., 2009).

Yardley's (2000) trustworthiness guidelines used in qualitative studies were employed for this study. These guidelines can be applied across all qualitative research

(Hefferon & Gil-Rodriguez, 2011). The first guideline requires sensitivity to the context in which the research is conducted. Therefore, I was sensitive to the contextual factors that might have influenced Black parents' and caregivers' perceptions of an ADHD diagnosis for their children and how those impacted their decision-making regarding different intervention options.

The second guideline focuses on approaching the research process with commitment and rigor achieved by thorough engagement with the research topic and conducting pilot studies to ensure the feasibility of the study. The study's sample size allowed for in-depth idiographic interviews that provided depth in data analysis and presentation.

Yardley (2000) emphasizes transparency and coherence as another measure to check trustworthiness in qualitative research. I provided appendices of the ethics clearance certificate, participants' information sheets, and interview schedules for transparency and credibility checks by the readers. I gave excerpts from the participants' transcripts to validate the data analysis. To add to transparency, I was open about the limitations and delimitations of the study. I thrived to produce coherent and well-organized coding, interpretations, and analysis of the research.

Finally, Yardley (2000) and Smith et al. (2009) suggest that good qualitative research must have a measure of impact and importance. This study's impact and importance were highlighted in the Study's Rationale and Recommendations sections.

### **Reflexivity**

Reflexivity in qualitative research involves the researchers' continuous awareness of all aspects of themselves that may contribute to influencing the research study (Barrett et al., 2020).

During the study, I was aware that my characteristics and background as a Black female educational psychologist from a Christian background and an aunt to a child with

ADHD have shaped my worldview in a way that could have influenced my reporting and interpretations of the current study.

For example, with my background as a former student and intern educational psychologist, I had struggled to comprehend parents who, as gatekeepers for their children's well-being, rejected ADHD diagnoses. During the data collection, I was mindful not to let my prior conceptions trigger judgmental attitudes toward the participants. As such, I ensured that I reflected on my feelings, processed them, and bracketed them so that I did not project them on the participants. This process helped me to be non-judgmental toward the participants. As the participants shared their stories, especially the mothers who lacked support from their spouses, I had to guard against colluding with them, which could have clouded my interpretations of their lived experiences. For instance, when participant P1 indicated that her spouse had never been to any consultation visit with professionals and never inquired about them, I had to bracket my need to sympathize with the participant in perceiving the spouse as irresponsible. Colluding with the participant would have prevented me from hearing the participant's story. Instead, I would have become part of the story, which could have resulted in the misinterpretations of the participant's subjective experience. Furthermore, I also had to guard against judging participant P2, a father who refused an ADHD diagnosis for his son based on his beliefs that ADHD did not exist, as a selfish parent putting his beliefs first at the expense of seeking help for the child. I had to remind myself that the participant had made that decision as a measure to protect his child. Therefore, he had the best interest of his child at heart.

I had a personal experience with an extended family member who discontinued ADHD medication for his son due to pressure from kin and friends who convinced him that ADHD is a White people's disease. That decision left me frustrated because I understood that ADHD symptoms could be effectively managed for most children struggling with the

disorder. As such, during the data collection, I had to keep my frustrations in check so they were not projected on the medication-non-compliant participants. Ignoring the influence of my worldview and preconceptions would have potentially biased my interpretations as a researcher, as I could have been drawn into seeking validation for my assumptions. Being constantly cognizant of my feelings and emotions, even during the data analysis process, allowed me to bracket them so that the preconceptions did not shift the study in a particular direction.

Importantly, I reflected on how my background training as an educational psychologist impacted my data collection using interviews. I utilized my active listening and empathy skills to understand the participants' subjective experiences regarding the issue under study. Furthermore, my training allowed me to engage in ethical research practice throughout the study. However, I had to guard against making therapeutic reflections and interpretations during the study interviews to avoid shifting the focus of the participants' narratives. Consequently, it could be that I may not have probed enough during the interviews for fear of leading the participants.

I had observed that some members of the second focus group appeared to have strong personalities, and I had worried about them dominating the discussions. Therefore, I encouraged all the participants to engage by constantly asking if anyone wanted to add to the discussion. Nonetheless, all group members firmly held the views they had shared in the individual interviews. Their views were not modified by the different personalities of group members.

During the data analysis process, I was overwhelmed by the amount of data I had to 'microscopically' sift through. I began to doubt my abilities to do justice to the IPA approach, leading me to question my research abilities. Self-doubt led to brain fog that delayed my data analysis process. However, I strived to remain meticulous despite the overwhelming data, and

I continued to read about the API approach to boost my confidence as a first-time IPA researcher.

During the beginning stages of this research study, I had anxiety about the prospect of failing to complete it on time due to my sense of helplessness and lack of control caused by the COVID-19 pandemic. Attempts to secure permission to advertise my study recruitment flyer from some places were futile as some sampling sites were concerned about COVID-19 safety issues for the potential participants. Nonetheless, keeping a reflexivity journal and the support from my supervisors helped me gain confidence in the research process.

### **Summary**

This Chapter focused on the study's methodology, justifying the chosen study design and approach. It also described the strategies pursued in the data collection, ensuring ethical considerations for the study were maintained. The next five chapters, Chapters 5-9, will present findings and discussion sections of the collected data. The summary table for the themes will be presented at the beginning of each chapter of findings as a recap for the reader.

## CHAPTER 5: FINDINGS AND DISCUSSION

### **Receiving the Diagnosis and Understanding ADHD**

This interpretative, phenomenological study aimed at exploring Black parents' and caregivers' perceptions and decision-making regarding ADHD for their children and the implications of these on interventions. The current chapter is dedicated to the first two superordinate themes, 'Receiving the diagnosis' and 'Understanding ADHD.' To understand Black parents' and caregivers' perceptions regarding the diagnosis for their children and how the perceptions influenced decision-making on intervention pursuits, it was imperative first to explore how participants viewed their children's behavior before the ADHD diagnosis, their reaction, and receptiveness to the diagnosis. These were examined under the superordinate theme termed 'Receiving the diagnosis.' After that, the participants' awareness and understanding of ADHD were explored.

Furthermore, it was essential to explore the participants' perceptions regarding the nature of ADHD and how they believed the ADHD symptoms in their children could be managed. This was examined under the superordinate theme of 'Understanding ADHD.' To preserve the thesis flow, a discussion section of each superordinate theme followed immediately after presenting findings under each theme. Below is Table 2, as presented in the previous chapter, summarizing the themes of the study. The themes under discussion in this chapter are underscored in **bold**.

**Table 2:***Superordinate and Subordinate Themes*

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Receiving the diagnosis	<i>Child's behavior prior to diagnosis</i> <i>Own diagnosis reaction</i> <i>Do I accept or reject the diagnosis?</i>
Understanding ADHD	<i>Perception of cause</i> <i>Conceptions about the nature of ADHD</i> <i>Beliefs about the management of symptoms</i>
Role of the school	Positive impact of the school Negative impact of the school
Sources of support	Positive support experience Negative support experience
Factors influencing perceptions of ADHD	Culture Stigma Awareness and Knowledge Religious and Spiritual beliefs
Implications of the child's behavior: the significance attributed to the diagnosis	Negative implications of the child's behavior Positive implications of the child's behavior
Decision-making on intervention pursuits	Reasons for intervention pursuits Motivations for chosen interventions Perceptions about ADHD medications Hindrances to intervention pursuits

**Receiving the Diagnosis**

Participants received and responded to their children's ADHD diagnosis differently. Their perceptions of their children's behavior before the diagnosis significantly influenced how they received it. Many participants shared that they experienced adverse psychological reactions to the diagnosis. However, a few indicated that they reacted to the diagnosis positively. Based on several factors, 19 participants accepted the ADHD diagnosis for their children, while two rejected it. Three subordinate themes were identified under this superordinate theme, 'Receiving the diagnosis.' These were: 'Child's behavior prior to diagnosis,' 'Own diagnosis reaction,' and 'Do I accept or reject the diagnosis?'

### *Child's Behavior Before Diagnosis*

Most participants expressed that they experienced their children's behavior as typical childhood behavior before the ADHD diagnosis. They indicated that they perceived the behavior as a normal developmental phase that the children would outgrow. In the first focus group, some stated that they thought "boys are generally busy people," "there is nothing wrong," and "never thought much of them." In contrast, eight participants shared that before the diagnosis, they experienced their children's behavior as a cause for concern. Mainly, worrying about the child's behavior was influenced by the severity of the undesired behavior.

Participant P2, a father of a 14-year-old boy diagnosed five years earlier, revealed that he regarded his child's behavior as typical before the diagnosis. He eloquently stated, "to my understanding, boys' behavior is always associated with hyperactivity. That's how boys are supposed to grow up." This statement revealed that he considered hyperactivity and impulsivity a sign of ordinary boys' childhood behavior, as confirmed by his elaboration, "that's what boys are expected to do." P2 indicated that he still regarded his child's behavior as typical and not a cause for concern five years later.

Also sharing how she perceived her child's behavior as nothing out of the ordinary before the diagnosis, participant P10 revealed that although she had experienced her child as "aggressive" and having poor interpersonal skills from a young age, she "never had a problem" with her child's behavior. Despite others pointing out that the child might have a "problem," P10 dismissed those suggestions as follows:

At first, before I could even know about D...ADHD, my cousin used to visit me, like during the holidays and had a young child. And my child would mistreat her child and only because *nna* (me) I knew that's naughty and my cousin said to me, no this is serious like she has a problem. And I was like, no, she doesn't, and she was like, she has.

Participant P10's perception of her child's behavior as merely naughty made her blind to the seriousness of her child's negative behavior. For her, the child would "outgrow" the negative behavior. She confirmed her position when she stated in the focus group that initially, her child's symptoms "never bothered" her.

Participant P8, a mother with two children diagnosed with ADHD, shared that she viewed her children's behavior differently before the diagnosis. Her first child, a girl, struggled with the severe, predominantly inattentive type of ADHD, significant developmental communication delays, and anxiety disorders. Those were a serious cause for concern for her. Describing her child's behavior before the diagnosis, P8 had this to say:

At the age of 3 years, she couldn't talk, and then she couldn't follow instructions. If you say, "could you pick up that one," like on her mind always she act confused. Like with instructions, you need to repeat time and again... Like she was kinda in her own world. Like the brain is like...you could even see that she need to talk, she can't do it... Like somewhere somehow, you could see that her brain and the mouth, somewhere somehow, it's not connecting. Even when you talk to her, she can't follow instructions, actually.

Participant P8 shared that her daughter's behavior was a significant concern for her because it was clear that the child had challenges that required intervention.

On the other hand, participant P8's second child, a boy, had the predominantly hyperactivity-impulsivity type of ADHD. Being aware of only the predominantly inattentive type of the disorder displayed by her daughter, P8 did not consider her son's hyperactivity-impulsivity as a concern. She revealed that although indicators suggested "it's like he is not fine this boy," she dismissed that thought and "really thought maybe he was fine." She attributed the boy's behavior to a developmental phase as he was "4 years" old. This suggests

that her initial perception of ADHD in her daughter influenced how she interpreted and viewed her son's behavior before his diagnosis.

Expressing how her child's symptoms bothered her even before a diagnosis, participant P1, a registered nurse and a mother to a 7-year-old child who had been diagnosed three years earlier at the time of the study, stated during the individual interview:

She had speech delay, she couldn't assoc...*kakhoni ukudlala nabanye abantwana* (she could not play with other kids), she couldn't mix with other children...And then the other things, she was overactive, always moving around. But she loved moving on her toes which I was not aware could be an issue. I only thought because she was using a baby walker so...and she would...yooh...(sighs). She would beat us. She would...she is hyperactive; she wouldn't sleep the whole day. She would only sleep maybe during the day an hour and then at night. She was hyperactive.

Participant P1 felt overwhelmed and was bothered by her child's behavior. She had revealed that her child walking on her toes was not a cause for concern at first but later, as time progressed. During the focus group discussion, participant P1 said, "she couldn't even say mama and she was walking on her toes. So I was suspicious like, how this child was walking? I needed to know what was making her not talk like any other children." The severity of the child's seemingly unusual behavior prompted P1 to perceive that the child had challenges that required intervention.

Two other participants, P13 and P21, whose children's ADHD diagnoses were accompanied by comorbid disorders, indicated their significant concern about their children's behaviors prior to receiving the diagnosis. Participant P13, whose 11-year-old son was diagnosed with ADHD and oppositional defiant disorder (ODD), expressed that she was aware and worried about her child's challenging behaviors before she received the ADHD

and its comorbid diagnoses. She shared, “He was always angry. He was so short-tempered, and then he was always in fights.” The participant also highlighted that she had received complaints about the child’s behaviors when the child was still in crèche. Similarly, sharing her concerns about her child’s behavior before receiving the ADHD diagnosis, P21, a mother to a 13-year-old boy diagnosed with ADHD, anxiety disorder, and cluster B personality disorders, revealed that she had been troubled by her child’s aggressive and complex behavior, prompting her to take the child to the hospital. She said, “...me and my mom when we saw that he had a problem, then we take him Bheki Mlangeni Hospital...He was 6 years,” highlighting that the child’s complex behavior was already prevalent early in his early childhood.

Participant P3, a mother of a 9-year-old child who had been diagnosed with the disorder for a year at the time of the interview, shared that she “noticed that these behaviors are a little bit above normal” when describing her child’s behavior before the ADHD diagnosis. Her child struggled with hyperactivity, inattention, outbursts of anger, and aggression.

### ***Own Diagnosis Reaction***

Nearly all of the 21 participants experienced multiple adverse psychological reactions when they received their children’s ADHD diagnosis. Most described experiencing feelings of shock, denial, and confusion. Some shared feelings of disbelief, being overwhelmed, a sense of helplessness, pain, distress, and trauma. Other participants revealed that they felt sadness and anger. Worry and regret were also some of the emotions experienced by some participants upon receiving the ADHD diagnosis for their children. In contrast, not all participants experienced adverse reactions when they received their children’s diagnosis. A few indicated that they felt a sense of relief when they were given the diagnosis.

Sharing her reaction to her child's ADHD diagnosis, participant P17, a mother of a 5-year-old boy diagnosed four months earlier, revealed that she was still processing the diagnosis at the time of the individual interview. She said, "I found this during May this year, so this is still new to me. I'm not an expert. I'm still trying to grasp, remember." She stated experiencing "shock and disbelief" and being "overwhelmed" when the child was diagnosed. She struggled to accept the results of the psychologist's assessment, as revealed by her statement, "Are you sure my child is ADHD?" leading her to be in "denial." As she described her reaction to the diagnosis, I sensed anger in her voice. Her statement, "I had anger towards the educational psychologist and the teacher," validated this observation. She was angry at the professionals who referred the child for assessment and for giving the diagnosis, respectively.

During the individual interview, participant P6, who had two children diagnosed with ADHD, indicated she did not take her younger son's diagnosis well. She shared, "when the teachers told me about my little one, that he was not paying attention, I cried. Literally cried." Her reaction to her older child's diagnosis had not negatively impacted her compared to her younger child's diagnosis. Describing how she handled her older child's diagnosis, she said, "it felt like whatever battle it was, I had won it with my elder son." She could not accept that both her children had inattention challenges that affected their functioning. To her, that was "traumatic in a sense that it felt like" her children had a "disability," which was devastating for her.

Furthermore, participant P6 perceived her child as misunderstood by the White psychiatrist despite his attempts to "coerce" her to accept the diagnosis. This caused her to initially deny her younger child's diagnosis, switching him to a Black psychiatrist she believed would "have a different view about...about Black kids...or their parents." She had initially perceived her younger child's diagnosis as a misdiagnosis. Additionally, she further

shared in the focus group that when her younger child was diagnosed with ADHD, she experienced “shock,” which caused her a sense of being overwhelmed and “worry” that she described during the individual interview.

Also describing the difficulty of handling her second and younger child’s diagnosis, participant P8, a mother of two children, both diagnosed with ADHD, revealed that she was distressed and shocked that her younger child had a dual diagnosis of ADHD and autism. She expressed, “I was crying a lot with the diagnosis for my son.” She had found it difficult to accept that her younger child had any disorder because she had thought, “at least he’s fine.” Instead, she expressed, “it was so bad, I cried from the neurologist’s office.” Having her younger child also diagnosed with ADHD caused her significant distress and emotional pain, leading her to deny her second child’s diagnosis initially.

Conversely, during the individual interview, participant P8 stated that she was “very relieved” when she received the diagnosis for her older child due to the severity of the child’s symptoms. Before the ADHD diagnosis, she had struggled to understand and tolerate her child’s behavior, thinking that the child was lazy. This had caused her to physically punish the child often, not realizing that the child had ADHD, a disorder compounded by the comorbidity of developmental communication delay and anxiety disorders. In the focus group, she shared that when she received her older child’s diagnosis, she felt extremely remorseful and regretful for previously ignorantly punishing the child. She expressed:

For me, because I grew up in a family wherein we all went to school until varsity, and here I was with my daughter...whom when you say two plus two, she’s only gonna hear a one. You can’t even send her to fetch something. If it’s raining and she is sitting outside, she will just sit there until you tell her that Tshilidzi\*, look, it’s raining come inside (speaking slowly). It was tough. I don’t know how many times I cried. I used to think she was just lazy, she

does not want to write maybe number one, two, three. How come she is 6 years not knowing her name? What the hell is that? Until I got advice from one of the pediatricians to say that, you know what, take her to the eeh neurologist. The sense of relief that she experienced when her first child was diagnosed with ADHD was the anticipation of getting help for the child.

Participant P19 shared that he initially denied the ADHD diagnosis for his child because “he didn’t see any problem with the child.” However, when he eventually accepted the diagnosis, he experienced regret, stating that “we could be looking back and saying we could have avoided 1, 2, 3, and 4, it could not have been on this stage now.” These sentiments were motivated by his belief that his 8-year-old son’s ADHD diagnosis resulted from the mother consuming too much sugar when pregnant. Therefore, he believed they were responsible and to blame as parents for their child’s ADHD due to their failure to maintain the mother’s healthy diet when she was pregnant.

Like several participants, P13, a mother of an 11-year-old boy diagnosed over five years earlier, expressed feeling “confused” about her child’s diagnosis. However, unlike most participants whose confusion was caused by perceiving their children’s behavior as a no cause for concern, participant P13 knew that her child had significant aggressive behavioral challenges that required intervention. A lack of understanding of the disorder caused her confusion about the diagnosis. Furthermore, her child had an underlying comorbid oppositional defiant disorder. She revealed, “I was just confused. Even those psychologists they didn’t explain to us what ADHD is.” She further highlighted, “they just said he has ADHD and ODD.” Therefore, a lack of awareness and understanding of ADHD made P13 react with confusion to her child’s diagnosis.

Some participants who had concerns about their children’s behaviors expressed feeling relieved about the ADHD diagnosis for their children. It meant they were getting

explanations for their concerns and hope for intervention. Describing her experience of receiving her child's diagnosis, participant P3 stated, "when you finally say okay, so what I was suspecting...here it is," it validated her concerns. She indicated that she was "already emotionally prepared" that something might be wrong with her child before the diagnosis and that her child could have some challenges requiring "attention." Emotional preparedness made it easier for her to accept the diagnosis.

Participant P20, an occupational therapist who works with children with ADHD, shared that her occupation and exposure to ADHD prepared her for her 15-year-old child's diagnosis. She indicated that she had struggled for a long time to accept that her child had behavioral challenges, but when he was finally diagnosed, she felt "relieved" that he would get the help he needed. She expressed that she was "expecting" the diagnosis based on her professional experiences. In addition, her exposure to children with ADHD made her finally accept the claims she had been disputing for years that her child had behavioral issues. However, she highlighted that despite expecting the diagnosis and feeling relieved, it was still "hard" to process the confirmation of the diagnosis. Thus, the diagnosis came with conflicting feelings for her.

One participant, P10, a 26-year-old mother of a 6-year-old child diagnosed a few months earlier, shared that regarding her child's ADHD diagnosis, she "didn't take it as a big deal." Her reaction to the diagnosis was caused by her lack of understanding of ADHD and underestimating the severity of her child's condition. She had initially dismissed the existence of ADHD, causing her not to be bothered by the diagnosis. Furthermore, she revealed that she had previously not perceived her child's behavior as a cause for concern. Therefore, when her child was diagnosed, she had thought ADHD was a minor condition that "will pass." However, participant P10 insinuated that reflecting on the teacher's concerns about her child's aggressive behavior, she experienced a sense of relief when she received an

ADHD diagnosis for her child. Participant P10 had feared her child being diagnosed with a condition she perceived as worse, such as “crazy.” Her child’s diagnosis as “crazy” would have meant dealing with social stigma associated with mental illness, which she believed was rife in Black communities.

Generally, the participants’ reactions to their children’s ADHD diagnosis were influenced by their perceptions of their children’s behavior and ADHD understanding before the diagnosis.

### ***Do I Accept or Reject the Diagnosis?***

Despite most participants experiencing varied adverse psychological reactions to the news of their children’s ADHD diagnosis, almost all accepted it. However, most of them indicated that the process of acceptance was a challenging experience for them, “not easy,” as it meant acknowledging that their children had a disorder negatively perceived in the Black communities. On the other hand, diagnosis acceptance was an easy process for some participants.

It had been hard for some participants to understand and accept the diagnosis for their children at first due to denial and lack of understanding of the disorder. However, getting exposure to and knowledge of ADHD through personal research or other ways of gathering information about the disorder influenced several participants to accept the diagnosis for their children eventually.

Participant P1, a registered nurse, highlighted that she “only got to know about the disorder when the doctor explained it to” her upon her child’s diagnosis. She believed “getting more information about the condition” influenced her to accept the diagnosis despite her initial denial. Other participants shared the same sentiment, highlighting that they had little or no knowledge of ADHD before their children were diagnosed. Participant P16, who also initially struggled with diagnosis acceptance, concurred in the focus group that

awareness of the disorder leads to diagnosis acceptance. He indicated that diagnosis acceptance becomes easier when “you get an understanding of what you’re working with.”

Also confirming that awareness and understanding of ADHD motivate diagnosis acceptance, participant P5, a caregiver who had believed “separation anxiety” caused ADHD for his niece, shared that he “completely accepted” the diagnosis “based on research.” He felt the ADHD awareness he acquired while researching a solution for his niece’s inattentiveness, “depression,” and “anxiety” prepared him to receive the child’s diagnosis with “no rejection at all.” Thus, awareness and understanding of the disorder made him receptive to the diagnosis without objection.

Participant P15 indicated that having family members with confirmed ADHD diagnoses helped her accept her child’s diagnosis. During the individual interview, she said, “so eeh what you were asking is did I accept it easily or was it difficult? No, I did accept it easily based on the information that I already had and the background.” She further highlighted her understanding that ADHD is manageable based on her observations of her family members coping well with the disorder. That observation motivated her to accept the diagnosis for her child and reassured her that all would be well with the child.

Holding a different experience from other participants influenced by gaining awareness as a motivator for ADHD diagnosis acceptance, participant P10 said, “I never thought that it was something that I’m going to deal with every day because I was just okay. But then dealing with someone who is ADHD is overwhelming.” The inferred connotation from her narrative indicated that due to her lack of understanding of ADHD, participant P10 underestimated the severity of her child’s symptoms, motivating her to accept the diagnosis without concerns.

A dominant emergent theme of eventually realizing that the children had challenges also prompted most participants to accept the given diagnosis. Some participants had been

aware of their children's challenges even before the diagnosis; hence, it was easier to accept that the children had ADHD. On the other hand, some participants had not perceived their children's behavior as a cause for concern before the diagnosis, causing them to experience denial. However, with exposure to ADHD, they realized that the negative behavior they had assumed to be characteristic of a normal childhood developmental phase impacted the children's functioning. Therefore, that awareness made them receptive to the ADHD diagnosis for their children.

Participant P8 captured the essence of participants concerned about their children's behavior before the diagnosis, leading to diagnosis acceptance. She was also illustrative of those who had assumed their children's behavior was normal but later had a perception shift about their children's behavior after the diagnosis. For example, she had two children diagnosed with ADHD, yet their symptoms displayed differently. She was concerned about her older child's behavior and readily accepted the ADHD diagnosis and the comorbid disorders. Regarding her motivation for diagnosis acceptance for her older child, she stated that her child "couldn't do anything," highlighting her concerns about the severity of the child's behavior so much that when she received the diagnosis, she embraced it with a sense of relief that her child would get help.

In contrast, P8 had perceived that her younger child's behavior was characteristic of the childhood developmental phase; thus, she initially struggled to accept his diagnosis. Participant P8 depicted the initial denial of her younger child's diagnosis and later experiencing a perception shift towards acceptance when she stated, "I just thought aah maybe it is a behavior thing of a little one and it's gonna pass, you understand." However, after a year of engaging with a neurologist and getting more information, she "started accepting bit by bit" and "felt some relief."

Participants P1 and P13, mothers of children with ADHD, mentioned that they fully accepted their children's diagnoses after encountering other children with more severe conditions than ADHD at the hospital when they were taking their children for consultations. Describing the experience, participant P1 expressed, "some children are worse...but at least she is...(pauses) she is on the mild side," while participant P13 stated, "because when you get there *neh* (right), there are children who's worse than him...that's the thing that encourages you to accept the situation." The implied meaning projected by the two participants was gratitude after realizing that the condition could have been worse for their children.

Trusting the professionals motivated two participants, P11 and P19, to accept the ADHD diagnosis given to their children. The implied meaning projected by the two participants during their narrative was that they could not dispute the professionals' opinions as they regarded them as experts in their field. Expressing this implied meaning, participant P11 shared, "after the doctor had told me, I received it and I accepted it because when the doctors they explained to me, I thought them since they...they see it, they know better." Participant P11 gave the impression that she perceived that doctors or professionals could not be questioned. Hence her need to accept her child's ADHD diagnosis. Expressing a similar feeling of trusting the professionals, participant P19, who said that he "accepted the information as it was" despite not seeing "any problem with the child," indicated that he also perceived the professionals as knowing best; hence, accepting his child's ADHD diagnosis. This was despite his conviction that his child had no behavioral challenges.

Participants P2 and P17, who only participated in the individual interviews, rejected the ADHD diagnosis for their children. The two participants did not believe their children had the disorder and felt they were misdiagnosed. They shared a similar misdiagnosis sentiment, although they perceived their children's behaviors differently. Participant P2 did not view his child's behavior as problematic, while P17 admitted that her child's behavior

was sometimes challenging. Thus, despite sharing a similar perception of ADHD misdiagnosis for their children, some of their reasons for rejecting the diagnosis differed. Participant P2, with a child diagnosed five years earlier, was convinced that ADHD did not exist and that the teachers and the psychologist were pathologizing his child's normal behaviors, hence his refusal to accept the diagnosis. He expressed:

It was hard for me to accept the diagnosis coz in my world eeh...ADHD doesn't exist...To me it's normal behaviors. Every child is naughty when growing up (pause). So...(pause) I don't see anything eeh...abnormal about eeh...hyperactivity and eeh...restlessness in young boys.

Participant P2 further expressed that culturally, boys are to be energetic, impulsive, and a little out of control at times because "that's what boys are expected to do." He indicated that he was surprised about the sudden pathologizing of these typical phases in the boys' development, which was not the case when he was growing up. According to P2's perception, ADHD is a made-up condition that does not exist, as validated by his expression, "maybe it's the new genera...it's the disease of the new generation. So, I don't believe in ADHD because in my world, it doesn't exist."

On the other hand, expressing her reasons for rejecting the ADHD diagnosis, participant P17, whose 5-year-old child had been diagnosed a few months earlier, stated that she "felt the child was young" to be diagnosed with ADHD. This suggests that P17 believed the child would not have been diagnosed with ADHD had he been assessed when older. She further articulated that she did not trust the accuracy of the assessment process. She discredited the assessment process because, at home, the child could perform all the assessment tasks the psychologist alleged the child could not. She was adamant that the psychologist's report was too "harsh" and not a true reflection of the child. She stated:

I said to this guy I don't think what you did was right. I don't think your diagnosis is correct. You know why? Based on what? He said I could not conclude most of the tests. Then, you cannot in your report say I could not conclude this test because should I have concluded it, the child would have been written off. Because at some point during the session, the child would just dream, daydream, do you understand? Then I said how do you conclude if the child could not...was not interacting with you throughout the session? He would interact maybe...maybe if the questions were 10, he would do 3, then the rest he would just not give you answers. And then you come with a conclusion to say the child is ADHD?

Participant P17's language use of phrases such as "then you conclude to say the child is ADHD?", "you are telling me that my child is ADHD?" and "all of a sudden, my child does not know those things?" reflect her disbelief and dismissal of the diagnosis given to her child.

The tone of Participant P17's voice, when explaining her reasons for rejecting her child's ADHD diagnosis echoed the anger she experienced at the perceived misdiagnosis. The repetition of the expression "you are wrong. You are wrong" to the psychologist indicated her conviction that she did not believe the accuracy of the diagnosis. Hence, she felt compelled to challenge the psychologist's report. Similarly, participant P2 shared, "I was angry" when he received the diagnosis because he believed the doctor was "lying" hence dismissing the diagnosis.

### **Discussion: Receiving the Diagnosis**

This section discusses the findings under the superordinate theme titled 'Receiving the diagnosis,' which addressed the study's research question: What are Black parents' and caregivers' perceptions of an ADHD diagnosis for their children? The superordinate theme was explored under three subordinate themes: 'Child's behavior prior to the diagnosis,' 'Own diagnosis reaction,' and 'Do I accept or reject the diagnosis?'

When exploring the participants' interpretations of their children's behavior before the diagnosis, 13 out of 21 participants indicated that they had perceived their children's behavior as typical developmental conduct that children would outgrow. The finding supports a study by Kediemetse (2017), which found that most Black parents in South Africa believed children would outgrow their ADHD behaviors. Other international studies are consistent with this finding, revealing that most parents perceived ADHD symptoms for their children as typical childhood naughty habits that children would outgrow as they matured (Alrahili et al., 2022; Dodangi et al., 2017; Fan et al., 2022).

However, the findings from the studies mentioned above indicate that the parents attributed ADHD-type behavior to bad parenting. In contrast, the participants in the current study perceived the ADHD-type behavior in their children as typical behavior expected of children, especially boys. They did not consider the behaviors problematic or blame it on poor parenting. This aligned with the study by Bathiche (2007), which showed that some cultures, such as Muslim and Christian Lebanese, normalized hyperactivity and impulsivity in boys. Perceiving the child's behavior as typical suggests that without external influences, such as the school recommending evaluations for the children's challenging behaviors, these parents may not have considered any behavior assessments for their children.

Bronfenbrenner (1977) purports that individuals should be understood within their cultural beliefs and norms that influence their developmental and experiential existence using the macrosystem level of the bioecological systems theory, which informed the study. Also, according to Dabić et al. (2015), culture shapes people's way of life and worldview. Therefore, cultural norms and beliefs determine members of a cultural population's perceptions and responses to challenging behavior in children (Slobodin & Crunelle, 2019).

In that effect, it was not surprising that most of the participants in the current study perceived their children's behavior before the ADHD diagnosis as typical. This finding

strengthened observations by Kediemetse (2017) that most parents from the Black population group in the African culture seemingly accepted their children's hyperactive-impulsive behaviors as freedom of expression and verve. This highlights the importance that professionals working with children in various sectors must consider cultural implications on Black parents' and caregivers' interpretations of their children's behavior when recommending ADHD evaluations and diagnoses.

This current study showed that participants who had perceived their children's ADHD-type behavior as normal before the diagnosis experienced adverse psychological reactions to the diagnosis, more so for parents with more than one child diagnosed with ADHD. Those reactions included feelings of shock, denial, confusion, disbelief, pain, trauma, and distress. The diagnosis shattered their traditional worldview regarding the children's behavior. It presented a challenge that required them to rethink their belief system regarding children's behaviors they had culturally perceived as acceptable.

However, most of those participants' eventual acceptance of the ADHD diagnosis for the children illustrates that Black parents and caregivers can disregard beliefs and perceptions that define their identity for the well-being of their children. Most parents claimed that diagnosis acceptance, though difficult, was motivated by the new insights regarding ADHD. Thus, the finding supports Corkum et al. (2015), who claim that Black parental perceptions of ADHD can be changed through interventions that may include awareness of the disorder. Therefore, the role players in the exosystemic level of the bioecological systems theory, such as the healthcare practitioners, therapists, and the media, have to escalate ADHD awareness among the Black population in South Africa to increase parental diagnosis acceptance.

Conversely, the study also revealed that some of the participants were concerned about their children's behavior before the diagnosis due to the severity of the ADHD symptomatology in their children. This finding agrees with some conclusions of a study by

Evans (2019), which established that some Black American parents and caregivers acknowledged that they would welcome any ADHD diagnosis if it facilitated their children getting help. There appears to be a sense of ‘emotional preparedness’ and a ‘sense of relief’ upon receiving the diagnosis for parents concerned about their children’s behavior before the diagnosis. The readiness and relief insinuate that such parents and caregivers will be open to exploring ADHD interventions to improve their children’s overall functioning that may be affected by the disorder.

In this current study, certain comorbid conditions affecting children were identified. As reported by four participants, these conditions included ODD, anxiety disorders, autism, cluster B personality disorders, and developmental communication delay. The symptoms of these comorbid conditions varied greatly, ranging from pronounced developmental delays such as speech and cognitive delays, tiptoeing, elaborate levels of inattention, defiance, and escalated aggression to severe mood dysregulation.

Based on the literature reviewed in Chapter 2, comorbid disorders can be found among children diagnosed with ADHD (APA, 2013; Wall, 2017; Wolfe, 2016). As such, it was crucial to consider the influence of those comorbid conditions mentioned by participants on ADHD diagnoses in children and their effect on parental views of their children’s behavior before receiving an ADHD diagnosis. This current study revealed that the presence of comorbid conditions in the children of the four participants (P1, P8, P13, & P21) exacerbated and complicated the children’s ADHD symptoms, triggering the participants to be considerably concerned about their children’s behaviors before the ADHD diagnosis compared to participants with children without ADHD comorbid conditions. The concerned participants were prompted to seek help for their children before the intervention of the school, which is often the main referral for children with ADHD-type behaviors (Layton et al., 2018; Morolake et al., 2022). Such actions signify parents’ and caregivers’ considerable

concerns about the severe behavior that strays from typical childhood norms in their children before an ADHD diagnosis, motivating willingness to seek intervention for their children with ADHD.

In the present study, some of the identified symptoms of the comorbid disorders mentioned earlier included severe aggression, pronounced inattentiveness, outbursts of anger, and defiance. In Black communities, such behavior characteristics may often be interpreted as intentional defiance of parental authority and labeled as a lack of discipline. Such labels often stigmatize affected children and their parents because the African cultural perspective states that a child's behavior reflects their parents (Mamaleka, 2019). Speculatively, it could be that the symptoms of the comorbid disorders highlighted above, often expressed as socio-culturally unacceptable behaviors in most African societies, triggered the abovementioned participants to be concerned about their children's behavior before ADHD diagnosis due to such behaviors associated with poor parenting and shame. Such speculations may not be overlooked because cultural values existing within Bronfenbrenner's (1977) macrosystem level influence behavior and decision-making processes.

However, not all parents concerned about their child's behavior before the diagnosis will receive it with acceptance, as revealed by participant P1. For example, despite noticing the significant delay in her child's development, participant P1 reacted with shock, denial, and a sense of helplessness. Therefore, healthcare professionals should be sensitive when giving ADHD diagnoses, notwithstanding the parents expecting a diagnosis.

Despite almost all the participants in the study eventually accepting the ADHD diagnosis for their children, two of them rejected the diagnosis, receiving it with anger. One of them based their diagnosis rejection on the basis that their child's problematic behavior was culturally accepted and their belief that ADHD in their culture did not exist. The other participant expressed that their child was misdiagnosed due to his young age despite

acknowledging that the child had significant behavioral challenges. The participant also alleged that the assessment process conducted on their child was inaccurate. It is evident from the study that cultural perceptions of the child's behavior and lack of trust in the assessment process may significantly influence parents and caregivers, who are gatekeepers of their children's health decision-making, to reject ADHD diagnosis for their child.

As highlighted in Chapter 4, although the IPA approach emphasizes focusing on the participants' reality based on the meanings they attach to their subjective experiences (Tomkins, 2017), it is also grounded on double hermeneutics "whereby the researcher is trying to make sense of the participant trying to make sense of what is happening to them" (Smith, 2011, p.10). Therefore, IPA analysis allows the researcher to bring their interpretation to the meanings participants attach to their reality. In this regard, although speculated with considerable caution not to judge the participants' meanings of their lived realities, it could be that although the two participants mentioned above rejected the ADHD diagnoses for their children based on cultural beliefs and lack of trust in the professionals, respectively, parent personality influences may have also contributed to the rejection. Participant P1's refusal to accept the diagnosis because in his "world, [ADHD] doesn't exist," and participant P17's adamancy that the psychologist was "wrong" despite psychological evidence and her earlier acknowledgment that the child had some challenges, especially socially, may be suggestive of projected subconscious narcissistic defenses embodied in their personalities.

According to Dentale et al. (2015), narcissism is associated with vulnerability, while Hepper et al. (2010) claim that narcissist traits involve self-protection attempts that manifest in defended behaviors. Therefore, the two participants' denial of their children's ADHD diagnoses may have been a subconscious attempt to protect themselves from the shame of having a child with a mental disorder. In an effort to self-protect, parents may miss their

children's actual needs when they prioritize their own protection (Dentale et al., 2015). However, further studies are required to establish the extent of the influence of parental personality on perceptions of their children's ADHD diagnoses among Black parents and caregivers in South Africa, as such an inquiry was beyond the scope of this present study.

ADHD diagnosis rejection by Black parents and caregivers in South Africa is not peculiar to the study. The rejection validates research by Alrahili et al. (2022), whose study on parental attitudes and perceptions towards ADHD in South Africa established that a third of the participants did not believe in ADHD diagnoses for their children. As a result, such children would miss ADHD interventions that may assist them in managing and coping with the ADHD symptoms, consequently having an unfavorable prognosis on their overall functioning. When parents and caregivers hinder their children with ADHD from accessing relevant interventions due to the ADHD diagnosis denial, the children's development is negatively affected. According to Bronfenbrenner's bioecological systems theory (1989), a child's development is influenced by the interplay between the child and the microsystemic role players, including the parents and caregivers. Therefore, this study highlights the importance for professionals working with children to acquaint themselves with every Black parent's and caregiver's perspective toward ADHD symptomatology and diagnosis for their child. When parents and caregivers understand how ADHD manifests, it increases the likelihood of every child diagnosed with ADHD within the Black population in South Africa accessing interventions that may significantly improve their functioning.

### **Understanding ADHD**

Having explored the participants' perceptions about their children's behavior before the ADHD diagnosis and their responses, it was critical to ascertain their understanding of the disorder. Ascertaining this understanding would be explored under the superordinate theme, 'Understanding ADHD.' This superordinate theme is broken down into three subordinate

themes: 'Perception of cause,' 'Conceptions about the nature of ADHD,' and 'Belief about the management of symptoms.' Exploring the participants' understanding of ADHD would give the reader a better contextual understanding of their decision-making on intervention pursuits and preferences for their children, as discussed later in the thesis.

### *Perception of Cause*

When asked what they believed to be the cause of ADHD, most participants were unsure but speculated on different etiological factors. Heredity as a cause of the disorder appeared to be the most popular belief amongst the participants. The words "genetics," "gene," and "inherent" were used to express that belief. Some participants cited themselves or other family members who displayed ADHD symptoms to validate their speculation. In the individual interview, one mother, participant P4, stated, "It could also be genetic because I'm also suspecting now he gets it from me because I couldn't figure it out. I don't recall ever having long concentration spans at school." In the focus group, she backed her speculation that ADHD could be genetic when she expressed:

I realize that my second child is also starting to have...I'm picking the signs that he might be ADHD. I'm starting to get uhm messages from school to say I should get him checked out and stuff like that and I'm thinking well between the two of them, I'm the common denominator (laughs). So I'm just thinking, you know, maybe it could also just be genetic.

Participant P4 believed she might have undiagnosed ADHD and that her two sons, although the younger one had not yet been assessed for ADHD, might have inherited it from her since the sons share the same mother but different fathers.

Another participant, P20, an occupational therapist who only participated in the individual interview, expressed her belief that her son inherited the disorder when she stated:

Some children get it because it runs in the family, like my son. His father has it, although he will never admit it. I see the signs now that I know a lot about ADHD.

My husband is very, very, very impulsive.

Using her career expertise and the alleged explicit ADHD-type behavior her husband displayed, participant P20 was convinced that ADHD is primarily genetic.

Concurring with the above participants that ADHD may run in families was a 54-year-old male participant, P12. He was a primary caregiver to his 8-year-old nephew diagnosed with ADHD. He said, “Yah, I’m seeing it with my brother. I’m seeing it with my brother’s kids. One of my brother’s kids was diagnosed... two of them, they have been diagnosed with it.” He further alleged that his nephew, whom he called his son, was “exhibiting those similar characteristics, you know, that all his aunts and uncles were struggling with.”

Despite most participants attributing the cause of ADHD primarily to heredity, they also acknowledged the multi-etologies of the disorder. For example, other causes of ADHD highlighted by these participants varied from diet, brain imbalance, head injury, natural causes such as the will of God, pregnancy difficulty, neglect of culture, comorbidity, drugs and alcohol use during pregnancy, separation anxiety, and depression during pregnancy.

However, a few participants believed in a single cause of ADHD. For example, participant P14, a 30-year-old female, revealed that she believed ADHD was only caused by issues with brain “chemical balance,” while participant P19, a 43-year-old male, thought “it is a diet problem.” For them, ADHD has no other etiological explanations.

It is important to note that although almost all participants shared or speculated on what they believed could be the causes of ADHD, three participants indicated that they did not know the cause of ADHD for their children. With participants P10 and P13, their response “I don’t know” appeared to be based on a lack of understanding about the disorder.

On the other hand, participant P2's response, "I'm not sure since it has never occurred to me. I've never had any experience with ADHD," seemed to be fueled by his rejection of the existence of ADHD.

### ***Conceptions about the Nature of ADHD***

Participants seemed to have differing views and understanding of the nature of ADHD. Most participants classified ADHD as a mental condition. Their accounts revealed that although most of them speculated on the causes of ADHD, they were aware that the disorder affected the cognitive functioning of their children. Thus, they classified ADHD as a mental condition. Four participants viewed ADHD as a medical disorder, while two perceived it as a dietary condition. Two other participants categorized ADHD as a social condition. Few participants also believed in the dual nature of ADHD, while one classified ADHD as a multi-natured disorder. Some participants accepted ADHD as a chronic disorder, while others perceived it as a curable condition. A few participants said they did not regard ADHD as a disability.

Capturing the popular shared perception by most participants that ADHD is a mental disorder, participant P3, a mother of a 9-year-old child diagnosed a year earlier, stated, "Eeh...to me, it sounds more like a mental illness." Also, participant P11, a mother of an 11-year-old child diagnosed two years earlier, indicated that she believed that ADHD was a "mental condition" based on "the way" her child behaved.

However, there seemed to be uncertainty in the narrative of participant P7, a mother of an 11-year-old child diagnosed with ADHD 4 years earlier. During the individual interview, she seemed unsure if ADHD was a mental disorder when she said, "I don't know if I can say it's just a mental disorder, you know." However, during the focus group discussion, her perception of the classification of the disorder appeared to have been settled when she declared, "it is not a mental disorder." Participant P7's account depicts that despite

the duration an individual may have been exposed to ADHD, it may take time to understand the disorder fully.

Participant P18 considered ADHD as a “medical” condition only. Still, some participants believed ADHD has a dual nature, as described by participant P16, who stated, “I would say it is both a social and medical uh...both contribute to uh this ADHD.” Participant P4 believed ADHD to be a mental condition when she stated, “certain things in his brain are not wired as what we deem as ‘normal’ (*using the pointing fingers to quote the word normal*).” She also expressed that “it’s a medical condition.” Highlighting the dual nature of ADHD, participant P19 voiced that ADHD is a “dietary problem” and a “social problem.”

Participant P9, a mother whose child had been diagnosed with ADHD a year earlier, appeared to believe that ADHD has a multiple nature. She perceived the condition as a mental and dietary condition when she shared:

Eeh...I would combine the two, mental and dietary as well... I would combine the two because...eeh for an example if she doesn’t have too much sugar, it’s much better...But again, when she is taking medication, when the stimulant is there, she behaves properly.

However, based on her narrative, participant P9 also perceived ADHD as a medical condition. She described ADHD as “a medical thing” grounding her perception on her realization that her child needed medication to control her behavior.

Most participants (15 out of 21) perceived ADHD as a chronic condition, accepting that their children would live with the lifelong disease. For example, conveying her understanding that her niece would have to live with the disorder for the rest of her life, participant P5 stated that “she will live with it forever,” while participant P3 acknowledged that ADHD for her daughter “cannot be cured.” These sentiments summarized most participants’ understanding that any interventions their children may receive would only help manage the disorder to enable them to have fulfilling lives.

In contrast, six out of 21 participants considered ADHD a curable condition. For example, participant P15, a mother of an 8-year-old child diagnosed a year earlier, believed that ADHD “can be corrected.” She also supported her position by declaring that when ADHD for a child is caused by neglecting cultural rituals, “children really eeh do change after doing all those rituals for them.” Also sharing the belief that ADHD can be cured, participant P19, a father of an 8-year-old child who struggled with inattention and impulsivity, said, “I think it can be changeable.”

Expressing her understanding of the nature of ADHD, participant P7 indicated that she regarded ADHD as “not a disability” when she expressed, “I don’t look at my child as...as if she’s having a disability.” This gave the impression that her perception of her child did not define ADHD as a disability despite its assigned classification. Perceiving ADHD as a disability seemed to provoke negative connotations for some participants, as expressed by participant P6 during the individual interview when she said, “it felt like it was a disability.” She stated that she had initially struggled to accept that her second child had an ADHD diagnosis like her first child because the diagnosis seemed to mean that her children had a disability. She described the strong negative psychological impact of perceiving her child with a mental “disability” as “traumatic.” However, during the focus group discussion, she referred to ADHD as a “disability,” indicative that over time and with more understanding of the disorder, she had accepted that ADHD is some form of disability.

In contrast, participant P5 appeared comfortable with classifying ADHD as a disability when he said, “in fact, for me, it’s a form of disability.” Also, in his statement, “when we completed forms when you are looking for a job, there is no disease...no disability called ADHD vis-à-vis are you blind”, he expressed his wish that ADHD as a disability could be given adequate awareness like other forms of disabilities.

### ***Belief about the Management of Symptoms***

The participants had varied understandings about how ADHD-type behaviors in their children could be managed. The ways of managing the ADHD-related behaviors that participants perceived as helpful included engaging the children in physical activities to burn their high energy levels, medication, parental psychosocial education, providing support through being fully involved in the children's academic and home lives, creating structure and consistency, academic support, managing diet, empowering the children to self-regulate, seeking divine intervention, performing cultural rituals, and using discipline.

Of the 21 participants, 19 understood that their children's ADHD-type behaviors could be controlled using multi-approaches by incorporating more than one of the abovementioned ways. Twelve of those 19 participants were receptive to embracing medication in the multi-approaches, while the other seven were comfortable with non-medicinal multi-approaches to ADHD symptom management. Two out of 21 participants believed a single approach could adequately manage their children's ADHD-type behaviors.

Participant P9, a 49-year-old mother whose 7-year-old child had been diagnosed a year earlier at the time of the interview, represented the participants who believed that multiple ways, including medication, could be used concurrently in managing ADHD-type behaviors. Participant P9 believed "decreasing too much sugar" minimized ADHD's symptoms based on her belief that consuming a "lot of sugar" caused the disorder. Also acknowledging that lack of structure aggravates the ADHD symptoms, she pointed out that maintaining "routine" in the child's life and limiting the use of "gadgets" were the best ways of managing the child's ADHD symptoms. In addition, she also highlighted that medication helped manage her child's behavior. Thus, participant P9 believed that combining dietary monitoring, limiting gadget use, maintaining routine, and medication use could be the best ways to alleviate ADHD symptoms for her child.

Another participant who believed in a multi-approach with medication use for their child's ADHD symptom management was participant P14, a nurse who interpreted her child's ADHD diagnosis from a medical perspective influenced by her profession. Expressing her belief, participant P14 indicated that she thought "the medication can help" to manage her child's ADHD symptoms. She also expressed that parents of children with ADHD needed to be equipped with "skills on how to manage" the behavior of children with ADHD. She believed parental psychosocial education would complement medication in ADHD behavior management for her children.

On the other hand, participant P12's narrative, an uncle and a primary caregiver of an 8-year-old child with ADHD, represented the accounts of the participants who believed in a non-medicinal multi-approach ADHD intervention. When highlighting the ADHD symptom management ways he experienced as beneficial for his nephew, participant P12 had this to say during the individual interview, "yah and I...I also, you know, like there were certain, certain foodstuff that, you know, like, I was not allowing him, you know, to touch." He further indicated that engaging the child in "physical activity" made the child "calmer." For him, monitoring the child's diet and keeping him physically active proved effective in controlling the ADHD symptoms of his nephew. These statements were consistent with the sentiments he shared in the focus group, where he indicated that there were "many ways to do it, eeh depending on what works best for the child." He stated that "the food monitoring and the eeh you know, physical exercises work eeh you know, for us. But children are different...so you know, it depends with the child." P12 stated that he had "reservations about medication" and indicated in the individual and focus group interviews that he chose not to adhere to the doctor's instructions regarding medicating his nephew.

Also falling in the category of the participants who believed in various ways of minimizing ADHD symptoms without medication was participant P4. She shared:

Look, prior to lockdown I used to take him to classes for Edu-blocks which helped with cognitive skills...I do natural stuff at home. I give him Omega 3 and 6. Uhm, I give him Mentat, you know...I try to stay on a healthy diet as much as possible...Uhm, he was also doing swimming, which was helping a lot, but obviously, pheew...lockdown and stuff like that happened.

Although during the individual interview, P4 indicated that she preferred her son not to use medication to manage his ADHD symptoms, when she stated, “we said it is better to take him off medication,” she was nonjudgmental about parents and caregivers who chose to use medication. During the focus group, she declared, “but I always say to people, try medication... if it doesn’t work, try something else. It’s always a trial and error uh eventually for everybody.” She also believed parents and caregivers should settle for ways of managing ADHD that worked best for their children.

Two participants in the study believed in a single approach to ADHD symptom management for their children. Influenced by his belief that his child’s ADHD-type behavior was typical of teenage boys’ behavior, participant P2, a father of a 14-year-old child, believed “more discipline” was the only way to manage his child’s behavior. He firmly believed that his child was undergoing a developmental phase and that stricter discipline and nothing else would check the child’s behavior. Thus, he believed in that single approach to managing his child’s negative behavior.

Also trusting in a single ADHD-type behavior management approach, participant P7 shared that “medication” was the effective method for her child with ADHD. Hence, she was convinced that a single approach to ADHD behavior management through medication effectively controlled the ADHD symptoms of her 11-year-old child.

At this stage, it is essential to note that these various understandings of ADHD symptom management reflected what the participants believed were ways to help their

children control their undesirable behaviors. Participants employed the perceived management beliefs as choices for ADHD interventions for their children. The influencing factors on intervention choices participants settled for will be explored later in Chapter 9 of the thesis.

### **Discussion: Understanding ADHD**

This section discusses the findings under the superordinate theme of understanding ADHD. The superordinate theme addresses the study's research question: What are Black parents' and caregivers' perceptions of the nature and causes of ADHD? To tackle this research question, it was imperative to explore what participants understood to be the causes of ADHD, how they classified the disorder, and their beliefs on how the ADHD-type behavior and symptoms for their children could be managed.

In understanding participants' perceptions of the etiology of ADHD, it is crucial to note that the disorder has multi-causal determinants and risk factors (Speerforck et al., 2019; Wong, 2022). As a result, it is understandable that the participants in the current study had varied ADHD etiological beliefs. Most participants gave multiple varied causes of the disorder, while a few believed in a single cause. Participants' understandings of the genesis of ADHD were mainly based on uncertainty and speculation, as they appeared not entirely sure of the causes of the disorder. Such uncertainty may influence their perception of the disorder and intervention decision-making for their children. This finding concurred with studies conducted by Alrahili et al. (2022) and Evans (2019), which found that many parents of children with ADHD were unsure about the causes of the disorder. Some of the beliefs that the participants in the study had about the causes of ADHD are well-informed by professionals and generally accepted. In contrast, others are considered to be generally inaccurate. Inaccurate information about the causes of ADHD may lead some parents to

pursue ineffective symptom management approaches for their children diagnosed with ADHD.

Despite their uncertainty, several participants in the study cited genetics as the leading cause of ADHD, stating that they identified some of the ADHD symptoms in some members of their families. These findings were consistent with those of Evans (2019), where some of the parents and caregivers of children with ADHD believed the disorder was heritable. Thus, these participants inexplicitly implied that they could not have prevented their ADHD-genetically vulnerable children from developing the condition. However, the awareness that their children acquired the ADHD predisposition from them created a sense of self-blame for most parents. Dodangi et al. (2017) indicate that when parents feel responsible for their children's ADHD, they may develop feelings of guilt. There is a sense of feeling responsible for the child's condition among the parents, which may positively influence them to seek interventions for their child to reduce the guilt feelings.

On the other hand, some participants did not attribute ADHD to heredity, supporting research conducted by Dodangi et al. (2017) that revealed that 46% of parents did not attribute ADHD to genetics. This suggests that parents of children with ADHD may always have a differing perception regarding the development of ADHD, which may later influence their decision-making on symptom management.

Other participants who also believed ADHD in their children could not have been prevented perceived the disorder to be caused by the will of God, suggesting that they do not hold themselves responsible in any way for the development of ADHD in their children. Holding this perspective about the cause of ADHD exonerated the parents from self-blame.

Some participants also perceived that diet, particularly consuming too much sugar, caused ADHD. This finding was in alignment with studies that claim that most parents of children with ADHD attribute the cause of the disorder to increased sugar consumption in

children (Alrahili et al., 2022; Fan et al., 2022). Some views from the current study attributed the cause of ADHD to pregnancy difficulties, post-natal trauma such as head injuries, separation anxiety, depression, neglect of culture, and comorbidity with other childhood disorders. All these views on the genesis of ADHD imply that parents perceived ADHD as a preventable condition. Dodangi et al. (2017) indicated that when parents attribute the cause of ADHD to preventable factors, they may feel guilty. Such guilt may motivate them to seek help for their children with ADHD, making them receptive to interventions.

ADHD is one of the children's most common mental disorders (Vélez-Pastrana, 2020). When exploring participants' perceptions of ADHD, most classified ADHD as a mental disorder, aligning their perceptions to the above view. They observed that ADHD affected their children's behavior, mood regulation, and cognitive and social functioning, classifying the disorder as a mental condition. By viewing ADHD as a mental condition, the parents and caregivers indicate an understanding that children diagnosed with ADHD struggle to control their behavior and may need interventions. This supports findings by Fan et al. (2022) that show that after children are diagnosed with ADHD, 60.95% of parents understand that ADHD is a disorder and not an expression of a child's naughtiness.

The present study finding revealed that some parents and caregivers within the Black population group in South Africa may classify ADHD according to their etiological belief of the disorder and their approach to managing the symptoms. As such, some may categorize ADHD as a multi-natured condition. These classifications may include medical, dietary, and social conditions. This confirms the complexity of ADHD in support of Ford-Jones (2015), who highlights that the nature of ADHD is controversial. This controversy surrounding the nature of ADHD may also contribute to the parents' and caregivers' uncertainty regarding the disorder and its causes. Consequently, healthcare professionals dealing with ADHD need to establish the Black parents' and caregivers' understanding of the nature of ADHD, which

significantly impacts decision-making on intervention pursuits and preferences. Furthermore, healthcare professionals may clear any misconceptions parents and caregivers may hold about ADHD.

Concerning the prognosis of ADHD, the current study showed that the majority of the participants regarded ADHD as a chronic condition. This current study's findings extend the findings by Dodangi et al. (2017), which indicated that a small number of participants in their study perceived ADHD as a lifetime disorder. Therefore, it is apparent that despite some uncertainties about the nature of ADHD, Black parents and caregivers understand that ADHD symptoms are not curable. Instead, interventions help to alleviate the ADHD symptoms but still do not wholly eradicate the disorder. As a result, some parents understand that their children may need to be on intervention for an ongoing period. Therefore, at the mesosystem level of the bioecological systems theory, interdisciplinary professionals such as healthcare practitioners and teachers need to work together with the parents at a decision-making level. This collaboration would be to support and encourage parents and caregivers to maintain ADHD intervention adherence for the well-being of the child.

It was observed from the current study that some parents defaulted on ADHD interventions for their children, as will be later discussed in the thesis. Baweja et al. (2021) raised their concern in their study regarding ADHD intervention adherence, stating that when interventions for ADHD are commenced, they often become irregular or discontinued altogether. Confirming this observation, Chacko et al. (2016) stated that intervention disruption often occurs within the first year of intervention commencement. This observation highlights the importance of promotion of intervention adherence among the parents of children who have commenced ADHD interventions, especially within the first year.

Interestingly, the current study also indicated that some participants perceived ADHD as a curable condition, indicating that it can be corrected. This means that despite some Black

parents and caregivers in South Africa understanding that ADHD is a lifelong condition, some parents may cling to the hope that their children will be cured of ADHD at some point in life. This finding unearthed misconceptions some Black parents and caregivers may hold regarding the nature of ADHD. These misconceptions correlate with the study of Alrahili et al. (2022), whereby some parents also had misconceptions regarding ADHD, perceiving it as a form of behavioral issue caused by poor parenting. This implied that such parents believe that if parents corrected their parenting style, the ADHD behavior in children would disappear. Fan et al. (2022) also confirm in their research about parents' knowledge of ADHD that many parents in their study had inaccurate conceptions about the nature of ADHD. Taking cognizance of this pattern of misconceptions among parents and caregivers of children diagnosed with ADHD, it is also crucial for multidisciplinary professionals working with children to understand these misconceptions and correct them. When parents, including Black parents and caregivers in South Africa, have the correct understanding of ADHD, they are more likely to make informed decisions regarding ADHD.

It is important to note that the perceptions of ADHD etiology and symptom manifestations for the child may significantly shape parental and caregivers' beliefs on ADHD management. For example, some of the management beliefs highlighted in the study involved diet management based on the belief that certain foods, such as excess sugar, trigger ADHD. As such, participants varied in their perceptions of ADHD management for their children. The variations in parental management beliefs about ADHD confirmed other studies' findings, where some parents believed in medical interventions while others believed in psychological interventions (Fan et al., 2022). Also, some parents believed in herbal interventions, as found by Dodangi et al. (2017), while others believed in dietary symptom management approaches (Alrahili et al., 2022).

Further exploring what participants thought would be the best ways of managing their children's atypical behavior since the diagnosis, the current study's findings revealed that 90.48% of the participants believed that a multi-approach would help manage the ADHD symptoms for their children. This finding supports a study by Vitulano et al. (2022), which indicated that some parents of children with ADHD were open to exploring several intervention options to manage ADHD symptoms displayed by their children. The multi-approach interventions participants in the current study believed in comprised two or more of the following ways: creating structure in the form of consistency, physical exercise, teaching the child self-regulation techniques, time management, supporting the child academically and socially based on the child's capabilities, parental psychoeducation, seeking God's intervention, and performing cultural rituals.

More than half of the participants in the current study (63.16%) believed that incorporating pharmacological interventions in the multi-approach to ADHD management for their children may be effective in addressing their children's negative behavior. This finding aligns with that of Fan et al. (2022), who conducted a cross-sectional survey and reported that 78.10% of the parents in their study also believed in medications as an ADHD intervention choice. However, 36.84% of the participants in the current study did not believe in ADHD pharmacological interventions. Thus, this finding is consistent with literature where the use of medications to treat ADHD did not align with the beliefs and values of some parents and caregivers of children with ADHD, especially African Americans (Evans, 2019; Walls et al., 2018).

It is clear from the above finding that some parents and caregivers within the Black communities in South Africa will reject ADHD medications recommended for their children. This finding can be used as an advocacy tool to promote non-pharmacological ADHD interventions to be considered by professionals who may favor medication as their first line

of ADHD treatment. Parents' and caregivers' beliefs regarding ADHD management should be considered by professionals when setting a treatment plan for children with ADHD (Vitulano et al., 2022). This statement is supported by Lu et al. (2022), who advocated for flexibility and an accommodating attitude by professionals when recommending ADHD interventions. When parents perceive that they are listened to and their perceptions are valued, there is an increased likelihood of parents' and health professionals' collaboration in ADHD interventions for children diagnosed with ADHD.

### **Summary**

This chapter addressed the study's research question, 'What are Black parents' and caregivers' perceptions of an ADHD diagnosis for their children?' under the superordinate theme, 'Receive the diagnosis.' The participants' perceptions of their children's behavior before the diagnosis influenced their response and receptiveness to the diagnosis. Also, the chapter answered the research question, 'What are Black parents' and caregivers' perceptions of the nature and causes of ADHD?', exploring the superordinate theme, 'Understanding ADHD.' The participants' perceptions of ADHD had a significant impact on how they believed the ADHD-induced behaviors of their children could be managed. The study's theoretical framework based on Bronfenbrenner's bioecological systems theory was incorporated in addressing the two research questions. The next chapter will present the study's findings and discussion based on addressing the third research question, 'What factors influence Black parents' and caregivers' perceptions of an ADHD diagnosis for their children?'

## CHAPTER 6: FINDINGS AND DISCUSSION

### **Role of the School and Sources of Support**

This chapter focuses on two superordinate themes, ‘The role of the school’ and the ‘Support system.’ Through the narratives of the participants, it was discovered that the school played a crucial role in identifying most ADHD symptoms in their children, leading to recommendations for ADHD assessments and management. The school’s approach and attitude towards addressing ADHD-like behavior in students can significantly influence how parents and caregivers view an ADHD diagnosis and their decision-making regarding interventions. Therefore, examining the participants’ experiences with the school in this context is crucial. The subordinate themes explored under the ‘Role of the school’ are highlighted in Table 2 below, as presented in Chapter 4.

In this thesis, the term ‘mainstream schools’ refers to public and private schools catering to students without specific educational needs. On the other hand, ‘special needs schools’ refer to public and private schools designed to meet the educational requirements of learners who need additional academic support due to physical, cognitive, or developmental disabilities.

The experiences of participants in terms of support or lack of support they received regarding their child’s ADHD behavior and diagnosis played a role in how they perceived ADHD. Moreover, the support experiences had an impact on the participants’ decision-making regarding intervention for ADHD diagnosis for their children. The support experiences of participants will be considered under the superordinate theme of ‘Sources of support.’ Two subordinate themes, namely ‘Positive support experience’ and ‘Negative support experience,’ will be examined in support of the superordinate theme.

It is beneficial at this juncture to highlight that the two superordinate themes presented in this chapter partially address the study's research question: 'What factors influence Black parents' and caregivers' perceptions of an ADHD diagnosis for their children?' This research question will, however, be fully addressed in the subsequent chapter 7, when I explore the superordinate theme 'Factors influencing the perception of ADHD.'

**Table 2:***Superordinate and Subordinate Themes*

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Receiving the diagnosis	Child's behavior prior to diagnosis Own diagnosis reaction Do I accept or reject the diagnosis?
Understanding ADHD	Perception of cause Conceptions about the nature of ADHD Beliefs about the management of symptoms
<b>Role of the school</b>	<i>Positive impact of the school</i> <i>Negative impact of the school</i>
<b>Sources of support</b>	<i>Positive support experience</i> <i>Negative support experience</i>
Factors influencing perceptions of ADHD	Culture Stigma Awareness and Knowledge Religious and Spiritual beliefs
Implications of the child's behavior: the significance attributed to the diagnosis	Negative implications of the child's behavior Positive implications of the child's behavior
Decision-making on intervention pursuits	Reasons for intervention pursuits Motivations for chosen interventions Perceptions about ADHD medications Hindrances to intervention pursuits

**Role of the School**

This superordinate theme explored the participants' perceptions of the school's attitude towards their children diagnosed with ADHD. Through concerns regarding the children's academic performance and behavior, the school played a critical role in enabling participants to be exposed to ADHD. It was through those concerns raised by the school that most of the children in the study were referred for assessments that led to ADHD diagnoses.

*Positive Impact of the School*

Describing their experiences with the school regarding their children's ADHD-type behavior, less than half of the participants implicitly expressed satisfaction with the school's approach. These participants felt supported by the school. The most candid description of positive experiences with the school came from participant P3's account. In the focus group, she expressed:

As much as I noticed certain behaviors that were not uh something that I could easily overlook, but I really wasn't going to seek out help without crèche also alerting me to say can you please get your child uhm assessed.

Participant P3 acknowledged that the school was pivotal in her decision to have her child assessed for ADHD.

Furthermore, during the individual interview, P3 perceived the teacher as supportive and accommodating of her child's academic needs. She shared, "she's very supportive to a certain extent that she also advises me the extra time she's giving her compared to...to other children who are not having this challenge." Participant P3's use of the phrases "she was so free" and "I contact and speak to her so almost every other day or on a daily basis" was reflective of her experiencing the teacher as approachable and ready to help. Participant P3 expressed gratitude for the teacher's effort in managing her child's academic challenges when she stated, "her being able to come down to her level [child's] has been the greatest support."

Participant P7, a mother with a child struggling at school, highlighted in the individual interview that the school was also instrumental in referring her child for ADHD assessment, which led to her diagnosis. She indicated that long before her child started school, she had dismissed an extended family member's suggestion that the child could have ADHD. However, when the school recommended assessment for the child, the ADHD journey began. Participant P7 validated her belief that the school was the motivation for her

daughter's diagnosis when she stated in the focus group, "So it was the school that made me take her for assessment."

Participant P7 was grateful for the positive attitude of the teachers toward her child's diagnosis in the two schools her child had attended. She perceived the teachers as "very supportive" and nonjudgmental toward her and her child. She expressed:

And even the feedback I could get from them, it wasn't negative, but they would let's say, in the morning we forgot to take a pill, they would...I would just then receive an 'SMS' that says okay, you guys didn't take the pill today.

Participant P7 felt she could rely on the teachers to help her manage her child's ADHD symptoms at school. She appreciated and welcomed the reminders from the teachers to medicate her child. She took such communication as a positive involvement from the teachers and perceived it "not in a bad way but just to say I can see her today that she is off meds today, you know." She believed the open-minded approach used by the teachers created an effective home-school collaborative relationship in managing the child's academic struggles caused by ADHD.

Recounting how the teachers addressed them concerning ADHD-type behaviors displayed by their children, participant P9, a mother whose child was falling behind in her schoolwork, and participant P12, an uncle of a super hyperactive nephew, appreciated the teachers' sensitivity. Participant P9 expressed:

She wanted me to take the lead because obviously that some parents are very sensitive She didn't really say to me it's ADHD. She just said that the child is not finishing the task and if they are not finishing the task, then sometimes they could end up going to special schools and all those things.

Similarly, participant P12 stated, "the teacher didn't actually tell us, you know, that you know, the child has ADHD," and "she was cautious about such things." Both participants

experienced the teachers as cautious and tactful in recommending assessments for the children.

The teachers' sensitivity about their concerns regarding the children's behaviors allowed both participants to be receptive to the news that the children were experiencing challenges at school, thus collaborating with the teachers to address them. These participants felt the teachers were concerned about the children's behaviors without labeling them. They also perceived the teachers as giving them autonomy in help-seeking decision-making regarding their concerns about their child's behavior.

### *Negative impact of the school*

All the children in the study started school in mainstream schools. However, six of the participants reported that their children were no longer attending mainstream schools but had shifted to schools that cater specifically to children with special needs. While some participants acknowledged that the mainstream schools played a role in identifying their children's ADHD and getting them the necessary interventions, most of them expressed dissatisfaction with how these schools dealt with ADHD-related behaviors in their children.

Participant P4, a mother who had sent her son to an expensive private school because she believed her child's every need would be accommodated, expressed anger and disappointment at how her child's ADHD behavior was addressed. During the individual interview, she stated, "You know, the primary that he was at...I'll never forget the principal. She actually spit it out and said to me, if I had space for all 'the-se' other children, I would take them." Participant P4 used a despising tone of voice, imitating the alleged insensitive manner the school principal spoke of her child's challenges.

Participant P4 stressed the word 'the-se' emphasizing the prejudice she perceived the school principal regarded children with challenges. As participant P4 described the "insensitive" and "clinical" manner the school addressed her child's ADHD-induced

behavior, I could sense anger in her voice. She started speaking very fast, and her facial expressions indicated that recalling the incident aroused fresh feelings of anger toward the school.

During the focus group discussion, P4 validated her above-expressed opinions and wished the school could be sensitive and nondiscriminatory towards children with disorders that affect their academic functioning. To describe the long-lasting negative impact of the school principal's attitude toward her, she expressed:

I found it quite insensitive eh, you know. You know, at some point uh, the principal uh...I'll never forget the words...the principal turned around and said oh if I had eh eh a special wing for children like this, I would keep him. Uhm you know, like your child is some kind of an alien, I don't know. Uh I just wish that they could be a little more sensitive to the fact that certain parents uh don't know about it, don't understand uh yo...you know.

Also expressing the insensitivity that she encountered from her child's teacher concerning her child's ADHD-motivated behavior, participant P15, an early childhood practitioner, stated:

It was the approach of the teacher actually that made me eeh upset more than anything because the teacher described him as rude, disruptive and eeh and not disciplined, you know. The way she addressed it to me it was as if I don't discipline him.

Participant P15 perceived her parenting skills as judged and attacked by the teacher. She also perceived her child as labeled, causing her to counter-react in anger towards the teacher. She felt she needed to defend herself and her child from the teacher's attacks. She indicated that she felt compelled to address the teacher's insensitive approach when she shared her response to the teacher:

You have to be sensitive how you approach these things because I can easily be...those moms, those helicopter moms who will gangster on you, wait by the gate for you and deal with you because I'm Black like that.

Sharing her experience of the school's insensitivity towards her son's ADHD-type behaviors, participant P20 described the discriminatory manner the school managed the child's behavior by isolating him to the storeroom. P20 believed the school was unable to handle her son's behavior appropriately; thus, she reported developing a negative "attitude towards" the teacher. She also developed feelings of anger toward the school. P20 believed her son's challenging ADHD behavior could have been handled better.

Narrating her account of the role of school leading to her child's ADHD diagnosis, another participant, P6, shared that she felt the school coerced her to take her child for an ADHD assessment. She stated that the teacher imposed that decision on her by threatening that if the child was not taken "for a psychiatric evaluation, the child will have to repeat a class." The implied interpretation P6 gave for the teacher's behavior was that the school was taking away the power from her as a parent to make the ADHD assessment decision for her child. She felt she was given an ultimatum, causing her to be unhappy about the school's approach.

Although acknowledging the role of mainstream schools in identifying ADHD-type behavior challenges in their children, several participants considered mainstream schools not conducive to catering to the needs of children with ADHD. They believed mainstream public or private schools did not accommodate children with ADHD and other special educational needs. There was a sense of being failed by the school among these participants. A rich summary of these participants' shared perceptions regarding this unsuitability of the mainstream schools came from participant P8, whose older child struggled with predominantly inattentive-type ADHD and other comorbid disorders. During the individual

interview, she expressed that according to her, “the mainstream schools and ADHD, they...they...they are not families, they don’t correlate. As long as the child has a condition, must go straight to the remedial school.”

In the focus group, P8 corroborated her position of viewing mainstream schools as unsuitable for children with ADHD when she stated:

And you know what, also it’s...it’s...it’s...in South Africa, in South Africa, in general *nhe* (right), there is one out of five schools, mainstream schools, wherein they will support you as they say from January. As soon as you register your child, you gonna go there, talk to the principal to say you know what, this is my daughter, she has ADHD. And then after that...they’re not gonna support her. They will even tell you that I have thirty children in the class, I can’t be able to monitor your child every hour or every second.

Participant P8 expressed her frustration at the mainstream schools’ lack of support and commitment to children with ADHD. She believed the lack of support was influenced by the lack of “enough awareness” in mainstream schools.

### **Discussion: Role of the School**

Despite no explicit probe into the attitudes and approaches of teachers or schools towards children diagnosed with ADHD, the majority of participants’ narratives revolved around their interactions with the school. This highlights schools’ noteworthy impact on shaping perceptions and understanding of ADHD and cannot be overlooked. As such, this section discusses the school’s role, a theme that marked a noteworthy part of most participants’ narratives.

Fifteen out of 21 of this study’s participants highlighted that the school was very instrumental in identifying challenging behaviors in their children that led to an ADHD diagnosis. Within the school setting, ADHD-type behaviors in children are prone to intensify,

and the teachers would be the first to detect ADHD symptoms (Layton et al., 2018; Morolake et al., 2022). As such, most school-age-going children are referred for ADHD assessments on teachers' recommendations. A South African-based study revealed that about 90% of teachers reported that if they encountered a child displaying challenging behavior, they would refer that child for assessment (Yarde-Leavett, 2018). Thus, based on this finding, many school-going children in South Africa who display challenging behavior in schools are likely to be referred for assessment at some point in their school years.

Furthermore, the teachers are expected to work collaboratively with parents and caregivers in directly implementing ADHD interventions, especially classroom-based ones (Layton et al., 2018). This view dovetails with Bronfenbrenner's (1977) theoretical framework in the mesosystem level whereby the structures at the microsystems level, which in this instance, are the home and the school, interact with each other within the ecological setting a child actively engages, thus influencing the child's development. Hence, the teachers must work collaboratively with the parents and caregivers to identify and manage ADHD-type behaviors exhibited by the child.

The study participants described the school as having either a positive or a negative impact on their receptiveness to the school's reports concerning their children's ADHD behaviors and the assessment recommendations. The participants also reported experiencing the school as negative or positive in its ability to accommodate children with ADHD.

Findings revealed that seven of the participants in the present study shared a subordinate theme of the positive impact of the school when they described satisfaction with how the school addressed their children's ADHD behavior. These participants described the teachers as sensitive and careful not to label and stigmatize the ADHD-diagnosed children or their parents. The participants reported being content with the teachers' measures to facilitate the school-home collaboration in managing their children's ADHD symptoms. This finding

supports a study by Margalit et al. (2010), in which some mothers reported experiencing the schools positively regarding the help offered to their children with ADHD. Thus, they gained faith and confidence in the school's ability to manage their children's ADHD symptoms.

A trusting, working relationship described above between the parents and the school promotes an effective school-home collaboration in ADHD symptom management for children diagnosed with the disorder. Consequently, parents and caregivers who experience the school positively perceive that they could rely on the school for support regarding their children diagnosed with ADHD. Furthermore, the parents and caregivers experience a sense of being given autonomy to help-seeking decision-making when there is a healthy working relationship between the school and the parents. One participant in the study confirmed the above claim when they explicitly stated that the teacher "wanted me to make my own decision." As such, the relevance of this finding is that when parents and caregivers of children with ADHD perceive the school has the best interest of their child and is accommodative and willing to help their child, powerful, fruitful school-home collaborative relationships that benefit the child are established.

Despite the positive school impact experienced by a third of the participants in the study, over two-thirds of the participants reported a negative experience with the school. Some described the teachers as insensitive to them or their children with ADHD. These participants also shared a common experience of the teachers lacking an empathic professional approach to addressing the children's challenging behavior. Some participants highlighted that the school failed to consider their feelings, given that some parents were hearing of ADHD for the first time. As a result, some participants described their child's ADHD assessment referrals as coerced threats by the school. The participants concluded that the teachers were impatient and unwilling to accommodate children with ADHD academically.

Furthermore, these participants believed the school stereotyped and discriminated against children with ADHD in favor of those without the disorder. These current findings confirm the findings of previous studies, some stretching back over two decades ago, whereby parents and caregivers in varied study settings reported experiencing teachers of their children with ADHD as insensitive, irritable, judgmental, and unaccommodating of children with ADHD and their parents (Broomhead, 2013; Gaskell, 2011; Malacrida, 2001; Rogers et al., 2009). In one of the early studies by Malacrida (2001), some British and Canadian parents reported a sense of being pushed to have their child assessed for ADHD, a feeling shared by some participants in the current study. Sadly, it would be expected that with the increasing studies on ADHD globally, including in South Africa, children with ADHD, as well as their parents' concerns, would be favorably accommodated in schools in South Africa.

Interestingly, studies that explored teachers' feelings and attitudes toward teaching children with ADHD also confirmed that a significant number of teachers across studies reported exhibiting negative attitudes toward children with ADHD-type behaviors (Amha & Azale, 2022; Maema, 2021; Mulholland et al., 2023; Yarde-Leavett, 2018; Youssef et al., 2015). Therefore, findings from the current study whereby the participants experienced teachers as negative toward their children with ADHD confirm teachers' revelations from previous studies.

According to McHargue (2019), when teachers lack an understanding of ADHD, they are likely to have negative attitudes toward children diagnosed with it. Participants in the current study cited a lack of awareness among schoolteachers as a likely explanation of the negative impact of school on ADHD. The majority of the participants in the study unequivocally claimed that South African mainstream schools, public or private, are not conducive to cater for the needs of children with ADHD due to a lack of awareness among

teachers. Research conducted in South Africa confirms that most teachers reported limited ADHD knowledge to support learners with the disorder (De Jongh et al., 2019; Dwarika & Braude, 2020; Maema, 2021).

Limited ADHD knowledge among schoolteachers in South Africa raises a concern because, according to the Department of Basic Education [DBE] (2016), education policies require that learners with special educational needs, including ADHD, be included in mainstream schools. However, from the current study, it is clear that inclusive education is ineffective because most children with ADHD are still academically excluded from schools. Such incongruency between policy and practice causes confusion among parents and caregivers of children with ADHD who expect school support. One utterance of confusion came from a participant in the study when she exclaimed, “why not accommodate him?” questioning why an expensive private school had categorically indicated to her that her son could not be accommodated in that school anymore due to his ADHD-type behaviors.

Some participants indicated that despite the education policy promoting inclusive education in South Africa, they did not believe mainstream schools could support their children with ADHD. One participant validating her stance against mainstream schools stated, “mainstream schools and ADHD...are not families...they do not correlate.” These words represent the sentiments of all parents and caregivers who have lost complete trust and hope in mainstream schools’ ability to support children with ADHD.

It is clear from the discussion section that the role of the school has a significant impact on the development of a child with ADHD. The impact could be either positive or negative, but it considerably influences the parents’ and caregivers’ perceptions of the abilities of the schools in South Africa to deal with ADHD. Considering that nearly all the participants in the study got their first or complete awareness of ADHD from teachers’

referrals of their child for ADHD, it is apparent that teachers play a significant role in ADHD awareness.

Additionally, after the ADHD diagnosis, most parents will depend on teachers to implement school-based ADHD interventions and provide behavior reports of their children diagnosed with ADHD. Therefore, practicing teachers in South Africa require in-service ADHD workshops that will count as continued professional development programs to equip them fully in the area of ADHD. When teachers become well-informed about ADHD, they may be helpful sources of information and support for parents and caregivers, particularly Black parents and caregivers, whom the study indicates most of them have limited ADHD awareness. It would be beneficial for teachers if training institutions included a mandatory intensive ADHD course so that new teachers commence their teaching journeys adequately informed about ADHD.

Notwithstanding the theme of the negative impact of the school, which seems to dominate this section, the role of the school in South Africa in exposing Black parents and caregivers to ADHD cannot be negated. Had it not been for the teachers identifying concerning behaviors in participants' children and referring them for assessment, most participants would not have been aware that such a disorder, ADHD, exists and that it affects most children indiscriminately, including Black children in South Africa.

### **Sources of Support**

After exposure to the participants' narratives of the school's role and the impact it had on their experience of an ADHD diagnosis and management for their children, it became crucial to explore other societal support structures that featured in the participants' narratives similarly. These structures included healthcare professionals, family, and friends, explored under the superordinate theme 'Sources of support' to examine how they influenced the participants' perceptions and decision-making regarding their children's ADHD diagnosis.

All the participants in the study shared support experiences they encountered due to their children's ADHD behaviors and diagnoses. Some encounters were positive, while some were negative, giving rise to two subordinate themes termed 'Positive support experience' and 'Negative support experience.'

### *Positive Support Experience*

Over half of the participants regarded healthcare professionals as supportive. The perceived support was in the form of information that the professionals shared with the participants. Participant P6, who had initially struggled with accepting that her second child also had ADHD, reported that her child's psychiatrist was her support system. During the individual interview, she shared, "I asked her for her cell number. I would ask her questions even if we are not at the practice. I would say this is what I found out, what do you think about this?" In the focus group, she stated that she felt heard and understood by the psychiatrist because even her mother did not understand ADHD and was unsupportive. She was grateful that the psychiatrist would go the extra mile to support her. Thus, she felt motivated to adhere to ADHD intervention for her children for as long as she could.

Sharing the same perception about health practitioners, participant P4 stated that she perceived her child's neurologist as supportive and accommodating of her views as a parent. Participant P4 appreciated her collaborative approach with the neurologist, which enabled her to partake in intervention decision-making, as shown by her statement, "also in conjunction with the neurologist, we said it is better to take him off medication." In addition to the health professional, P4 indicated that she found the support from other parents of children with ADHD valuable. Participant P4 appreciated the support from other parents of children with ADHD because she experienced her family as unsupportive. She shared:

Especially knowing that your other side of the family doesn't understand. So, you get to hear what other people are going through, which you can relate to. And maybe

certain things that they go through can help you with certain challenges you are having at home, you know, with your child. So, it is just a lot easier that way for me. She referred to those parents as her “tribe” to denote her sense of belonging and being understood by other parents with whom she shared an experience of having a child diagnosed with ADHD.

Some participants, constituting nearly half of the sample, shared positive experiences of support from their family members and friends. They described the support they received from these social structures as helpful in their acceptance of their children’s ADHD diagnosis. They described feeling grateful for the support they received, as it indicated that those supportive family members and friends accepted their children with ADHD. Participant P7 shared that the support she received from her family and friends made it easier for her not to perceive her child’s ADHD negatively. She shared:

In a way that I don’t look at my child as...as if she’s having a disability. It... it’s not a disability. I think just to be fair, it’s only...I don’t know if I can say just a mental disorder, you know. Yah.

Participant P16, a father whose friend encouraged him to take his daughter for an ADHD assessment, was grateful for the support he received from his “very supportive network of eeh eeh people and the family.” He experienced them as helpful in sharing valuable information and resources as stated as follows:

I would say that I was fortunate to be around them...and some people actually sent me some links to say hey, read about this, check this out uhm, go check out this person. There was many referrals to other individual families that have got kids who have ADHD.

Participant P16 stated that the positive support experiences vindicated him of self-blame and encouraged him to embrace his child’s diagnosis.

### *Negative Support Experience*

In contrast to some participants' positive support experiences, a handful indicated that they experienced the health professionals as unsupportive. Participant P12 stated that the health professionals did not provide them with information regarding ADHD or ways to manage the disorder for their nephew. He expressed that as caregivers, they were left to do their "own research." Words used by participant P12 during a focus group also concurred with this perception. He shared that "professionals are not much as uh diligent to sharing the information that is needed."

Participant P17, whose 5-year-old child had recently been diagnosed with ADHD at the time of the interview, voiced her frustrations and annoyance that while she was still trying to process her child's ADHD diagnosis, which she was rejecting, she felt unsupported in trying to find the suitable placement of her child in a remedial school. She expressed her exasperation when she said, "I can't be doing this alone as a parent." She was upset that the professionals, teachers at her child's school, and the psychologist who gave the diagnosis were quick to provide recommendations for a diagnosis she did not believe was accurate yet were unsupportive in assisting her in following through with the recommendation.

Narrating her own experience with unsupportive health professionals, participant P13, whose child struggled with ADHD comorbid with ODD, indicated that her lack of information regarding the etiology of ADHD stemmed from health professionals who were not forthcoming with explanations. She perceived the health professionals as unhelpful, stating, "even those psychologists, they didn't explain to us what ADHD is."

Sharing the hurt she experienced from lack of support from family members when her child displayed ADHD symptoms and was diagnosed with the disorder, participant P11 revealed that she was concerned that no one would take care of her child when she died. She stated that her family members had expressed that she should take her "child to the grave"

with her when she died. This revealed her family members' unwillingness to support her regarding her child's ADHD diagnosis.

Participant P21, who only participated in the focus group discussion, became emotional when recounting the lack of support from her family members because of her child's ADHD. She expressed feeling isolated, as reflected by her statement, "they tend to refrain from you because of your child." She shared that she was pained when her brother suggested that she put her child in a care home. She perceived her family as rejecting her child. However, she showed determination to protect and keep her child when she stated:

He's my son. For me to...to make them happy eeh...eeh...eeh...for me to make them happy by taking my son...by putting my son somewhere where he will be taken care of, it's not gonna work for me. I can't do that.

Three female participants, P1, P8, and P20, each expressed frustration with their husbands' lack of support concerning their child's ADHD diagnosis. They described feeling alone and burdened with the psychological strain of their children's condition. Voicing the frustration during the individual interview, P1, a nurse whose husband was in denial that their child had ADHD, shared:

He has never attended a single visit to the doctors or therapists and when even when I come back from them, he never asks me what they said about the child. He is in complete (pauses) denial, yes denial. Maybe he thinks by denying the child will be normal, I don't know. His attitude and no support when I need him on this issue is frustrating and I have stopped counting on him. Now I'm busy working with the therapists and doctors to get the child placed in remedial school but *yena* (him), he is not bothered.

Nonetheless, P1's perception of her child's diagnosis was unaffected by her husband's denial and lack of support. Instead, she felt she was determined to be a responsible parent and seek

help for her child, unlike her husband, whom she implicitly regarded as irresponsible by denying their child's ADHD diagnosis. However, she appreciated her co-worker nurses who supported and encouraged her to accept the diagnosis and seek intervention for her child.

Participant P8, a mother of two children diagnosed with ADHD and other comorbid developmental disorders mentioned that managing the children's conditions was demanding and required her to be a "hard worker." She had to invest a lot of time and attention in her children. Given the magnitude of the task of managing her children's conditions as a working mother, support from her husband would have made her life a little easier. Instead, she said she shouldered the challenges of her children's needs independently. She perceived her husband as indifferent, uninterested, and unsupportive, which she experienced as immensely frustrating. She shared:

Then, for him, it's kinda of normal. So, on this note, I'm the one who goes up and down with the kids. I'm the one who goes to pick up medications. I'm the one who go to the neurologist with the children coz for him, it's...it's... I would just tell him like, "Oh! Hubby I'm coming from the eeh...the educational therapist," and he would just say, "Oh okay" and he talks about other things.

Notwithstanding the lack of support from her husband, P8 was resolute in giving her children the best interventions to provide them with a fulfilling life. This was revealed in her statement, "I've tried everything." Thus, the lack of support from her husband did not deter her from seeking the best interventions for her two children diagnosed with ADHD that came with other challenging comorbid disorders. Instead, she felt motivated to pursue all possible interventions to give her children fulfilling lives and alleviate the burden of managing her children's conditions independently.

However, it should be considered that P8 had indicated that her husband, mother-in-law, and brother-in-law displayed some significant ADHD behavior characteristics.

Therefore, she had concluded that they also had undiagnosed ADHD, based on the ADHD knowledge she had gathered as a mother of children diagnosed with the disorder and from her extensive research as an ADHD awareness advocate. She indicated that although she felt the heavy weight of dealing with her children's diagnosis, which sometimes frustrated her, she partially understood her husband's lack of support to be stemming from his own undiagnosed ADHD.

### **Discussion: Sources of Support**

The superordinate theme 'Sources of support' summarized the participants' experiences of the help they received or lacked from healthcare professionals, family members, and friends. The participants believed that the support or lack of support was instrumental in shaping their understanding and decision-making regarding ADHD diagnosis for their children. As previously highlighted, this superordinate theme partially addressed the study's research question, 'What factors influence Black parents' and caregivers' perceptions of an ADHD diagnosis for their children?'

A little over half of the participants described feeling supported by healthcare professionals who addressed some of their questions, fears, confusion, misconceptions, and a sense of helplessness regarding an ADHD diagnosis for their children. Most of these participants felt supported regarding intervention guidance. Thus, they believed the support and information from the healthcare professionals were instrumental in the amount of ADHD awareness they obtained since their children's diagnosis. A few participants expressed a sense of control due to the collaborative relationship with healthcare professionals, thus, an opportunity for autonomy to be part of the intervention decision-making.

However, this finding of positive support from healthcare professionals experienced by some participants in the current study differs from previous studies, which found that parents of children diagnosed with ADHD experienced healthcare professionals as

unsupportive (Ching'oma et al., 2022; Leitch et al., 2019). Some may dispute these studies conducted outside of South Africa as not reflective of the experiences of Black parents and caregivers of children diagnosed with ADHD within the South African context. However, the current study also revealed that some participants reported experiencing healthcare professionals as unsupportive in providing information about ADHD or assisting in accessing recommendations. This lack of support theme is consistent with and supports the previous studies mentioned above (Ching'oma et al., 2022; Leitch et al., 2019) despite being conducted outside the South African context. Therefore, the narratives of parents and caregivers regarding their experiences of support from healthcare professionals within the South African context are subjective and should be understood idiographically from each individual.

The findings of the present study highlighted that parents' and caregivers' experiences of lack of support from healthcare professionals regarding information on interventions may hinder parents from accessing help for their children with ADHD. A lack of information about ADHD may affect parents' and caregivers' intervention decision-making (Fan et al., 2022). According to Bronfenbrenner's (1977) bioecological systems theory, a disconnect between the elements of the ecological structures in which the child exists negatively influences that child's development. The child is negatively affected when there is a perceived lack of support through information sharing among the healthcare professionals in the mesosystemic structure and the parents and caregivers in the microsystemic structure.

In addition, a lack of professional support in terms of adequate information about ADHD may also leave parents and caregivers susceptible to misconceptions about the disorder. Misconceptions about ADHD may lead to misinformed and ineffective intervention pursuits (Evans, 2019). For instance, one participant in the current study indicated that she never received the etiological explanation for her child's ADHD and ODD conditions. When

asked what she believed to be the cause of her child's ADHD, she responded, "I don't know." She was genuinely clueless despite the number of years her child had been diagnosed with ADHD and ODD. Such an individual may be at risk of being misinformed. Therefore, this study highlights the need for healthcare professionals to support parents and caregivers in providing information about ADHD. When parents are adequately supported, like those in the study who described feeling supported by healthcare professionals, their fears and sense of helplessness regarding ADHD diagnosis for their children may diminish. Thus, they can better make informed decisions regarding intervention choices for their children.

Regarding perceptions of being supported by family and friends, some participants in the current study reported feeling supported even by those who had not been exposed to ADHD. This was an encouraging finding, given the limited ADHD awareness among Black communities in South Africa, as revealed by this study. The finding suggests that there are individuals who are accommodative and receptive children with ADHD. When there is acceptance, there is less stigmatization and labeling of children with the disorder.

Nonetheless, the current study also revealed that some parents and caregivers of children with ADHD experienced a lack of support from their families and friends. This finding confirms previous research that asserts that many parents and caregivers of children with ADHD experience a lack of support from families and communities due to their children's ADHD-related behaviors and diagnoses (Ching'oma et al., 2022; Treichel et al., 2020). A lack of ADHD awareness often perpetuates the lack of support, hence a need for escalated ADHD awareness campaigns in the Black communities in South Africa.

Interestingly, in the current study, participants who reported experiencing a lack of support from their families were some of the female participants and not male. Although it can be argued that the proportion of female participants versus male participants was notably higher, as revealed by Table 1, hence the explanation of only female participants affected by

the above statement, it cannot be dismissed that in most African cultures, child rearing is still primarily a responsibility of females (Ching'oma et al., 2022; Sharma et al., 2016; Treichel et al., 2020). The above explanation could also explain the higher number of female participants who responded to the invitation to participate in this study than male participants. Thus, it is unsurprising that some female participants experienced a lack of family support because they are the most affected by the burden of caring for their children with ADHD.

Three participants voiced their frustration with their husbands' lack of support regarding managing ADHD symptoms for their diagnosed children. This theme of the lack of spousal support agrees with a study by Harazni and Alkaissi (2016), which reveals that female parents of children diagnosed with ADHD encounter a lack of spousal support in the care of their children. The lack of support for mothers results in them feeling overburdened and overwhelmed by the excessive demand of caring for a child with ADHD. Feeling overburdened may be coupled with feeling isolated and frustrated, likely leading to family conflicts (Harazni & Alkaissi, 2016).

Therefore, the current study revealed that mothers of children with ADHD, despite most appearing to be holding it together and managing in caring for the children with the disorder and also fulfilling other roles in the family, would benefit from spousal support. That is, if the husbands accept their children's ADHD diagnosis and that it often takes teamwork to manage children's ADHD-induced behaviors. As such, healthcare and other relevant multidisciplinary professionals, such as the school, should consider using a systemic approach when suggesting ADHD interventions for children with ADHD. In that way, all members of the family system may be involved in implementing interventions for the diagnosed child.

Encouragingly, a lack of support from family and friends did not impact how participants viewed the ADHD diagnosis for their children. If anything, lack of support

motivated the participants to continue pursuing interventions to minimize ADHD negative behaviors for their children. When undesirable ADHD behaviors are managed and minimized, children diagnosed with the disorder are less likely to be targets of societal negative attitudes and behaviors.

### **Summary**

This chapter revealed the role of the school in shaping parents' and caregivers' perceptions of ADHD for their children. The school can have either a positive or a negative impact on parents' understanding of ADHD. Based on the participants' narratives, the school can also be an important resource for ADHD awareness and support for children with ADHD and their parents. On the other hand, how the school addresses children with ADHD-type behaviors may cause parents to lose confidence in the school's ability to manage children diagnosed with ADHD. Also, the sources of support that the children with ADHD and their parents receive from professionals and other people in society play a vital role in parental understanding of ADHD and willingness to seek interventions for their children diagnosed with the disorder. The subsequent chapter will present findings and discussion sections of other dominant themes that emerged regarding factors that influenced participants' perceptions of an ADHD diagnosis for their children.

## CHAPTER 7: FINDINGS AND DISCUSSION

### Factors Influencing Perceptions of ADHD

The preceding chapter was based on two superordinate themes: the ‘Role of the school’ and the ‘Sources of support.’ These two superordinate themes partially addressed the study’s research question, ‘What factors influence Black parents’ and caregivers’ perceptions of an ADHD diagnosis for their children?’ This current chapter titled ‘Factors influencing perceptions of ADHD’ addresses the same research question by exploring other influences that shaped the participants’ perceptions of ADHD diagnosis for their children. The subordinate themes that emerged from this overarching theme are highlighted in **bold** in Table 2 below, as presented in the Methodology chapter:

**Table 2:***Superordinate and Subordinate Themes*

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Receiving the diagnosis	Child's behavior prior to diagnosis Own diagnosis reaction Do I accept or reject the diagnosis?
Understanding ADHD	Perception of cause Conceptions about the nature of ADHD Beliefs about the management of symptoms
Role of the school	Positive impact of the school Negative impact of the school
Sources of support	Positive support experience Negative support experience
<b>Factors influencing perceptions of ADHD</b>	<b><i>Culture</i></b> <b><i>Stigma</i></b> <b><i>Awareness and Knowledge</i></b> <b><i>Religious and Spiritual beliefs</i></b>
Implications of the child's behavior: the significance attributed to the diagnosis	Negative implications of the child's behavior Positive implications of the child's behavior
Decision-making on intervention pursuits	Reasons for intervention pursuits Motivations for chosen interventions Perceptions about ADHD medications Hindrances to intervention pursuits

***Culture***

In Chapter 5 of this thesis, it was highlighted that most participants in the study (15 out of 21) had viewed their children's behavior before the ADHD diagnosis as typical. This suggests that these participants perceived their children's ADHD-induced behaviors, such as hyperactivity-impulsivity, inattention, and distractibility, as normal behaviors within their cultural contexts. They had not regarded the behaviors as pathological. Participant P2, from a Zulu culture, validated this observation by stating, "In my culture, boys need to be hyperactive and they need to do what boys need to do." Describing how her child's

hyperactivity was not a cause for concern to her before the diagnosis, participant P18 of the Tswana culture stated, “but her hyper, for me, it wasn’t much of a big deal.” Similarly, participant P10, a Pedi mother, highlighted that she had initially perceived her child’s unpredictable, extremely aggressive, and hyperactive behavior as normal childhood behaviors the child would outgrow. She said:

She was very aggressive when playing with other people. She is a bully-like.

Whenever they [with other kids] do something that is bad, I know that she is the one who started it. But then, I’ve always thought maybe like she’s just a child, she is naughty, she will outgrow this behavior.

At this juncture, it is essential to consider that the Black population groups in South Africa are not entirely culturally or linguistically homogenous. Their ethnic disparities are represented in the nine official Black linguistics groups found in South Africa (Zulu, Xhosa, Venda, Pedi, Sotho, Ndebele, Swati, Tswana, and Tsonga). The study participants represented all nine Black linguistic groups. Interestingly, according to the participants, despite the cultural disparities of the different ethnicities within the Black South African population, Black parents and caregivers seemingly perceive ADHD-motivated behaviors of their children as culturally typical. Supporting this claim is the account of participant 4, who expressed in the focus group:

I agree with the previous speaker to say that I think culturally as Black people, we are just not exposed to anything like this. Uh if anything, a child that is hyper, uh uh, you know, would because of *ustout* (s/he is naughty), you know. You know, like they’re saying, you just not disciplining enough, you know that kinda thing.

Thus, the study suggests that the Black racial population in South Africa shares that commonality. Consequently, when their children received an ADHD diagnosis, some

participants reacted with shock, anger, and initial denial because they had not perceived their children's behavior as odd.

Participant P15, an early childhood development practitioner of the Zulu culture who ran two private schools, believed ADHD was hereditary. Still, she also firmly attributed its etiology to the neglect of 'culture' by Black people in Africa. During the individual interview, she said:

[I] associate it [cause of ADHD] with maybe *imbeleko* (cultural ritual of introducing a newborn to the ancestors), you know those ancestral things. You know because as we are the...this eeh our generation, I can say our generation and the next coming one, we have dropped our...our cultural things that we used to do because they ended up being associated with eeh eeh eeh Satanism and there is no such thing, you know.... So, you have to go there [home to the elders] and say eeh okay we now have a child, you know, *bambike nje* (they just introduce the child) without having to slaughter anything but just to say *bogogo bomkhulu* (ancestral grandmothers, ancestral grandfathers).

Although P15 indicated that she was a Christian, she firmly believed that cultural rituals and traditions took precedence in Black people's lives. Expressing this belief in the focus group, she said:

Because we've left culture as well. We've adopted modern ways of living and we forget that we are Africans, you know, because we wanted to follow things that we don't know, that we are not confident in, and we don't have information as well.

She believed that rejecting one's cultural tradition in favor of other people's cultures through acculturation led to mental and behavioral challenges, including ADHD in children.

### ***Stigma***

Most participants in the study (16 out of 21) expressed concerns about the magnitude of stigma emanating from Black communities regarding disorders that affect mental functioning in general, including ADHD. Participant P6's narrative encapsulated that shared concern, "there is a lot of mental illness out there that Black people don't want to resonate with." Consequently, most participants (19 of 21) initially struggled with processing the ADHD diagnosis for their children, as mentioned in Chapter 5, under the superordinate 'Receiving the diagnosis.'

The perceived 'stigma' attached to ADHD motivated some participants, such as P19, to keep their children's diagnosis within the confines of their inner family circles and professionals only. Voicing that fear of stigmatization, participant P19 believed to be rife in Black communities, he expressed, "Some they will think like he's [son with ADHD] mentally retarded and they will treat him likewise."

Elaborating on the effects and magnitude of stigmatization of children with ADHD in Black communities, participant P19 shared:

What I can say, especially us Black parents *neh* (right), a lot of our children they have ADHD but the parents they don't want to accept that because they scared that if they say that their children have ADHD, people they will say they are crazy.

Expanding the shared perception of the 'stigma' Black communities attach to people with mental disorders, including children diagnosed with ADHD, participant P10 stated, "Black people, when you tell them something, they twist it to what they want to believe." Therefore, to protect their children from being labeled and treated as mentally ill, some participants decided not to disclose their children's ADHD diagnoses.

### ***Awareness and knowledge***

In the context of this study, the term 'awareness' pertains to having exposure to ADHD and acknowledging its existence, even if one does not possess a comprehensive

understanding of the disorder. Conversely, the term ‘knowledge’ implies a more profound comprehension of ADHD, including its symptoms, causes, and treatment options. According to the study, it was found that 16 out of 21 participants had no prior knowledge of the existence of ADHD until their children were diagnosed with the disorder.

When asked about what information or awareness he had about ADHD before his child was diagnosed, participant P2 responded in the individual interview, “I had no knowledge about ADHD. It had never occurred to me that there is any diagnosis called ADHD.” Also expressing the same lack of awareness and knowledge, participant P11 stated, “I did not have any information about the... about this disease because I’ve never heard about it before. So, uhm I was...I was...I did not know. I did not have any information.” Participant 10 shared the same sentiments in the individual interview when she said, “No, I had never heard anything about ADHD. Like, I had never heard anything like that.” She further revealed in the focus group that even after the diagnosis, at the time of the data collection, she was still ignorant about ADHD when she said, “*Nna* (me) I don’t know. Even now, I don’t know, but I was told she has this ADHD and must take medication,” Participant P10’s account indicated that she had no ‘knowledge’ of the disorder despite being aware of its existence.

The lack of ADHD ‘awareness’ might have negatively influenced the participants’ understanding of their children’s behavior before the diagnosis. Describing her self-reported misconception that her daughter’s condition, who displayed severe ADHD symptoms of inattentiveness compounded by severe comorbid developmental delays, was bewitchment participant P8 shared during the individual interview, “I was still running around [seeking interventions from traditional healers and prophets] believing that maybe she’s being bewitched.” Thus, her lack of awareness about ADHD caused participant P8 to have misconceptions about the cause of her daughter’s behavior. As a result, she delayed seeking

relevant interventions for her daughter. It was only after gaining ‘knowledge’ about the disorder that she pursued the professionals’ ADHD-recommended intervention that proved to be effective in managing her daughter’s condition.

Participant P11 shared that her lack of ADHD ‘awareness’ before her daughter’s diagnosis caused her to misunderstand her daughter, which in turn negatively affected her parenting. She revealed:

I thought my child she is those child that they don’t want to listen to the parents. Eer I...I...regretted a lot of things that I did to my child because I used to beat her a lot. I used to scream at her. I used to call her names *ukuthi awulaleli wena* (that you don’t listen). So, now I feel like I’m a bad mother since now the doctor has made me understand what is happening with my child.

Corroborating on how lack of ADHD ‘awareness’ can negatively influence parenting, P10 stated, “I used to snap a lot and so much at her because I didn’t understand what was wrong with her.” The underlying feelings of guilt and regret are detected in these narratives.

The findings of the study also revealed that all the participants believed there was very limited, if any, ‘knowledge’ about ADHD in Black communities in South Africa. Highlighting the lack of ‘awareness’ and limited ‘knowledge,’ participant P9 stated in the individual interview, “I wish people can be, especially in our African community, they can be aware of this disease.” During the focus group, participant P4 said, “I think generally as Black people, we just don’t understand”, reiterating the sentiments she expressed in the individual interview.

The prevalence of lack of information and awareness on ADHD in Black communities was a concern for the participants because they believed it caused many members of the Black communities, including some of the participants’ family members, to have negative attitudes toward children with ADHD. Participants believed that when people

are ignorant about ADHD, most tend to be judgmental and stigmatize not only the children with ADHD but also their parents, leading to labeling. Sharing her experience in the focus group, participant P6 said:

It was more like my kids lacked discipline. I don't discipline my kids enough. They don't listen. You don't...you know, these kids they don't understand eeh being smacked because you don't smack them enough. So, the family members couldn't understand.

Sharing a similar experience in the focus group, participant P3 said:

Speaking of the community, if we are to go by what people say, we will beat and smack our kids all the time. Some people instead of supporting you, they will be discouraging, saying that the child is not sick but needs more discipline. Don't get me wrong, I'm not advocating for ill-mannered children who rule us, but our children have ADHD meaning they are not lacking discipline. But people often don't view it that way and it makes it hard for us to be...to be able to manage this. It's like we are being labeled as failures in parenting, especially when you are in family gatherings with extended families. People just don't understand.

The participants also believed that lack of awareness and information in Black communities caused many to be in denial about the existence of ADHD. Participant P2 served as a good representative of Black people who deny the existence of ADHD due to a lack of 'awareness and knowledge' about ADHD. Participant 2 indicated that when his child was diagnosed with ADHD, he had "no knowledge about ADHD" or heard about it. Consequently, when his child received the ADHD diagnosis, he refused to accept it with the intervention recommendations offered. He refused to take a diagnosis he had never heard of.

Interestingly, the study revealed that the participants perceived that the lack of ADHD 'awareness' and 'knowledge' was far-reaching, such that some professionals, such as

teachers and healthcare practitioners, also had limited knowledge of ADHD. Participant P12 summarized this shared observation by participants when he expressed in the focus group:

I think awareness is very important because firstly, most uh professionals, you know, from teachers to healthcare professionals, you know, they as...as it has been mentioned, you know, they are not actually aware of this condition. And then if they are not aware, you know, how will they make it...how will they make their knowledge, you know, available to parents.

Describing her family doctor's ignorance of ADHD, P8 shared:

Actually, even some of the doctors, the general practitioners, they don't know ADHD. Some of them they don't know...I have my GP, my family GP that I usually go to for my children, she learnt ADHD from my kids and myself. I think now she has around 15 years of practicing there, but then she didn't understand ADHD. She has also mentioned that one of her child has ADHD, but she was not aware until she was treating my kids... When I explain to her that my dear, Fhatu\* [participant's daughter] has hyper and what not, it was something new to her. Then at least now she has put her daughter on medication, and she has also moved her daughter from the mainstream to the remedial school around Pretoria North. So, you understand, this is tough.

The participants were concerned that if some of these professionals were ADHD ignorant, they would not be competent in addressing ADHD, as expressed by P12, "And then if they are not aware, you know, how will they make it...how will they make their knowledge available to parents."

Confirming the lack of ADHD 'awareness' and 'knowledge' among some healthcare practitioners was participant P1, a practicing registered nurse who had indicated during the individual interview that she had no 'awareness' or 'knowledge' of ADHD before her child's

diagnosis. Corroborating her initial ignorance of ADHD, she expressed in the focus group, “I don’t know...the awareness is not that much coz for me as...as a professional, I’m sorry I have to admit, I was not aware about this condition until my daughter was diagnosed with it.”

Based on the participants’ accounts of the lack of ADHD ‘awareness’ and ‘knowledge’ in Black communities and among some professionals (teachers and healthcare practitioners), participants called for massive campaigns to raise ADHD ‘awareness’ and ‘knowledge’ among communities and during the professional training of teachers and healthcare practitioners. Regarding that, participant P1 shared in the focus group:

You know what I wish...I wish eh on this condition. I don’t know...the...the awareness is not that much coz for me as...as a professional, I’m sorry I have to admit, I was not aware about this condition until my daughter was diagnosed with it. So, I don’t know...It must be like COVID-19 whereby everyone knows that there is a condition like this and not only to be told about it only when your child is being diagnosed then you now only get to know about it. It must be something that is taught to every parent. We are told about the milestones, if your child is doing like this...if your child is doing like that, parents be aware. Like, there must be more awareness about the condition so that even I can diagnose the child myself before the child can even go to school.

Sharing similar views, participant P6 stated in a different focus group, “I just think the same way they raise awareness about coronavirus and meningitis should be done for ADHD.” The participants experienced ADHD as a condition that deserved the same level of attention as the coronavirus.

Despite the seeming prevalence of lack of ADHD ‘awareness’ and limited ‘knowledge’ in Black communities and among some professionals, as revealed by the study, five participants indicated that they were aware or had some knowledge of ADHD before

their children's diagnoses. This finding highlights that it is not all of the Black population who lack 'awareness' or 'knowledge' of ADHD in South Africa. However, the participants reported that they had not been immune to adverse psychological reactions of "worry," "shock," initial denial, and a "sense of helplessness," which accompanied an ADHD diagnosis for their child. This implies that having 'awareness' and information about ADHD does not usually protect the psychological well-being of parents or caregivers when their child receives an ADHD diagnosis.

An encouraging finding from the study showed that all the participants reported seeking information about ADHD from various sources, some from more than one. Twelve participants shared that they used the Internet as their information source regarding ADHD. The participants shared that the Internet provided easy access to information. Participant P11 highlighted that she preferred the Internet as her information source because it was affordable due to "free night data [mobile data]." On the other hand, participant P2, who rejected the diagnosis for his son, expressed, "I found that the internet offers me privacy," suggesting that he preferred his son's ADHD diagnosis to be a private matter he did not want to share with anyone. The Internet offered him the anonymity he desired to get information about the condition he did not believe his son had. It was encouraging that although participant P2 did not believe in the existence of ADHD, he was seemingly open to gaining information about the disorder that was unfamiliar to him.

Some participants (eight) shared that they sought ADHD information from professionals such as their children's doctors, psychologists, speech therapists, occupational therapists, and teachers. These participants believed it was more accessible and more convenient to seek information from professionals already in the ADHD management team for their children. Furthermore, some perceived the professionals as more resourceful and knowledgeable, as expressed by participant P7, who shared, "You will get more information

on people like them.” Other sources of information some participants employed included family members and reading books. Two participants, P14, a nurse, and P20, an occupational therapist, indicated that their professions equipped them with ADHD information. All the revelations about ADHD information sources participants preferred showed that parents and caregivers of children with ADHD sought information about ADHD from various sources.

The study revealed that the ADHD ‘awareness’ and ‘knowledge’ the participants accumulated since their children’s diagnoses had a positive impact on how they later perceived their children’s behavior and the diagnosis. There was acceptance for the participants who had reported struggling to accept the diagnosis, except for P2 and P17, who continued to reject it. For those who had struggled to perceive their children’s ADHD-type behaviors as atypical, there was the acknowledgment that the behavior they had regarded as normal had a dysfunctional effect on their children. This was shown by P16, who shared, “I guess it took a lot of understanding of what is normal.” Furthermore, increased ‘knowledge’ about ADHD motivated participants to be receptive to ADHD interventions for their children as P20 reported, “I insisted to give my son Ritalin.” Thus, these findings indicate that increased awareness and knowledge of ADHD increases the likelihood of positive perceptions of ADHD diagnoses among most Black parents and caregivers of children with ADHD.

### ***Religious and Spiritual beliefs***

The narratives of seven participants in the study revealed that their religious and spiritual beliefs played a role in their understanding of ADHD in their children. Some spiritual beliefs included superstitions, as highlighted by P12 when he spoke about his nephew with ADHD:

Superstitions also influence the way we view certain things. With all his [nephew with ADHD] behavioral problems, other people say... it's related to issues...like he doesn't know who he is, where he comes from [i.e. nephew did not know his father].

Participant P8, a mother whose two children were both diagnosed with ADHD, shared that before understanding ADHD, she had believed that her daughter, who was diagnosed first and displayed severe symptoms of ADHD and developmental delays, was “bewitched.” She revealed that through the influence of a friend and some people from her village, she became suspicious of her mother-in-law practicing witchcraft on her daughter. In the focus group, she revealed visiting a “*sangoma* (traditional healer)” to seek help for her daughter. In the individual interview, she divulged that she also visited “prophets” to pray and cleanse her daughter of the evil spirits cast on her. Thus, her belief in the existence of witchcraft had influenced her perception of her daughter’s condition and the intervention thereof.

One participant, P13, whose son had ADHD and ODD, blamed God for giving her a child with these disorders. She regarded her child’s ADHD as a punishment from God, although she did not know what she did to deserve it. Her tone of voice sounded pained when she exclaimed:

I still have that sore...I still have that sore...asking God why me? Especially when I was...I was...when I give birth to him, I was so young. He is my firstborn. And I have that sore, why? Why me? Why him?

P13 interpreted an ADHD diagnosis for her son as the unfairness of life to her and her son. The pain she was still experiencing emanated from her belief that God allowed her son to have the disorder that caused them suffering.

### **Discussion: Factors Influencing Perceptions of ADHD**

Various factors are at play when it comes to how parents perceive an ADHD diagnosis for their children (Hamed et al., 2015). This section will discuss the impact of

‘culture,’ ‘stigma,’ ‘awareness and knowledge,’ and ‘religious and spiritual beliefs’ as identified influences that shaped the participants’ understanding of their children’s ADHD diagnoses. These influences fall under the overarching superordinate theme, ‘Factors influencing perceptions of ADHD,’ which emerged from the interpretive analysis of the research question, ‘What factors influence Black parents’ and caregivers’ perceptions of an ADHD diagnosis for their children?’ Each factor will be carefully discussed in the sections below.

### ***Culture***

Cultural considerations are imperative when exploring individuals’ perceptions regarding mental health (Choudhry et al., 2016). This is due to the cultural disparities in the interpretation of mental health conditions. Given that ADHD is classified as a mental health disorder (Njuwa et al., 2020), it was essential to gain insight into how participants interpreted their children’s ADHD-like behavior prior to diagnosis. This is because, as Olatunji et al. (2023) noted, cultural norms can shape how children’s behavior is interpreted.

The results of the study indicate that a considerable number of the participants, precisely 71.4% (15 out of 21), did not view their children’s ADHD-related behaviors as pathological. Instead, they interpreted the behaviors as common developmental misbehavior, intentional defiance, or insufficient discipline. The ADHD-type behaviors are not often considered pathological in South African Black communities, as evidenced by Kediemetse (2017), who reported that many South African Black parents considered ADHD symptoms to be a normal part of childhood. To further illuminate cultural disparities in viewing children’s ADHD-type behaviors, a study by Filipe (2016) revealed that some cultures, such as the Muslim community and the Christian Lebanese communities, did not find ADHD-induced behaviors as atypical. Instead, they endorsed verve in children with hyperactivity and impulsivity as preferred behaviors, especially in boys. This mentioned study aligns with

research by Banhatti and Dwivedi (2009), which showed that parents from Italy, Spain, and some parts of Southeast Asian countries are accommodative and more accepting of boisterous ADHD-type behaviors in children.

The cultural perception of ADHD-like behavior as typical is a potential factor in why most parents reject ADHD diagnoses, as suggested by Filipe (2016) and Kediemetse (2017). Literature suggests that some parents suspect pharmaceutical companies of labeling culturally acceptable childhood behaviors as ADHD for profit, as noted by Bowden (2013) and McClure (2013). As a result, some parents may deny their children's ADHD diagnoses. This aligns with Kediemetse's (2017) findings, which revealed that the majority of Black parents in South Africa are likely to reject their children's ADHD diagnoses due to cultural interpretations of childhood behavior.

However, this current study presented a different finding. Although most participants initially perceived their children's behaviors as typical prior to an ADHD diagnosis, 19 out of 21 participants ultimately accepted the diagnosis. While the participants did not explicitly articulate a shift in their perception, the deduced meaning of this noteworthy finding suggests that Black parents and caregivers are willing to adjust their interpretation of childhood behaviors and accept ADHD diagnoses if it is in the best interest of their children's well-being. These new insights differ from the findings of Kediemetse (2017), who observed a similar phenomenon within a comparable context and found that most parents who believe their children's ADHD behaviors are typical tend to reject ADHD diagnoses. To the best of the researcher's knowledge, this dissonance in findings is unexplored, and the uniqueness of the findings will add to the body of ADHD knowledge within the South African context.

The present study also revealed a distinctive perspective on the etiology of ADHD based on cultural beliefs. In the study, one participant's view stood out, suggesting that the failure to adhere to African cultural rituals and practices, such as introducing newborns to

their ancestors, could lead to ADHD in children. The participant expressed concern that the Christian Westernization of African customs through acculturation often results in the displeasure of ancestors, leading to ADHD-type behaviors in children. This finding supports the work of Angermeyer et al. (2020), which emphasizes the impact of cultural factors in understanding mental disorders.

This finding mentioned above from the current study aligns with Bronfenbrenner's bioecological systems theory (1977), which proposes that a community's cultural viewpoint, including its values, norms, and beliefs, influences how individuals perceive meaning. Dabić et al. (2015) also support this theoretical premise, affirming that culture plays a vital role in meaning-making. The current study highlights the potential risks associated with the cultural lens that most Black parents and caregivers employ when interpreting their children's symptoms of ADHD. This lens may cause some children to miss out on vital ADHD assessments, diagnoses, and interventions that could positively impact their developmental trajectory and quality of life.

However, the present study has shown that when schools, which are part of the microsystem in Bronfenbrenner's (1977) bioecological systems theory, provide recommendations and referrals for ADHD assessments, as discussed in Chapter 6, it is highly likely that more Black children in South Africa will receive these assessments. This highlights the importance of parents and caregivers being open to cultural shifts if it benefits the child. Therefore, the current study reveals the importance of the interplay between the ecological structures within Bronfenbrenner's theory working together for the child's development, with the child at the center. The school, as part of the microsystem, can intervene in ADHD dysfunctional behaviors that parents may overlook at the macrosystem level. It is essential to remember that managing a child with ADHD requires a holistic approach that considers the interplay between these ecological structures.

### *Awareness and Knowledge*

As highlighted in the Findings section of this chapter, in the context of this study, awareness refers to the participants' familiarity with the existence of ADHD. On the other hand, knowledge pertains to a more comprehensive understanding of the disorder gained through facts, information, or personal experience.

Literature reveals that ADHD is considered to be one of the most prevalent childhood disorders, affecting 3% -10% of children globally (APA, 2013; Bussing et al., 2016). However, according to Schellack et al. (2019), ADHD among South African children is approximated to be 8% -10%. Nevertheless, despite being the most common childhood disorder, there appears to be very minimal 'awareness' and 'knowledge' among the Black population in African communities, including South Africa (Olatunji et al., 2023; Spittel et al., 2019). The findings of this current study confirm this claim. The findings reveal that 16 out of 21 participants had never heard of ADHD before their children's diagnoses. This study supports a cross-sectional survey conducted in Kwa-Zulu Natal, exploring knowledge and misconceptions about ADHD among parents of children diagnosed with the disorder (Rajcumar & Paruk, 2020). The mentioned study by Rajcumar and Paruk (2020), consisting of mainly Black parents, revealed that parents in South Africa had limited or no awareness of ADHD.

The statements above bring to light a concerning lack of ADHD 'awareness' within the South African Black community. Surprisingly, a study conducted in South Africa during the early 2000s revealed that little was known about ADHD among the Black population (Meyer et al., 2004). This indicates a potential lack of proactive efforts from relevant governmental bodies, like the Department of Health and the Department of Education, to promote ADHD awareness in Black communities. As a result, this present study underscores

the necessity for targeted, impactful, and extensive campaigns that increase ADHD knowledge and awareness throughout South Africa.

It is important to note that the level of information parents and caregivers have about ADHD informs their subjective perceptions of the disorder. For instance, due to their lack of awareness regarding the existence of ADHD, most participants attributed their children's ADHD signs as a mere manifestation of childhood misbehavior, defiance, and lack of discipline. According to the literature, many parents with this perspective attempt to curb these ADHD indicators through stricter discipline (Alrahili et al., 2022). Had it not been for the schools recommending and making ADHD referrals, possibly most of the participants would have remained ignorant of their children's ADHD disorder. Moreover, because of their lack of 'awareness' regarding ADHD, some parents, as exemplified by one of the participants in the research, may doubt its reality. Thus, they refuse to accept the diagnosis for their children.

Nonetheless, the rejection of ADHD's existence is not a confirmation of its absence. Therefore, communities require awareness that such a disorder exists and knowledge about it in order to make informed decisions. This rejection of ADHD diagnoses by parents and caregivers, who are responsible for safeguarding their children's health and welfare, often deprives their children of opportunities for a more enriching life.

While the study may appear to magnify the level of lack of ADHD awareness among the Black communities in South Africa, it also uncovered a small proportion of participants who had varying degrees of knowledge about the disorder. Out of the 21 participants, five knew about ADHD prior to their children's diagnoses, with one participant having learned about it through her profession as a registered nurse. Two others already knew of ADHD when their second-born children were diagnosed because they had older children with the same diagnosis. At the same time, the remaining two had learned about it through their

nephews and nieces, who were already diagnosed with the disorder. Notably, none of the participants had received information about the disorder from ADHD campaign initiatives by the government. All participants in the study expressed disappointment and a sense of neglect due to the government's lack of educational efforts about ADHD, which is a significant cause for concern.

An awareness of and having limited knowledge about ADHD does not shield parents from the negative psychological impact of receiving their child's ADHD diagnosis. All participants, regardless of prior 'awareness' or 'knowledge, reported experiencing a range of reactions, including shock, denial, worry, helplessness, anger, fear, and guilt. This highlights parents' and caregivers' need for empathy when receiving an ADHD diagnosis for their child and during early consultation visits, as most parents and caregivers will still be grappling with processing the diagnosis.

Participants in the present study reported that gaining more information about ADHD helped them overcome the negative psychological impact of the diagnosis. This suggests that increased knowledge about ADHD may act as an antidote to the psychological distress caused by the diagnosis. When parents have an understanding of their child's ADHD diagnosis, care plan, and prognosis, acceptance becomes more manageable. This idea is supported by Corkum et al. (2015), who found that understanding ADHD has a profound potential to shift Black parental perceptions of ADHD.

All the participants in the study, including the two who ultimately dismissed their children's diagnoses, reported being confronted by a need to seek health information regarding ADHD after their children's diagnoses. Health information seeking is prompted by an individual's need to gain information and knowledge regarding health promotion, health conditions, and diagnoses (Hurst, 2016; Zimmerman & Shaw, 2020). In the context of this present study, participants embarked on health information seeking in response to their

children's diagnoses. When individuals acquire knowledge regarding a health condition, they are empowered to confront the diagnosis psychologically; hence, the participant's earlier revelations that gaining more information about ADHD when their children were diagnosed had an impact on diagnosis acceptance. Additionally, most participants' understanding of the disorder improved due to knowledge acquisition.

Parents often seek information about ADHD from various sources to gain knowledge and control over their children's health. While this is commendable, it is essential to ensure that the sources of information are reliable and accurate. In the study, 12 participants reported obtaining ADHD information from the Internet, which is consistent with previous research showing that most parents of children with ADHD use media, particularly the Internet, for this purpose (Dodangi et al., 2017; Sage et al., 2018). However, while the Internet and social media platforms provide easy access to information, they also carry a risk of misinformation that can lead to misconceptions about ADHD (Abdelnour et al., 2022). This is due to the availability of both regulated and accurate information and unregulated and inaccurate information. Misinformation can lead to misconceptions about the disorder's etiology, nature, and intervention options. Moreover, conflicting information about ADHD from these information media platforms may fuel skepticism among people regarding its existence. However, there is a minimized likelihood of parents and caregivers obtaining inaccurate ADHD information when they obtain it from verified, accurate sources.

A study conducted in South Africa with 79 participants found that all received information about ADHD from medical staff involved in their children's interventions. At the same time, 89.8% had also obtained information from teachers and 56.9% from the Internet (Rajcumar & Paruk, 2020). Although some participants in the present study reported satisfaction with the ADHD information provided by their healthcare practitioners and children's teachers, there was a concern about the perceived lack of knowledge among some

professionals, unlike the findings from the study mentioned above. It is possible that the alleged knowledge gap among the professionals could explain why some participants in the current study did not receive enough information and support from their healthcare practitioners and teachers. Other studies have also shown limited ADHD knowledge among healthcare practitioners (French et al., 2020; Louw et al., 2009; Sayal et al., 2015) and teachers (De Jongh et al., 2019; Dwarika & Braude, 2020; Maema, 2021), underscoring the need for vigorous education and training in this area. When professionals, whom parents and caregivers expect to be adept in their professional fields, appear to be lacking and less knowledgeable in certain professional areas, parents and caregivers may lose trust in the professionals' abilities to effectively address their children's ADHD needs.

Interestingly, the current study found that none of the participants reported having gained ADHD awareness from television or radio, unlike previous research (Dodangi et al., 2017). With the power of broadcasting platforms demonstrated over the decades in the Human Immunodeficiency Virus (HIV) pandemic, government departments and policymakers can leverage television and radio to raise awareness and knowledge about ADHD on a large scale.

### ***Stigma***

As discussed in the previous section of this chapter, many individuals in the Black population of South Africa are not sufficiently informed about ADHD and its prevalence. Even those who have some exposure to ADHD may have limited knowledge about the disorder's nature, etiology, interventions, and prognosis of the disorder. This knowledge gap has contributed to the prevalent stigma associated with ADHD. This assertion is supported by Olatunji et al. (2023), who found that the lack of ADHD awareness and knowledge in Black communities led to societal stigmatization of both children and their parents. Stigma is a complex phenomenon associated with negative attitudes related to labeling, judging,

stereotyping, separating, and discriminating against people perceived as different from the general population (Schoeman & Voges, 2022).

The findings of the present study uncovered the participants' concerns about the magnitude of stigma toward mental disorders, including ADHD, that is rife among their racial group. This finding aligns with a study conducted in Kwa-Zulu Natal, revealing that many parents and their children diagnosed with ADHD experienced stigmatization linked to the disorder (Rajcumar & Paruk, 2020). As a result of the perceived and experienced stigma, most participants disclosed that they kept their children's ADHD diagnoses within their immediate family circles. They did not disclose their children's condition for fear of their children being labeled as "crazy." Some participants shared that other parents in their communities would refute an ADHD diagnosis in an attempt to shield their children from potential discrimination towards individuals with mental health conditions. The results gleaned from research conducted on an African American sample confirm the conclusions drawn from this study, which suggest that parents are apprehensive about subjecting their children to the heightened risk of stigmatization and labeling associated with an ADHD diagnosis (Bailey et al., 2014; Evans, 2019; Ohan et al., 2013).

The fear of parents and caregivers disclosing their children's ADHD diagnoses may elucidate the impact of stigma caused by no exposure to ADHD and limited knowledge about the disorder in Black communities. This is despite research concluding that ADHD is amongst the most commonly diagnosed childhood disorders globally (Bussing et al., 2016). The paradox of a widely researched and diagnosed disorder yet not well understood and linked to profound stigma in certain racial groups is perplexing. From one perspective, parents' well-intentioned choices not to disclose their child's ADHD diagnosis beyond close family members can unintentionally contribute to the stigma surrounding ADHD.

Acknowledging that this perspective does not invalidate or dismiss the fear of stigma that parents and children may experience is essential.

According to Morgan et al. (2013), stigmatization is mainly curbed through education. In the context of the present study, it is educating the Black communities about ADHD to increase knowledge about the disorder. Similarly, Kosyluk et al. (2016) found that education and contact exposure are effective strategies for raising awareness and knowledge about mental disorders, thus combating the stigma attached to these disorders. They describe the contact-based strategy as utilizing personal narratives of individuals with mental disorders to raise awareness, knowledge, and exposure. This implies that when parents and caregivers prefer not to talk about their children's ADHD to larger communities openly, people within those communities may remain with limited or no exposure to ADHD, consequently maintaining the vicious cycle of the stigma associated with the disorder.

Research has shown that many parents may reject their child's ADHD diagnosis out of fear of being judged or stigmatized for their parenting (Ahamed et al., 2013; Evans, 2019; Bailey, 2014; Ohan et al., 2013). Unfortunately, this rejection can prevent children from receiving the necessary support and interventions for their condition. These challenges arise from factors operating within the microsystem level, such as a parent's fear of ADHD stigma, which can impact the developing child at the core of Bronfenbrenner's bioecological systems theory (1977). Strikingly, the present study presented some conflicting results about previous literature. It was discovered that the fear of ADHD stigma did not result in participants rejecting their children's ADHD diagnoses. As will be explored in Chapter 9, under 'Decision-making on intervention pursuits,' the study indicates that some participants were motivated to pursue ADHD interventions as a means of reducing the stigma attached to the disorder. This noteworthy discovery suggests that rather than being deterred by stigma, parents were driven by it to seek interventions for their children.

Despite the perceived stigma attached to ADHD not influencing the current participants' receptiveness to ADHD diagnosis for their children, the results show that the participants were not immune to the negative experiences emanating from the stigma attached to ADHD. These negative experiences will be explored exhaustively in the next chapter, which will focus on both the positive and negative experiences participants encountered as a result of their children's ADHD behavior and diagnoses, as well as the meanings the participants attached to the ADHD diagnoses for their children.

### ***Religious and Spiritual Beliefs***

In this study, religious and spiritual beliefs influenced six out of 21 participants' understanding of their children's ADHD. As highlighted in Chapter 2, most Africans believe in the existence of preternatural powers that can cause mental illnesses (Asare & Danquah, 2017). Studies show that those supernatural powers are reputed to be from God, ancestral spirits, or forces of evil spirits that manifest through witchcraft (Bignall et al., 2015; Choudhry et al., 2016; Fellmeth et al., 2015; Hailemariam, 2015; Liu et al., 2015). Therefore, religious and spiritual beliefs play an integral part in shaping many Black people's worldviews, including understanding and interpretation of mental disorders. For one participant, her understanding of the onset of ADHD in Black children was the wrath of ancestral spirits.

In some African contexts, ancestors and ancestral spirituality are revered (Sehoana, 2014). It is believed that when individuals disregard certain rituals, taboos, and superstitions, ancestors withdraw their protection and plague an individual with misfortune, illness, or a mental disorder. This is regarded as an indication of the ancestors' displeasure toward a living member. It is from this premise that some Black people regard ADHD in children as an indignation of the ancestral spirits caused by parents' or caregivers' failure to observe the children's rituals, as revealed by the study. One participant raised concerns about Africans

neglecting their ancestral spirituality through acculturation by adopting Western Christian cultures. Consequently, the children whose birth rituals are neglected by their parents bear the brunt of their parents' choices by being afflicted with ADHD. Nonetheless, it is believed that appeasing the ancestral spirits purges the affected individual from ADHD or any curse from the ancestors. Mollifying the spirits is believed to restore the protection the ancestors may have revoked.

Another finding that emerged from the current study was the initial belief by one participant that her older child's ADHD was a result of witchcraft. The belief was compounded by the child's comorbid challenges of severe speech and developmental delays, which, to the participant and other members of her rural community, were a result of witchcraft. This finding supports a meticulous, systematic review by Olatunji et al. (2023) conducted to understand ADHD from an African perspective. The review established that some Africans attribute ADHD-type behaviors of hyperactivity-impulsivity and inattention to witchcraft or spiritual possession. Unfortunately, such beliefs often precipitate stigmatization and discrimination of children with ADHD.

Mukolo and Heflinger (2011) posit that individuals' attitudes toward an illness or disorder indicate their beliefs about it. This notion is supported by one participant in this study who expressed feelings of recurring anger towards God because of her son's ADHD and its comorbid ODD. She perceived her son's condition as an unfair divine punishment. The finding is suggestive that some people believe in the existence of an omnipotent transcendent being called God who has the power to afflict people with mental illnesses and disorders, including ADHD, as a retributory measure toward disobedience. Angermeyer et al. (2020) shared similar views when they reported that some people perceive mental illnesses as God's wrath towards sin an individual may have committed. For this particular participant, her child's complex behavioral disorder caused by ADHD required religious answers; hence,

she repeatedly asked God why her child had ADHD. For her, God was responsible for her child's condition.

It is noteworthy that the components of Bronfenbrenner's bioecological systems theory can significantly affect a child's emotional, social, and cognitive development and well-being (Bronfenbrenner, 1986). This means that the religious and spiritual beliefs of parents and caregivers, which exist within the microsystem level, may shape their perspectives on their child's ADHD-related behaviors. These viewpoints could ultimately impact the decision-making process regarding intervention preferences that could affect the child's overall functioning.

When parents and caregivers attach religious and spiritual meanings to the cause of their children's ADHD, they are more likely to seek religious and spiritual interventions such as interceding to God through prayer, consulting prophets, faith healers, traditional healers, witch doctors, and 'sangomas.' Such intervention choices may positively or negatively impact the child's prognosis, thus affecting its development. According to Olatunji et al. (2023), basing the grounding of the cause of ADHD-type behaviors on religious and spiritual beliefs is a misconstrued understanding of the etiology of the disorder. The researchers claim that such misunderstanding can have adverse outcomes, such as exposing children with ADHD to unfavorable customary spiritual rituals and purgation. They further allege that focusing on spiritual ADHD etiology belief leads to delays in the disorder's diagnosis and appropriate interventions, thus aggravating the negative impact of ADHD on the child.

However, this study holds two conflicting views towards the assertions presented by Olatunji et al. (2023). One participant confirmed that initially attributing the cause of ADHD to witchcraft and pursuing faith healers, prophets, and 'sangomas' was a misconception of her lack of understanding of the disorder, which delayed her from seeking appropriate medical care for her child. On the other hand, another participant testified witnessing children

with ADHD cured of the disorder after traditional rituals and spiritual appeasing of the ancestors were conducted. Although the latter cannot be used as a basis to draw conclusions because it was not the participant's direct experiential account, her witness testimony profoundly cemented her belief that traditional rituals cured ADHD symptoms in children. ADHD is a chronic condition (APA, 2013), and some parents' religious and spiritual beliefs regarding the nature and management of ADHD may unintentionally perpetuate misconceptions about the nature of ADHD.

### **Summary**

This chapter has explored the various influences that shaped the participants' perceptions regarding the diagnosis of ADHD in their children. The considered influences were 'Culture,' 'Stigma,' 'Awareness and Knowledge,' and 'Religious and Spiritual beliefs'. The ensuing chapter will focus on the meanings that participants associated with the experiences resulting from their children's ADHD diagnosis, under the superordinate theme of 'Implications arising from the child's behavior: the significance attributed to the diagnosis.'

## CHAPTER 8: FINDINGS AND DISCUSSION

### **Implications of the Child's Behavior: The Significance Attributed to the Diagnosis**

This chapter focuses on addressing the research question, 'What meanings do Black parents and caregivers attach to an ADHD diagnosis for their children, and how do those meanings influence their decision to pursue intervention options?' The superordinate theme, 'Implications arising from the child's behavior: the significance attributed to the diagnosis,' will frame the exploration that will address the research question under consideration. The negative and positive implications arising from the child's behavior provide a contextual foundation for understanding the meanings the participants attached to the diagnosis and the influence of those meanings on decision-making and willingness to explore interventions for their children diagnosed with ADHD. The theme under discussion is highlighted in the table of themes below, as presented in Chapter 4:

**Table 2:***Superordinate and Subordinate Themes*

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Receiving the diagnosis	Child's behavior prior to diagnosis Own diagnosis reaction Do I accept or reject the diagnosis?
Understanding ADHD	Perception of cause Conceptions about the nature of ADHD Beliefs about the management of symptoms
Role of the school	Positive impact of the school Negative impact of the school
Sources of support	Positive support experience Negative support experience
Factors influencing perceptions of ADHD	Culture Stigma Awareness and Knowledge Religious and Spiritual beliefs
<b>Implications of the child's behavior: the significance attributed to the diagnosis</b>	<i>Negative implications of the child's behavior</i> <i>Positive implications of the child's behavior</i>
Decision-making on intervention pursuits	Reasons for intervention pursuits Motivations for chosen interventions Perceptions about ADHD medications Hindrances to intervention pursuits

*Negative Implications of the Child's Behavior*

The study found that each participant had experienced negative encounters due to their child's ADHD-related behavior. The participants attached significant meanings to these negative experiences, including feeling that they and their children were negatively perceived by society, having their interpersonal relationships disrupted, perceiving discrimination, having their own well-being negatively affected, and experiencing the demands of managing ADHD.

***Parents Feeling Judged.*** Findings revealed that 16 out of the 21 participants in the study described feeling judged as 'permissive parents' who failed to control their children's behaviors. The participants disclosed that they were perceived as 'lacking parental

disciplining skills' toward their children. They felt 'blamed' for their children's negative ADHD behavior. Sharing her experiences of being judged as a 'bad parent,' participant P21 indicated that some people blamed her for 'always defending' her 13-year-old child's aggressive and negative behavior. She felt people perceived her as 'condoning' her child's unacceptable behavior. Participant P21 found it frustrating to be negatively viewed as a parent based on people's ignorance.

Some narratives shared by other participants depicted a shared perception of being judged negatively as 'lacking parental skills' were such as, "you don't smack them enough" (P6), "our disciplining methods are laxed" (P12), "you know your kids don't listen," and "you just let your child do everything they want" (P1). The participants highlighted that such statements were meant to make them "feel guilty" (P3) and "labeled as failures in parenting" (P3), leading to self-blame. Participant P5, a caregiver to his niece who lost her mother in infancy, described being perceived as a spoiling uncle - an uncle overcompensating for the child's loss of her mother by failing to discipline her. He said, "there was that perception of that she's spoilt...because she's my sister's child, I want to make up..." Thus, he felt people held him responsible for his niece's ADHD-related behaviors.

The above narratives of the participants' negative experiences of the attack on their parenting due to their children's ADHD-related behaviors led them to an understanding that ADHD was a disorder that led to social pressure on parents to apply stern discipline to their children with ADHD unnecessarily. It was also a disorder that made parents and caregivers of children diagnosed with ADHD often doubt their parenting competency. Therefore, the diagnosis meant that the participants had to develop resilience against social pressure.

***Society Misjudging the Child's Behavior.*** The participants became aware that ADHD was a disorder with symptoms that could be mistaken as children's intentional defiance and disobedience. As such, the social comparison of the disorder to those behaviors meant that

their children would be constant targets of labels such as “spoilt brats” (P8), “naughty” (P12), and “rude” (P12). There was also concern by participants, especially those with children who were on the severe end of the ADHD spectrum and those with comorbid conditions, that their children were labeled as “crazy” and “mad.” Participant P21 expressed that she could not understand people’s failure to comprehend that her child’s negative behavior was motivated by a condition beyond his control when she said, “the time he’s doing all those things, he’s not himself, he is not aware of what he is doing and other parents tend to say this child is naughty.”

The meaning the participants construed from those negative experiences was that ADHD was a misunderstood disorder that attracted unwanted attention of stigma, as discussed in Chapter 7. The stigma targeted not only the parents’ and caregivers’ parenting abilities but also the children’s social skills. Thus, the dignity of the participants and their children was constantly attacked because of ADHD. As such, the participants learned that they had to continually defend and justify their children’s ADHD behaviors to people, “which had become a norm” (P16). The participants found the constant defending and justification of their children’s negative behavior exhausting and frustrating, as articulated by participant P1, whose child displayed significant levels of hyperactivity-impulsivity and aggressive behavior:

As much as I have fully accepted that my child has this mental disorder, it’s very difficult because everywhere now you go you have to be explaining to say my child is like this so that they accommodate her. In church, you have to explain to everyone. In the shops... (sighs exasperatedly). So it is not easy to be explaining to everyone whilst they see you as the wrong person all the time. You are always made to feel guilty and judged by people who don’t understand your situation or your child’s disorder.

The ADHD-related behaviors displayed by the children implied that the participants continually needed to exonerate themselves and their children from society's negative judgments.

Elaborating on the need to defend their children with ADHD from being negatively perceived by society, participant P5 reported that it was an unending occurrence, sharing that he constantly had to defend his niece, who often got blamed for incidents that happened in her absence. He said:

Kids they...fight. Even if she is not there, they will start blaming her.

Especially where I stay, it's a flat type of set-up. When something is broken, she is the first to be suspected unless we go to cameras...and check.

Thus, because of the label "naughty" that society attaches to children with ADHD symptoms, the children are vulnerable to scapegoating by other people and need to be protected by their parents and caregivers.

***Interpersonal relationships are affected.*** During the interviews, 17 participants mentioned the negative impact of ADHD on interpersonal relationships, specifically on the 'child's friendships,' 'parental/guardian marriage,' and 'relationships with extended family members.'

**Child's Friendships.** According to the participants, children with ADHD struggle to regulate their emotions and behaviors. As such, they find it challenging to form or maintain friendships. Encapsulating this experience for her child, participant 10 reported that her child "struggles with social life because she cannot keep friends for so long because they think she is weird. They don't understand her." She stated that her child's unpredictable behavior made it difficult for other children to form lasting relationships with her. She indicated that she also struggled to understand her daughter sometimes when she said, "*nna* (I) myself find her very weird sometimes because...she is a very bubbly person and we would be playing and then

she would strangle me.” Thus, participant P10 did not blame other children when they did not want to play with her child because she was aware that her child’s aggressive and unpredictable behavior made it difficult for her to get along with them.

Also highlighting her awareness of the difficulty her child with ADHD had in forming and maintaining lasting friendships due to her hyperactivity, aggression, and being misunderstood, participant P1 said, “She ends up not having a friend to play with.” This was a concern for her because she believed children as social beings should play and interact with other children as part of their development, but ADHD hindered her child from experiencing that social interaction.

Sharing the same experience of the impact of her ADHD on her child’s friendships, participant P17 indicated that some people were offended by her child’s aggressive behavior. She said the child “would just cause a confusion among people...others would be very upset because...their children were hit by him,” hence the child did not have friends. Participant P17 reported that she had to make a difficult decision to withdraw the child socially due to his behavior challenges. She said, “I would rather have him being a loner now than be in company of his friends.” Participant P17 sounded sad that she had to decide to have her child as a “loner,” but she believed the decision was for the best for her child and the other children. Describing an incident that eventually led to that decision, she said:

We went to a birthday party. He was at his best behavior until they told them to go to a jumping castle. Oh Lord! You know, there are those things I choose that I don’t take him there. But it was a birthday party, you are supposed to enjoy but he created a scene, do you understand? Because when they jump all of them and when they reach the surface, others will fall and the fight started there. Things turned into a mess, tell you.

Participant P17 acknowledged that her child was struggling socially, behaviorally, and emotionally, as revealed by the child's dysfunctional social interaction, and was willing to seek intervention, but what she was struggling to accept was attaching an ADHD diagnosis to her child's challenges.

Due to their children's unpredictable and disruptive behaviors, other participants (P1, P6, & P10) reported that they often deliberately withdrew their children from social settings either by keeping them indoors, limiting visitors and visits to other people's homes, or turning down invitations to social events. This was an act of protecting their children from exposure to negative experiences from society. Elaborating on that decision participant P1 shared that for a while after her child's ADHD diagnosis, she kept her child "inside the house to avoid all those beatings" because her child would often be beaten by the children she played with due to her aggression. She further elaborated that sometimes the parents of the children would also hit her child if she was aggressive toward their children.

Participant P6, whose two children both had ADHD, reported that they "would seldom visit friends," preferring friends to do the visiting so that her children would be "comfortable" in their familiar environment. By so doing, participant P6 did not have to worry about her children breaking items in people's homes due to their hyperactivity-impulsivity.

According to the findings presented above, ADHD-related challenges for the participants meant social exclusion and isolation for their children diagnosed with the disorder. The children's challenging emotional, social, and behavioral problems meant the children missed out on forming healthy and memorable childhood interpersonal and social bonds with friends. Thus, ADHD symptoms robbed the children of that aspect of their childhood experience.

**Parental/Caregivers' Marriages.** Explaining the negative encounter in the form of marital tension he experienced in his home due to the financial burden caused by his niece's ADHD diagnosis, participant P5 mentioned the "home frustration." Taking care of a child with ADHD has financial implications for assessments and interventions required. Therefore, if the child with the disorder is not one's biological child, it may cause tension in the home due to the financial pressures that come with the diagnosis, leading to marital frustration and tension.

Also sharing her negative experience of marital conflict resulting from her child's diagnosis, participant P20, who accepted the diagnosis when she became an occupational therapist, and her husband remained in denial, causing conflict between them, said:

That hurt me because he was now insulting me and my job saying I think I now know too much. There were times when he would spend days without talking because we will be fighting about this ADHD that I believe it and he doesn't believe it. So the diagnosis caused a lot of tension in the house.

Participant P20's and her husband's differing perceptions about the child's undesirable behavior and how to manage it created disharmony in the home.

Similarly, participant P1 shared feeling frustrated by her unsupportive husband, who was denying that their child has ADHD, as discussed in Chapter 6 under the superordinate theme 'Sources of support.' Describing her experience, participant P1 said, "his attitude and no support when I need him on this issue is frustrating and I have stopped counting on him." Nuances of anger and frustration bordering on detachment could be sensed as participant P1 described her experience. She regarded her husband's denial of their child's ADHD despite profound noticeable symptoms displayed by the child as irresponsibility and negligence on his part, causing her to feel resentful towards him.

Regarding the three aforementioned participants who encountered implied or direct marital tension, the ADHD diagnosis for their children precipitated marital discord they may not have experienced were their children not diagnosed with the disorder. Therefore, the experiential truth for these participants was that an ADHD diagnosis causes marital disagreements among parents or caregivers of children with the disorder.

**Relationships with extended family members.** The findings of the study revealed that some participants experienced relationship tension with extended family members due to their children's ADHD-related behaviors. According to two participants' narratives of their lived experiences, P11 and P21, their children's ADHD behaviors triggered familial and sibling tensions. The participants became very emotional when sharing their experiences, indicating that those experiences hurt them. Participant P11 reported during the individual interview that her family members did not believe in the ADHD diagnosis for her child. Instead, they believed the child was intentionally defiant and responded to her by continually shouting and screaming, causing the child to feel unloved. When participant P11 stood up to defend and explain the child's behavior to her family members, they accused her of being a permissive parent, causing conflict between her and the family. The conflict escalated to a level where the family informed participant P11 to "go with her [child] to the grave" when she "dies" because no one would want the burden of being responsible for a child whom the mother deliberately spoiled.

Similarly, participant P21 shared in the focus group that her child was perceived as "naughty" and "mad" by her brother, who advised her to give away the child to a care home. She said, "I'm not gonna give away my child because my family doesn't understand." Participant P21 disclosed that she became estranged from her brother due to her child's condition, saying, "They tend to refrain from you because of your child." These two

narratives illustrate the reality that an ADHD diagnosis and its related behaviors in children can be the cause of family estrangement.

Sharing her experience of how ADHD disconnects her children from extended family because they believed that her two children with ADHD lacked discipline, participant P6 said, “Sometimes I’d send my kids for December holiday. My mom would complain that you cannot send your kids here. We can’t manage them...it was frustrating for me. To have the kids at home with family, it was challenging.” According to P6, her mother informed her not to send her children over if she was not accompanying them. She further shared that she only allowed her children to visit her husband’s extended family, who lived in a different province, when she was with them, and they would limit their stay to a weekend. She said:

My husband is from ... [name of the province withheld] but my kids have never went to visit during the school holidays. They only go when we go for a weekend because we knew that they will not be able to manage them. They will only go when we go for a weekend and they would come back with us.

In an African context where kin relationships are valued, participant P6’s children missed opportunities to form meaningful bonds with their parents’ extended families.

Furthermore, the parents and caregivers of children with ADHD also sacrificed social events, gatherings, and spiritual fellowship with family due to their children’s difficult ADHD behaviors. Participant P17, who described her family as very religious and valued church fellowships together, a family that enjoyed having social gatherings, said, “Even if somebody invites me...I just don’t go. If somebody is gonna babysit for me, I will go alone.” Thus, the ADHD behavior displayed by children may cause social exclusion and isolation when the parents decide not to join their families on social events. Additionally, they risked the loss of relationships, as experienced by participant P8, who indicated during the focus group that she had “recently lost a friendship with [her] friend” who was “like a sister” to her

because the friend did not believe participant P8's child's ADHD diagnosis, choosing to view her as a "very spoilt brat."

***Perceived Discrimination.*** Two participants' accounts, P20 and P6, projected a perceived belief that a Black child with ADHD symptoms is likely to be treated differently compared to other races, thus becoming a target of indirect racial discrimination in multi-racial schools. Their children were attending multi-racial schools at the time of the referrals.

Narrating her perception of her child's experience of racial targeting due to his ADHD-type behavior, participant P20 revealed during the individual interview that she experienced the targeting as an intentional act to undermine her. She described the behavior of the crèche's teacher of isolating her child to the storeroom during nap time due to his distracting behavior as a sign of disrespect for her as a parent and an attack on her race, causing her to take the experience "personal." She said:

And to think of the money I was paying for that creche because it is the best in the area, to have my son sleep in the storeroom like some stationery or toys kept there. I just wanted to take my son out of that creche. It's just that I don't like fighting. Honestly, I should have called the teachers to order. You know when they label and treat your child like that, they are also labeling you as a parent to say you are nothing and we can put your child in the storeroom even when you pay the same school fees as everyone else. *Ayi* (no) what they were doing still hurts me and makes me angry even now when I think about it. Would they do that to a White, Indian, or Colored child? Were they not able to control his behavior in a better way as teachers? They would never do that to a White child but Blacks. That was the most negative experience for me.

As participant P20 was articulating her sense of being attacked and disrespected, she started to speak very fast, and her tone of voice had a trace of rising anger. I sensed that revisiting that particular experience still triggered emotions of anger in her.

Perhaps there is a perception that Black children are more likely to be unfairly treated in multi-racial schools in South Africa compared to their counterparts. Hence, the above two participants' racial targeting interpretations of the manner the schools handled their children with ADHD. South African history is marred by an era of Apartheid where the non-White populations, including Black people, were racially segregated, oppressed, and dominated through the institutionalized systems that officially ended in 1994. Therefore, it is not surprising that some Black people may still interpret their encounters with their White counterparts through the Apartheid epoch frame of reference.

Corroborating the speculation above was participant P6, whose two children were both diagnosed with ADHD and also attended upmarket multi-racial private schools. She had disclosed that when her younger child, who was the focus of the study, also got diagnosed with ADHD, she had initially believed the "private schools" were "trying to control" their "kids." Participant P6 had struggled to accept that both her children would be reported to struggle with the same 'behavioral' condition at school. Thus, she said, "so now they don't know what to do with them, they wanna put them onto medication." That utterance was masked with some mistrust of White professionals' dealing with Black children. This deduction was confirmed by her rejection of her second son's ADHD diagnosis from a White psychiatrist as a misdiagnosis, but accepting the same diagnosis from a Black psychiatrist, as expressed in her revelation, "Dr. King\* tried to coerce me and speak some sense...still, I wasn't buying in... But there was a lady who was practicing in the same room...a psychiatrist ...and she is Black." An ADHD referral and diagnosis of a Black child by a non-Black

professional was interpreted as a misdiagnosis, potentially risking participant P6's child a denied ADHD intervention opportunity.

*Parental well-being Negatively Affected.* Two participants, P1 and P8, highlighted during the individual interviews that at some point after their children were diagnosed with ADHD, they struggled to cope with some of their daily functioning. Participant P1, a registered nurse by profession, shared that she constantly worried about the future and the prognosis of her child's condition. She verbalized, "if my child can't have a normal life, what will happen?" Participant P1 was struggling to process the impact of the diagnosis, compounded by her husband's diagnosis denial and his lack of support. The negative experience of shouldering the burden of her child's ADHD diagnosis without her spousal support led her to worry about the future of her child, especially if she were to die first. That would have meant that due to his diagnosis denial, her husband would terminate all the ADHD interventions the child required to manage the disorder. As a result of constant worrying, participant P1 said, "this diagnosis was too much for me...even at work I was not coping." Thus, her daily professional functioning was negatively affected by her child's diagnosis.

Similarly, sharing how her functioning was affected because of the negative encounter her child with ADHD received was participant P8. The participant, whose first child's ADHD symptoms were considerably severe due to multiple comorbid disorders compared to her second child's, described adverse incidents at school where the child was treated extremely impatiently by a teacher who allegedly lacked ADHD understanding and sensitivity. Recounting the profound resultant regression in her child, participant P8 said:

It went severely so in such a way that she couldn't even remember her name, she couldn't even remember which grade is she. Like when I drop her, I need to carry her

hand because you could see her brain questioning around, which way to go inside the school.

Consequently, participant P8 described undergoing considerable stress that affected her, causing her to drive into her wall, as she explained, “I even bump into my wall at home.” Thus, the negative experiences her child was exposed to at school adversely emotionally impacted her, disturbing her driving ability.

While sharing her experience, participant P21, whose 13-year-old child’s ADHD condition was compounded by anxiety disorder and cluster B personality disorders, was very emotional throughout the focus group session. She sounded significantly drained, and she indicated that dealing with her child’s ADHD and other comorbid conditions was physically and emotionally exhausting, causing her to be constantly physically tired as well. Participant P21 revealed that her child was getting extremely physically and verbally aggressive. She was struggling to manage his behavior. As a result, she repeatedly shared that she was “tired.” Participant P21’s repetition of the phrase “I am tired” illustrated that dealing with her child with complex disorders, including ADHD, was affecting her physical and mental well-being. Her child was growing strong as he grew older, meaning that restraining him during his physically aggressive episodes was difficult. The child’s swearing also emotionally affected her.

The challenges participant P21 had to overcome in caring for her child with multiple complex disorders without support from her family affected her health, as she shared that she often suffered from emotional breakdowns and severe headaches leading to constant hospital admissions. A few days after she participated in the focus group, I reached out to check on her and to refer her to free psychological services. She informed me that she was hospitalized again because she had another recurrent headache attack, and the doctors had said she had water that needed to be drained from her head. During the call, she worried that her stay in

the hospital was a cause for stress because she was the primary caregiver of her son.

Participant P21's health issues could have emanated from her child's condition.

The descriptions of participants P1, P8, and P21 above illustrated their understanding that an ADHD diagnosis for children has a high potential of detrimental impact on the psychological and physical health of parents and caregivers of those children, disrupting some aspects of their functioning.

***ADHD a Demanding Undertaking.*** All the participants in the study, except for P2, appeared to agree that managing a child with ADHD behaviors and dealing with them was a demanding undertaking. The demand that seemingly pervaded the participants' narratives was the realization that parents and caregivers of children with ADHD needed to work hard in collaborating with the schoolteachers in supporting their children's academic lives, given that most children with ADHD encounter academic challenges. This required parents and caregivers to dedicate effort and sacrifice time from their daily schedules to assist their children with homework, reinforce concepts their children learn at school, cover knowledge gaps, and maintain effective communication systems with the school to keep updated on the child's progress. Best encapsulating the experience was participant P8 during the individual interview, who said:

You need to be a hard worker... Meaning that you as a parent you just make sure that you're making her understand. You are attending her on one-on-one. I can teach now and ask her tomorrow and she forgets and not know what you were doing yesterday. And then you repeat...

Participant P8 further emphasized that working "hard" in academically supporting a child with ADHD was vital and non-negotiable if the child's learning style was not met at school. The parent would have to be the child's ADHD advocate at school to meet the child's academic needs.

The results of the study further revealed that the participants regarded ADHD as a condition that demanded time and financial commitment in taking children for assessments and intervention appointments. Relating his experience during the individual interview, P5 said, “You need to almost take three days off your work to send her to these different people...There is money involved. Medical aids run out.” Corroborating the claim that ADHD was financially demanding were other participants, “my funds run out,” (P6), “it’s a lot that I am paying a month,” (P8), and “now I am thinking of the finances” (P11). In essence, the participants interpreted an ADHD diagnosis as financially draining and time-consuming.

The study findings revealed that the participants’ negative encounters due to their children’s ADHD behaviors and the meanings they attached to the diagnosis based on those experiences had a profound positive impact on their decisions to seek interventions for their children, as will be explored in the next chapter.

### ***Positive Implications of the Child’s Behavior***

This subordinate theme reveals that despite the negative experiences the participants may have encountered in the ADHD journey with their children, not all attributes of ADHD were construed as detrimental. Some children were experienced as possessing distinctive positive traits ascribed to ADHD. In addition, the participants reported gaining self-awareness as a result of their children’s diagnoses. Furthermore, the participants’ ADHD diagnoses for their children played a positive role in providing the participants with explanations of their children’s ADHD-induced behaviors, shifting participants’ self-views, improving parenting, and influencing some participants to assume roles of being ADHD advocates and sources of support to others.

***Child’s Positive Attributes.*** Five participants highlighted their children’s positive characteristics and indicated that their children with ADHD were intelligent, with three

participants using the phrase “extremely intelligent” (P4, P6 & P15). However, they acknowledged that children with ADHD required prompting and encouragement to reach their full intelligence potential, as expressed by participant P4, “he’s very intelligent but lazy. Like you have to push him to get the marks.” Further illuminating their children’s level of intelligence brought about by their ADHD condition, P15 said, “...he talks about deep things and thoughts. Already at 8 years old, he knows things he has power over and things he doesn’t have power over. You are not gonna find an 8-year-old that has such skills,” while P6 stated, “...far ahead of their age...they explore. They explore in such a way that they would even open a phone.” Thus, participants P15 and P6 believed that their children’s higher-level self-awareness ability and inquisitive nature, respectively, were a special gift linked to ADHD.

Furthermore, participant P4 shared that their child was a great sportsman, an attribute they perceived to be linked to their child’s high energy levels caused by ADHD. Underscoring her child’s great sportsman aptitude, participant P4 said, “He is amazing sports-wise. I’m in awe of how he thrives on the field. He is very, very good with swimming. But with your soccer, athletics, you know, your rugby, he is amazing.” The narration reveals Participant P4’s recognition of the child’s unique abilities, which she believed were positive traits of ADHD.

One participant, P12, revealed that his nephew was “assertive” and “outspoken.” He indicated those were “positives that usually appear with this condition [ADHD].” Nonetheless, he highlighted that the nephew’s assertiveness was often misinterpreted as “rude or bad manners” because the child would often “blurt out whatever is on his mind.” This observation made the participant distinctly aware that what he regarded as the child’s strength might be interpreted as an undesirable trait by other people. Hence, he recognized that he needed to help the child manage the impulsivity caused by ADHD.

The participants recognized that the positive ADHD attributes their children possessed required nurturing, which could be achieved through managing the negative attributes. As such, the participants were encouraged to pursue ADHD interventions to enhance the positive ADHD characteristics.

***Diagnosis Helped Explain the Behavior.*** According to the study, an ADHD diagnosis provided 12 out of 21 participants with an explanation of their children's behaviors. Five of the participants had found their children's behaviors concerning, leading them to worry about the well-being of their children. Expressions such as "severe speech delay...I sent her to the physiotherapist because she was tiptoeing" (P1), "I noticed that these behaviors are a bit above normal" (P3), "I think that was the start of me to notice that there was something wrong with her" (P8), and "we saw that he had a problem" (P21), depicted the participants' recognition that there was something uncharacteristic about their children behaviors, yet they did not know the cause. Therefore, an ADHD diagnosis provided an explication of those behaviors that were a cause for concern, motivating the participants to seek help for their children as they then knew what they were dealing with.

In addition, seven participants had observed odd behaviors displayed by their children, which they, in retrospect, perceived could be linked to ADHD after receiving the diagnoses. Connecting the odd behavior, participant P9 recalled that when her child was "young, she used to pull her hair and eat it," which she had found abnormal. The recollection made her speculate that "maybe this thing [ADHD] started a long time" ago and not when the child was referred for assessment by the school due to inattentiveness, as she had initially thought.

Also recalling how her child's behaviors began to make sense after the diagnosis was participant P4, who said:

He, for a lo-ng time, would soil his pants at an age where it was like, no, no this should not be happening. When it was time to stop playing, he would ignore that and still play. So this happened for quite a long time. With his emotions, he was a little different emotionally from your average kid his age. He is 13 years old now, but I always see him relate to kids two or three years younger than him...

Thus, the diagnosis gave the participants an explanation and understanding of their children's behaviors they had previously found peculiar but never sought help for.

On the other hand, two participants shared that the ADHD knowledge they obtained after their children were diagnosed explained strange behaviors exhibited by their family members. Participant P8, who had two children with ADHD, indicated that the profound ADHD information she gained through research after her children were diagnosed helped her understand the behaviors displayed by her husband and some of his family members. Participant P8 reported that her husband, her mother-in-law, and her late brother-in-law displayed ADHD and autism symptoms, conditions they never got an opportunity to be evaluated and diagnosed for. She said, "The things that my kids are doing, it's how them [husband and the two in-laws] they do in a day-to-day basis at [their] home," and "there was a brother-in-law who was having more, because I understand autistic features, I really believe now, it was him having more of the autism and epilepsy. So I relate everything so fast." She said to her mother-in-law, "Sometimes she just blurts out words without even thinking. Even at church, she just mentions things that are not relevant, or not appropriate at a function." Consequently, participant P8 became tolerant of their seemingly 'odd' behaviors because "experiencing similar symptoms" with her children allowed her to "relate" and understand that undiagnosed ADHD and autism ran in her husband's family.

Similarly, sharing how his nephew's ADHD diagnosis helped him understand the behavior characteristics of some of his family members, participant P12 said during the focus

group, “there were certain strange behaviors...within the family we never took seriously, yet they considerably affected his [nephew’s] siblings’, aunts,’ and uncles’ academic performances negatively.” Participant 12 observed that his nephew “exhibiting those similar characteristics” gave him insight into why his family members “were struggling” at school. Therefore, an ADHD diagnosis for his nephew served as an eye-opener to the cause of participant P12’s family’s challenges and a realization that ADHD is heritable. P12 realized his older family members with ADHD-type behaviors would have received help had they known about the existence of ADHD and obtained a diagnosis.

***Self-diagnosis.*** Although none of the 21 participants were assessed and diagnosed with ADHD, three participants revealed that after their children received the diagnosis, they gained ADHD knowledge that enabled them to identify ADHD characteristics in themselves. Participant P6 disclosed her self-diagnosis when she said, “Based on all my findings, I came to the realization that I am actually ADHD...but I was never diagnosed as a child nor as an adult. The symptoms, I have them.” Suspecting the high likelihood that she has ADHD, participant P4 expressed, “I think as time goes by, I actually start to wonder if he got it from me because I’m finding my concentration is also problematic, even without being diagnosed.” Sharing the same sentiments was participant P15 who said:

I might as well have it because I also see sometimes how I do my work...I lose interest quickly. I understand it now because of research...I would have achieved so much more only if I knew that there is something like this.

The three participants’ narratives suggest that they perceived their children’s ADHD diagnoses as positive experiences that led to their self-awareness. Thus, they were able to understand themselves better.

***Self-exoneration.*** As discussed in Chapter 7, ADHD symptoms in children are often interpreted as intentional defiance and disobedience caused by a lack of discipline. More

often, parents of children with ADHD are blamed as permissive and lacking disciplining abilities. Twelve out of 21 participants disclosed initially internalizing the stigmatized beliefs that their parenting skills were lacking, leading to self-blame. Reflecting on the self-blame, participant P1 said, “I thought it was my fault,” while participant P10 expressed, “I thought I was a bad mother which...(is) what caused this behavior. I blamed myself.” However, after their children were diagnosed with ADHD, the participants had a shift in their self-perception. They no longer blamed themselves for their children’s unbecoming behaviors. Instead, the diagnosis gave rise to self-vindication whereby the participants realized they were not responsible for their children’s ADHD behaviors.

Participant P6’s expression, “I realized it got nothing to do with me,” captured and epitomized the participants’ self-exoneration. The diagnosis meant that the participants did not need to perceive themselves as bad parents, a label imposed by those who lacked ADHD understanding. The ADHD diagnoses absolved the 12 participants from feeling guilt for their children’s behaviors. Instead, the diagnosis implied that their children had a classifiable disorder requiring management care plans; hence, they felt motivated to seek interventions for their children.

***Improved Parenting.*** Nine out of 21 participants revealed that their parenting improved after their children received ADHD diagnoses. They reported being more patient and tolerant of their children’s behaviors. Describing her parenting approach while assisting her daughter with developmental delays with schoolwork before and after the ADHD diagnosis, participant P8 said:

I used to beat her. Like I used to pick a stick and bring it here and then I would sometimes hit her. But when, as soon as I got the diagnosis, I said, you know what, I just need to work on her. So we sing together, we go to the trampoline, we jump

counting and... I do that with the brother. I decided to change my parenting because with the sister, *nhe* (right), I used to beat her.

Participant P8 reported greatly regretting her earlier parenting. She was impatient with her daughter, who was profoundly struggling academically because of her condition, yet she showed impatience out of ignorance.

Participant P4, who described herself as a well-ordered person who expected things to be done systematically according to her standards, reported that she had struggled to tolerate her son's laid-back approach to things, especially his academic work, before the ADHD diagnosis. She reported experiencing feelings of anger toward her son's seeming lack of care approach to school. She said:

So it was a lot of anger...it was a lot of comparing because you know this is how you should behave in different situation, but you are not. But like I said, as the years go by, then you learn to accept him...And I remember I tried to control it [child's behavior]. I tried to control him even with the study methods. I tried to impose what worked for me not thinking about what would work for somebody like him... and over the years I've had to let it go. I've had to sort of let go over the years and stop being controlling because I was controlling.

Participant P4 had to accept that her way of approaching life would not work for her child with ADHD.

Participant P15 shared that after her child's ADHD diagnosis, she had to learn to be more attentive to her child's emotions because, before the diagnosis, they were not aware that he was a sensitive child. She reported becoming more conscious of her parenting as she supported her child. She said:

As we speak now, Sifiso\* is going for play therapy because he is too emotional. He doesn't take a joke. He's like this, and those are the things that we didn't know. In

this process I've also learned about myself. As I'm doing intervention for my son, I'm also doing intervention for myself as a parent *ukuthi* (that) I did this mistake, or must avoid this, or I must be like this. Then I must try and make sure that I'm present when I'm with him. My mind and body is here. So, as we intervene for our children as well, we must be open and receptive to everything that we learn about them to also look into ourselves and learn about us too, as parents of children with ADHD, you know. Like even with me when I start shouting, then I'll be like, oh! I'm sorry, Sifiso\*, *thina* (us), this is what we know. We were shouted at all the time, even for the good thing. We also have our cultural things that we need to...I could say, maybe adapt new ways of doing things.

The implied meaning conveyed by participants was that ADHD diagnoses for their children inspired self-development in their parenting that allowed them to manage their children's ADHD better.

***ADHD Advocates.*** Based on the findings, five participants revealed that after their children received ADHD diagnoses, they actively became ADHD awareness advocates or sources of support to other parents and caregivers who wanted information about ADHD and its management. Elaborating on her role as an ADHD advocate, participant P15, an early childhood practitioner, had this to say in the focus group, "I make it a point now as a practitioner wherever we go that we have trainings and whatever. I advocate for it *ukuthi* (saying that), please beware of this". Participant P15 stated that she raised ADHD awareness amongst both nursery school practitioners and parents due to her observations of limited knowledge and lack of ADHD awareness in the Black communities. On the other hand, participant P6 stated that she had "referred so many people" for ADHD assessments. Her advocacy role mainly focused on identifying children and people exhibiting ADHD characteristics and assisting them to get evaluated and treated for ADHD if diagnosed.

Participant P8's account revealed that she sacrificed and dedicated her time to forming a WhatsApp support group where she supported parents of children diagnosed with ADHD with resources to help manage their children's condition. Describing her role, she said:

I am supporting parents *koWhatsApp* (via WhatsApp). So in a day-to-day, they come back and say I have a child who is...[referring to the behavior/symptoms]...what can I do? There is a lot of resources that I know. There is books I was buying...copy and wipe books... There is also lot of videos that I send to them (on) a day-to-day basis.

Participant P8 also shared that she advocated for medication use to the parents who had reservations about using medicinal intervention as a way of managing ADHD for their children. She shared videos of her son's progress before and after medicinal interventions that motivated the parents she supported to be receptive to ADHD pharmaceutical interventions. She reported that parents in her support group expressed appreciation to her such as, "you have helped us a lot. Yoh! We don't even know what we were going to do without you... my son is now on Risperdal...and what what what...this this and this is happening..." Although it was hard work, this determined her to continue her supportive role. Participant P8 revealed that she also shared ADHD information on Facebook support groups for parents of children with ADHD.

The ADHD advocacy work the above participants took upon themselves after their children's diagnoses gave them a sense of purpose and altruistic satisfaction, a positive experience emanating from a negative experience of having a child diagnosed with a chronic disorder. They presented as a testimony to others to encourage and assure them that ADHD in children is manageable. Hence, these participants were motivated to pursue ADHD interventions as a lived, authentic truth to those they supported.

## **Discussion: Implications of the Child's Behavior: the Significance Attributed to the Diagnosis**

The research question addressed by this chapter is “What meanings do Black parents and caregivers attach to an ADHD diagnosis for their children and how do those meanings influence their decision to pursue intervention options?” To attend to the research question, it was imperative to explore the experiences the participants encountered arising from their children's ADHD-type behaviors and diagnoses to contextualize those meanings. This section discusses the study findings within the superordinate theme, ‘Implications arising from the child's behavior: the significance attributed to the disorder,’ while incorporating the theoretical framework that informed the study and insights from the pertinent literature review.

### ***Negative Implications of the Child's ADHD Behavior***

Parents and caregivers of children with ADHD may encounter negative experiences arising from their child's ADHD-related behaviors. The parents and caregivers attach significant meanings to these negative experiences.

***Parents/Caregivers and the Child Judged.*** ADHD often results in externalized behaviors that may be met with adverse reactions from others. This study found that 16 out of 21 participants reported receiving negative judgments from family members and society, who interpreted their children's behaviors as lacking discipline. This perception caused the participants to be viewed as incompetent parents who lacked the necessary skills to discipline their children. Unfortunately, children with ADHD were also sometimes seen as unruly, wayward, or weird. These findings are consistent with previous studies that suggest that parents of children with ADHD are often held responsible for their children's inappropriate behavior (Harazni & Alkaissi, 2016; Laugesen et al., 2016; Pretorius, 2021), while the children themselves are subjected to unfair and damaging labels (Olatunji et al., 2023;

Rajcumar & Paruk, 2020). These experiences can cause labeled parents and caregivers to feel guilty and blame themselves when they internalize the negative perceptions projected onto them (Laugesen et al., 2016), as observed in the present study.

It is worth noting that many Black communities still adhere to the African proverb that ‘it takes a village to raise a child.’ This means that extended family members and community members in Black societies can play a role in parenting by offering support, advice, and opinions that can impact a child’s development, as evidenced by negative judgments highlighted above against the parents and caregivers and their children with ADHD. Bronfenbrenner’s bioecological systems theory suggests that extended family and neighbors within the exosystem can directly influence the parenting of caregivers and parents, affecting a child’s experiences (Bronfenbrenner, 1977). The tendency of extended family or community members to negatively judge the parenting abilities of caregivers and parents of children with ADHD and their children can be understood through this lens. However, such tendencies can put negative pressure on parents and caregivers to discipline their children with challenging ADHD behaviors in order to meet societal expectations. Therefore, the exosystemic structure’s elements may dictate how parents should manage ADHD symptoms in their children. The findings of the present study reveal the need for caregivers and parents of children with ADHD to build resilience against ineffective societal pressures.

Based on the present study, one way of resisting societal pressure to discipline children with ADHD unwarrantedly was for participants to defend their children’s problematic behaviors constantly. Although Laugesen et al. (2016) highlight that mothers of children with ADHD found the need to justify their parenting and children’s behaviors to cause a sense of insecurity and apprehensions, participants in the current study experienced the incessant defending as exhausting and frustrating. The social pressure for Black parents

and caregivers to improve their parenting through disciplining their children with ADHD emanates from a lack of knowledge about ADHD. When parents and caregivers do not embrace the socially expected ways of handling their children's undesired behaviors, the 'village' often frowns on them.

***Interpersonal Relationships.*** One of the effects of ADHD on an individual is the disruption of their social functioning (APA, 2022). As noted by Dean (2005), socializing can become a profoundly challenging experience for children with ADHD and their parents. Participants in the present study (17 out of 21) expressed a concern that their children struggled with social skills, which prevented them from forming meaningful, lasting interpersonal relationships with their peers. Various prior studies also reveal that ADHD symptoms of inattentiveness and hyperactivity-impulsivity impede children's interpersonal skills (Feldman et al., 2017; Ragnarsdottir et al., 2018; Ros & Graziano, 2018; Zendarski et al., 2021), causing them to be socially rejected by peers (Forner et al., 2017). Peer relationships and friendships are an integral part of children's social growth, where they develop healthy attachments with other people outside the family (Berk, 2017). Correspondingly, participants in the present study perceived that ADHD deprives children with the disorder of an opportunity for age-appropriate psychosocial development because they are often excluded and isolated in peer interactions.

According to the current study, children with ADHD may not experience social exclusion through rejection by their friends only. Sometimes, parents and caregivers of children with ADHD intentionally exclude their children from extended family, social, or religious events in an attempt to protect children from the social stigma associated with ADHD's challenging and often embarrassing behaviors. This finding affirms a South African-based study by Tom (2010), whereby the researcher observed that many parents of children with ADHD declined invitations to social celebrations or slumber parties for their

children in fear that they would cause disruptions to the events. Thus, the parents and caregivers, with good intentions, may seemingly perpetuate social exclusion for their children. Furthermore, because ADHD may often co-exist with other disorders that fuel aggression and antisocial characteristics (Retz et al., 2021), some extended family members may reject and discriminate against children with ADHD and their parents (Harazni & Alkaissi, 2016; Malatji & Ndebele, 2018; Spindler et al., 2017), leading to isolation and exclusion that negatively affects interpersonal relationships, as experienced by some participants in the study.

Bronfenbrenner's bioecological systems theory (1977) emphasizes that the child's interactions with the elements in the microsystem influence the child's development. In this context, the rejection and exclusion of the child from social interactions and events happening at the microsystem level may affect their development. Attesting to this, Loades et al. (2020) state that children who are socially isolated often have challenges with interpersonal interactions with their peers. Furthermore, such children are more likely to develop additional mental health challenges such as depression, anxiety, low self-control, and low self-esteem (Loades et al., 2020). However, it is essential to note that not all excluded and socially isolated children develop the mentioned mental health challenges (Thompson et al., 2023). Nonetheless, Loades et al.'s (2020) observations raise concerns that some excluded children with ADHD may be at risk of experiencing cumulative social exclusion and mental health challenges. As a result, children with ADHD require interpersonal skills that will allow them to integrate into social events and peer interactions rather than withdrawing, potentially hindering their development.

***Family Tension and Conflicts.*** The findings from the current study reveal that ADHD may contribute to conflicts within families, confirming previous studies that show that ADHD has the potential to trigger family discord (APA, 2022; Leitch et al., 2019;

Pretorius, 2021). Such family conflict may be marital tension arising from differing opinions regarding the child's diagnosis and management, as revealed by several studies (Iseselo et al., 2016; Leitch et al., 2019; Mofokeng & van der Wath, 2017; Sikirica et al., 2015) and perceived lack of support by one spouse in managing the child's condition (Laugesen et al., 2016). Lack of spousal support causes the burden of care to be shouldered by one parent, which may lead to marital tension. Also, the financial strain associated with an ADHD diagnosis may lead to marital tension (Iseselo et al., 2016; Sikirica et al., 2015), as shown in the present study. According to the literature, marital conflicts may result in the breakdown of marital unions (Laugesen et al., 2016; Spindler et al., 2017), highlighting the graveness of the impact of ADHD on marital unions.

Conversely, familial discord resulting from a child's ADHD behavior or diagnosis may emerge between parents or caregivers and their close family members such as siblings or parents. The present study has revealed that two participants underwent extreme strain in their relationships with their family members: one due to the rejection of their child with ADHD on account of comorbid antisocial personality disorders and the other due to repudiation of an ADHD diagnosis and application of severe and punitive behavior management strategies on the child instead. In both cases, the participants felt hurt and unsupported by their families, leading to strained relationships. It is crucial to remember that in Black communities, kinship ties are a source of strength in times of hardship and stress, as noted by Tom (2010). When the interaction of parents or caregivers with the extended family located within the exosystemic level of Bronfenbrenner's (1977) bioecological systems is strained, the child is inevitably affected by how the family members may respond to their ADHD.

Utilizing a systemic approach that accommodates kin members involved in managing ADHD for a child may be beneficial. When all the members in the kinship structure that

influence the child comprehend the nature of ADHD, there is a likelihood of minimized familial conflicts arising from the child's ADHD-related behaviors.

***Perceived Discrimination.*** This present study has an implied undertone that there may be Black parents and caregivers in South Africa who may harbor distrust towards White professionals regarding referring, diagnosing, and proposing management strategies for their children with ADHD characteristics. Such perceptions may cause them to believe that Black children with ADHD-type behaviors are managed differently in some multiracial schools compared to their counterparts. According to Sullivan et al. (2019), Black learners are more likely to experience immoderate disciplinary measures as opposed to White learners in United States schools. It could be argued that the educational environment in the United States and South Africa are not comparable. However, it is plausible that the display of distrust portrayed by the two participants in the present study may be rooted in South Africa's apartheid era, where the governance systems in place at the time operated on racial discrimination, even in schools.

Despite nearly 30 years into democratic dispensation in South Africa, racial discrimination in schools is still perceived as prevalent (Joorst, 2019; Karrim, 2020; Moorosi, 2021), which may trigger the distrust experiences of the participants mentioned above. According to Mental Health America [MHA], (2023), a history of oppression and dehumanizing treatment of Black and American Black groups in the United States may result in the non-White population groups being hesitant to seek medicinal interventions for mental disorders such as ADHD. This could be the case with some people in the South African context who may interpret their experiences through a racial lens because, in the past, they experienced the oppressive legacy of the apartheid era and are currently seeing its traces in the democratic nation.

*Parental Well-being Negatively Affected.* Three participants in the current study discussed the implications of having a child with ADHD on their well-being. The impact affected their mental health, resulting in disruption of their functioning and physical health challenges. The participants implied an understanding that ADHD does not only impact the well-being of the child diagnosed with the disorder but poses a health risk factor to those closest to the child, such as the primary caregivers. In the existing literature, there is agreement that having a child with ADHD is an emotional, stress-evoking experience (Leitch et al., 2019; Mofokeng & van Wath, 2017; Theule et al., 2013) that has the likelihood to adversely affect parents' and caregivers' psychological health (Moen et al., 2016). This current study extends this existing knowledge by highlighting that the physical health of a parent or caregiver of a child with ADHD may be considerably affected as well. Participant P21 experienced this in the present study. She related her constant headaches that led to constant hospitalizations to her intense stress and emotional breakdowns exacerbated by her lack of familial support regarding her child's condition.

The experience of participant P21 can be understood from the bioecological systems theory, which purports that an impact on one ecological structure has a bearing on other structures, affecting the child who is at the core. (Bronfenbrenner, 1977). In this context, the lack of support the participant, who is at the microsystem level, experienced from kin who are at the exosystemic level exacerbated the negative psychological impact her child's ADHD and comorbid disorders had on her being. In turn, the participant developed physical medical challenges requiring recurrent hospital admission. Inevitably, the child, at the center of the structure of the bioecological system, was left without a primary caregiver during those hospitalizations. This caused disruptions in the routine and functioning of the child. The bioecological systems theory's relevance in revealing the importance of family support for parents and caregivers in ADHD management for their children is acknowledged by Spindler

et al. (2017), who confirm that family members play a pivotal support role to parents and caregivers of children with ADHD.

***ADHD a Demanding Undertaking.*** The findings from the current study showed that all the participants agreed that managing a child with ADHD was an exacting task requiring dedication and sacrifice in terms of time, effort, and finances. These findings paralleled existing literature, which reveals that having a child with ADHD means unabating support and tracking of the child's academic performance, perpetual maintenance of the child's routine (Harazni & Alkaissi, 2016), and financial strain that comes with ADHD intervention demands (Balagan, 2022; Ching'oma et al., 2022; Malatji & Ndebele, 2016; Pretorius, 2021). Parents and caregivers need to have sufficient information about the different demands of the disorder, such as the time and effort required, as well as the financial implications of the diagnosis and intervention pursuits. An ADHD diagnosis for parents and caregivers means making sacrifices to care for the child with ADHD adequately. They must prepare for the challenges associated with caregiving to minimize stress, which can negatively affect the child.

In general, the participants' understanding that ADHD can lead to stigmatization, perceived discrimination, impact parental welfare, strain personal relationships, and present significant challenges prompted them to take action and seek to alter the prevailing narrative surrounding the disorder - both for their own sake and that of their children.

### ***Positive Implications of the Child's Behavior***

Despite the negative impact of ADHD on child development and family functioning (Hai & Climie, 2022), research claims that the disorder comes with positive aspects that could be used to shape positive mindsets about individuals with ADHD (Climie & Henley, 2016). Furthermore, an ADHD diagnosis for the child may bring insights into the parents' and caregivers' views of their persona, thus enabling them to understand themselves better

(Halleröd et al., 2015). The findings of the present study validate the above claims whereby some participants reported encountering positive experiences in the ADHD journey with their diagnosed children.

***Child's Positive Attributes.*** The exploration of the present study revealed that some children with ADHD possess positive attributes that make them unique despite the atypical, impairing behaviors associated with the disorder. According to Able et al. (2007), ADHD is often perceived through a limiting impairing lens that views the disorder from a deficit position. Such a stance only perceives ADHD as a disability that impairs a child's cognitive, behavioral, emotional, and social development, restricting them from attaining optimal functioning in these domains. However, the findings of the current study dispute this viewpoint. Five participants perceived their children as highly intelligent and inquisitive, notwithstanding the academic intervention they received as part of their ADHD management plan. Also, one indicated their child had remarkable sportsman aptitude in various sporting games. The participants attributed these positive traits in their children specifically to ADHD. These findings validate Sedgwick et al.'s (2019) study, which found that individuals with ADHD possess 'cognitive dynamism,' whereby the thinking processes of individuals with ADHD are marked by impromptu, random, hyper-mental focus. These episodes of cognitive dynamism trigger inquisitiveness and expressiveness in individuals with ADHD, especially in activities that capture their interest, allowing them to master the activity.

The results of this study indicate that parents and caregivers of children with ADHD can recognize their children's strengths despite the challenges that come with the disorder. Rather than focusing solely on the negative aspects, these individuals view their children through a lens of capability rather than deficiency. This approach represents a positive shift away from pathologizing ADHD.

According to Sabapathy et al. (2017), when parents of children with ADHD have a positive outlook on their children, the relationship between them is strengthened, promoting increased parental well-being. It, therefore, can be seen that when parents and caregivers of children with ADHD, existing within the microsystemic level of the bioecological system's structure, do not focus on the impairing aspect of ADHD, their perspective may change the narratives about children with ADHD, thus, likely to reduce stigma surrounding the disorder. A stigma-free environment allows children with ADHD to explore their capabilities and boundaries without fear of judgment and discrimination.

***Diagnosis Helped Explain the Behavior.*** The evidence of this study, as presented in Chapter 5, revealed that although the ADHD diagnosis had been difficult for most participants to process, they turned receiving the diagnosis for their children into a positive experience. The diagnosis meant obtaining an explanation of their children's behavior. This finding aligns with a qualitative evidence review based on 69 qualitative studies, which found that for parents, getting an ADHD diagnosis provided answers for children's challenging behaviors (National Institute for Health and Care Excellence [NICE], 2018). This was especially relevant to the five participants concerned by their children's behaviors before the diagnosis. The diagnosis meant opportunities for obtaining help for their children to improve their functioning. Even to the participants who had initially perceived their children's behaviors as normal, the diagnosis turned into a positive experience in that it afforded the participants insights into childhood developmental behaviors that, when ignored, could hinder the children's optimal overall functioning.

Moreover, the ADHD diagnosis exonerated the participants in the present study from perceiving themselves as incompetent parents as they began understanding the cause of their children's unbecoming behaviors. They no longer had to blame themselves for failed parenting based on their children's ADHD-related behaviors. Instead, the diagnosis validated

their parenting abilities. This finding from the present study resonates with an Australian study, where Ghosh et al. (2016) found that parents experienced a sense of relief upon receiving their children's ADHD diagnosis as it validated that their children's challenging behaviors were not an indication of failed parenting.

Additionally, the parental experience of an ADHD diagnosis for their children implies that some parents and caregivers gain insights into their life histories, obtaining a new understanding of some of their behaviors or those of family members (Halleröd et al., 2015; NICE; 2018). Consistent with this understanding, the findings of this present study revealed that three participants regarded an ADHD diagnosis for their children as an experience of self-awareness. A new sense of self-understanding developed as they realized that they also exhibited comparable ADHD characteristics displayed by their children, leading to self-diagnosis. Thus, they could reflect and know themselves better, understanding the causes of their inattentiveness. As such, the diagnosis allowed them to gain improved self-awareness and how their overall functioning could have been optimized had they been diagnosed and received ADHD interventions.

Two of the participants gained insights and increased understanding of some of their family members who, in retrospect, displayed ADHD symptoms that were hard to understand to understand but never received interventions due to the history of lack of ADHD awareness among Black communities. The participants' accounts depicted a sense of sadness and mourning over their family members who never received help for the probable ADHD they had. Halleröd et al. (2015) and NICE (2018) indicate that individuals treated for ADHD may grieve for their family who had ADHD symptoms and were likely given incorrect labels but failed to get help due to non-diagnosis.

Therefore, gaining awareness about self and family members and the realization that non-diagnosis shuts windows of opportunity for interventions that could improve the quality

of life for individuals with ADHD, the participants were motivated not to deny their children interventions that could enhance their overall functioning, as early diagnosis and management improve the long-term prognosis of the disorder (Agarwal et al., 2012).

***Improved Parenting.*** An ADHD diagnosis for a child may mean avenues of improved parenting, especially in Black communities, where stricter and harsher parenting and disciplining approaches are often promoted. As previously noted in Chapter 7, other participants, due to a lack of ADHD awareness or knowledge, had resorted to harsher disciplining measures as a way of managing their children's ADHD-related behaviors before the diagnosis. However, after the diagnosis and attaining an understanding that their children's behaviors were beyond the children's control, they changed their parenting approach for the better.

According to Ghosh et al. (2016), when individuals gain an understanding of ADHD, problematic and difficult behaviors would no longer be perceived as intentional defiance; instead, they would be understood and interpreted as a diagnosable disorder requiring professional interventions. Therefore, instead of resorting to negative and harsh parenting that could exacerbate their children's ADHD symptoms, parents develop emotional intelligence to be aware of their children's needs and respond in a non-destructive way, such as being patient, empathic, and tolerant. Thus, according to Pretorius (2021), by being cognizant and sensitive to their children's needs, the parents and caregivers of children with ADHD establish solid emotional attachments with their children when they embrace them for who they are.

***ADHD Advocates.*** Through the ADHD journey with their children and gaining awareness and understanding of the disorder and its impact on the children's functioning and management, five participants took the role of advocacy in raising awareness about the disorder among people within their spheres of influence. One participant went the extra mile

to create an online WhatsApp support group. Thus, those participants turned their experiences as a starting point to embark on a purposeful altruistic endeavor to support parents and caregivers who are struggling to process their children's ADHD diagnosis and intervention adherence. Klein et al. (2022) state that peer support groups, which could include parental support groups of parents of children with ADHD, provide opportunities for shared burden in the solidarity of care and help other parents not to suffer from isolation and social exclusion that often come with the diagnosis. Additionally, Alat (2017) found that online parent support groups can allow members to reach out to each other without time and geographical limitations.

A sense of connectedness and empathic understanding through sharing experiences could be felt among group members during the focus groups. Participants appeared to have an unspoken sense of relief in finding a group of people who had similar experiences like them, validating each other's encounters and concerns, and sharing the highs and lows of having a child with ADHD. Specifically, in the second focus group, some participants shared contact details to continue supporting and referring each other to professionals they have experienced as helpful and to stay connected as a tribe of individuals on a similar journey. Based on this observation and the selfless act of the five participants who had started engaging in ADHD advocacy and support roles, it is clear that Black parents and caregivers of children diagnosed with ADHD in South Africa are willing to share their experiences in safe spaces to support each other and raise ADHD awareness.

The above observations give the insight that when given safe platforms, Black parents and caregivers with children with ADHD are willing to take responsibility for contributing to the well-being of other parents and their children with the disorder. They are willing to be ADHD intervention compliance and adherence sources of support for each other for the benefit of their children with ADHD.

**Summary**

This chapter discussed the meanings participants attached to having a child diagnosed with ADHD, including both positive and negative implications. It explored the interpretations that parents and caregivers placed on their children's ADHD diagnoses. These implications served as a driving force for parents, motivating them to seek ADHD interventions to improve their children's capabilities.

## CHAPTER 9: FINDINGS AND DISCUSSION

### Decision-Making on Intervention Pursuits

This current study aimed to explore the perceptions and decision-making of Black parents and caregivers concerning the diagnosis of ADHD for their children and the subsequent impact on the pursuit of interventions. This chapter will focus on presenting and discussing the findings that pertain to how participants' perceptions of the disorder, as outlined in previous chapters, influenced their decision-making regarding willingness to pursue ADHD interventions and preferences for their children. Furthermore, the perceived barriers to ADHD intervention pursuits that participants encountered will be examined. The chapter will address the study's research question, 'Which ADHD intervention options, if pursued, do Black parents and caregivers prefer based on their perceptions and decision-making regarding an ADHD diagnosis for their children?' The superordinate theme, 'Decision-making on intervention pursuits,' and its subordinate themes that will be explored to address the research question are highlighted in **bold** in Table 2 below:

**Table 2:***Superordinate and Subordinate Themes*

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Receiving the diagnosis	Child's behavior prior to diagnosis Own diagnosis reaction Do I accept or reject the diagnosis?
Understanding ADHD	Perception of cause Conceptions about the nature of ADHD Beliefs about the management of symptoms
Role of the school	Positive impact of the school Negative impact of the school
Sources of support	Positive support experience Negative support experience
Factors influencing perceptions of ADHD	Culture Stigma Awareness and Knowledge Religious and Spiritual beliefs
Implications of the child's behavior: the significance attributed to the diagnosis	Negative implications of the child's behavior Positive implications of the child's behavior
<b>Decision-making on intervention pursuits</b>	<i>Reasons for intervention pursuits</i> <i>Motivations for chosen interventions</i> <i>Perceptions about ADHD medications</i> <i>Hindrances to intervention pursuits</i>

***Reasons for Intervention Pursuits***

This subordinate theme focuses on the motivating influences that led the participants to pursue interventions for their children after an ADHD diagnosis.

***Seeking the best for the child.*** All the participants in the study reported that they were engaged in one form of intervention or the other for their children with ADHD. The shared motivation to seek interventions for their children with ADHD for 20 out of 21 participants was the realization and acknowledgment that their children had challenges that affected their development academically, socially, emotionally, and behaviorally and would need help

managing the behaviors. Although many participants in the study had initially struggled to perceive their children's ADHD behaviors as dysfunctional, as presented in Chapter 5, the participants' desire for the best for their children after the diagnosis made them willing to seek help to enable the children to achieve optimal functioning. Expressions such as "wanted her to do better at school" (P18), "I wanted the best for my child" (P16), "I saw that I cannot control him" (P13), and "noticing that something was wrong" (P12) explicitly revealed the participants' attitudes of wanting the best for their children as a motivation for intervention pursuits. The participants understood that as the gatekeepers of their children's well-being, seeking ADHD interventions for the children was the responsible action to take, as revealed by participants P15 and P20, respectively, "I cannot sit and be silent when my son needs help" and "I am taking responsibility for my child." Hence, they sought ADHD interventions for the children.

Participant P2 declined an ADHD diagnosis for his child because he perceived that the child's behaviors were typical. He believed that the ADHD diagnosis was incorrect and rejected it out of concern for his child's well-being. However, he indicated that his spouse "believes in ADHD," and she wanted the child to be on ADHD interventions. To involve his spouse in their child's care, he allowed for herbal interventions. In the individual interview, he said, "She is the parent; we are in this together. So, I really love to give her a chance as well coz that's what she believes. I'm sure she is also considering the good for the boy." Participant P2 explained that he wanted to support his spouse's beliefs and parenting style, as they were on a parenting journey together. Therefore, allowing the herbal intervention was not an acknowledgment of the child's ADHD diagnosis but rather an effort to share parenting responsibilities with his spouse, who also had the child's best interest at heart.

***To End Perceived Social Stigma.*** Given the societal stigma attached to ADHD-related behaviors in children, as discussed in Chapter 7, three participants reported that they

pursued ADHD interventions for their children to minimize the negative behaviors associated with the disorder that attracted the perceived stigma. The participants' position was best epitomized by participant P1, who expressed in the individual interview, "They make me want to give my child interventions for this disorder so that they stop judging me and my child. If she gets help, she gets better...they will have no reason to blame us," when describing the impact of the negative social experiences they faced due to ADHD. Thus, for these participants, ADHD interventions served as a means that would protect them and their children with ADHD from the stigma attached to the disorder.

### ***Motivations for Chosen Interventions***

Chapter 5 explored the participants' beliefs about ways of managing ADHD symptoms for their children. The study found that the participants' opted-for methods of interventions for their children were consistent with their perceptions presented in Chapter 5. The interventions the participants were actively engaged in at the time of data collection, as shown in Table 1 in Chapter 4, with the number of participants under each option, were as follows: medication (14), academic intervention (7), physical activity (6), dietary monitoring (4), speech therapy (4), parent psychoeducation and support on behavior management (4), occupational therapy (3), play therapy (3), herbal intervention (2), music therapy (2), divine intervention (2), and cultural ritual (1). The study found that 19 out of 21 participants believed in utilizing more than one of the abovementioned approaches to ADHD symptom management. Twelve of the participants believed in multi-approaches that integrated pharmaceutical treatments, while seven believed in non-medicinal multi-approaches. Two participants from the study relied on a single approach to manage their children's ADHD symptoms.

***Professionals' Recommendations.*** The participants mentioned various influences that motivated their ADHD intervention choices for their children with the disorder. According to

the participants, the professionals who diagnosed their children with ADHD recommended specific interventions for them. The intervention recommendations for the participants included one or more of the following: medication, speech therapy, occupational therapy, play therapy, psychoeducation, and academic interventions. The findings revealed that 15 out of 21 participants followed the recommended interventions initially. However, some of the participants reported that they felt obligated to follow the recommendations from the professionals because they were not presented with any other intervention options. Those participants felt as though the professionals imposed the interventions on them, as evidenced by phrases such as, “I did not choose, but what the doctor chose” (P20), “that was the only option” (P10), “we did not have much of an influence” (P12), “it was a forced decision...the decision for me to put him on treatment was a threat, so to speak...the teacher told me if there was no intervention, he [son] will have to repeat a class” (P6), and, “they never gave us any other options. We were not given that platform to choose” (P18). These findings suggest that these particular participants may not have been accorded the opportunity to be involved in the decision-making process regarding their children’s ADHD interventions.

Five participants from the study reported that their lack of knowledge and understanding about ADHD and its treatment options at the time of their children’s diagnoses prevented them from exploring alternative interventions beyond those recommended by healthcare professionals. One participant, P8, emphasized the impact of that limited awareness on their decision-making process, saying, “Maybe let me say because of lack of knowledge...coz some of the interventions, you know them when you are already in.” As a result, they settled on the professionals’ intervention recommendations.

***Trusting the Professionals.*** The study found that two participants indicated that they were motivated to follow the intervention suggestions of professionals because they trusted the judgment of the professionals. One participant, P11, conveyed that trust by stating that

healthcare professionals “know better,” while participant P12 said, “We were just being guided by the professionals...whom we say knew better than us.” It can be inferred that these participants felt obliged to pursue the recommended intervention options because they considered the professionals to be experts whose opinions were to be trusted without question.

***Perceptions of the Nature of ADHD Influence on Intervention Preference.***

Participant P14, a registered nurse, expressed a preference for medical interventions regarding her child’s ADHD. She expressed that “as a medical person,” she viewed ADHD as a “medical disorder.” Consequently, her medical profession and familiarity with medical interventions influenced her preference for ADHD treatments for her child. On the other hand, participant P19, who attributed the ADHD etiology for his child to “diets...poor eating habits...sugars,” preferred dietary modification interventions as a method of managing his child’s ADHD.

***Religious Beliefs’ Influence on Intervention Preference*** Although the healthcare professionals had recommended specific ADHD treatments for the participants’ children, six participants did not follow through with the prescribed interventions. Two participants cited religious beliefs as the reason for rejecting the recommendations. Reporting on the influence of religion on her intervention preference, participant P3 said, “When it comes to the intervention I’ve chosen, I am Christian ...so according to my religion...” She explained that her Christian faith encouraged using “natural herbal” and “dietary” interventions for health concerns.

***Exercising Decision-making Autonomy.*** The participants who did not adopt the professionals’ recommended interventions emphasized the importance of parental involvement in choosing the best interventions for their children. Participant P1 said, “as a parent, you don’t take everything they [professionals] say at times,” implying that it is

important for parents and caregivers as gatekeepers of their children's health to participate in decision-making concerning the children's well-being actively and not unthinkingly follow recommendations.

Eight participants' ADHD intervention preferences for their children were later based on "trial and error," whereby after seeking more information on the disorder, participants explored many ADHD symptom management strategies. When the strategies were found to be ineffective or to cause adverse side effects, they were discarded for other options that the participants experienced as effective and more favorable to their children. As shown in Table 1, previous interventions some participants had explored for their children were diets and supplements (P5, P6, & P8), interventions from religious prophets (P8), and cultural rituals (P5 & P9). It is clear that when empowered through increased knowledge of ADHD, Black parents and caregivers are willing to independently employ that knowledge to explore the perceived effective ADHD symptom management methods for their children.

### ***Perceptions about ADHD Medications***

All the participants highlighted that healthcare professionals had recommended pharmaceutical treatments as part of symptom management care plans for their children with ADHD. However, as shown in Table 1, only 14 out of 21 participants were administering ADHD medications to their children at the time of the study. The other participants had misgivings about the use of ADHD medications. Those who pursued medicines for their children reported satisfaction with their effectiveness, as substantiated by their comments, "as she is taking the medication, she is very calm" (P7), "I don't know how to manage without medication... I don't think I will take them off Ritalin" (P6), "it is working for me" (P13), and "medication is the best" (P8).

On the other hand, the participants who had misgivings about medical treatments for their children's ADHD expressed concerns regarding the perceived and experienced side

effects of the medications. They believed ADHD medications could alter the child's personality, cause severe mood fluctuations, affect appetite and sleeping patterns, and possibly cause chemical dependence that could lead to addiction. In addition, one of the participants believed ADHD medication use left the children vulnerable to social stigma. Also, another participant perceived that ADHD medications are pushed onto children as a money-making scheme for pharmaceutical companies.

Expressing his misgivings about ADHD medications for his diagnosed son, participant P2, who rejected the diagnosis despite his spouse allegedly being pro-ADHD medicinal treatments, shared his beliefs and concerns that the ADHD medications robbed the children of their personalities and that allowing such was unfair on the children. The participant was also apprehensive about the alleged dependence on the medication that could lead to "addiction." Participant P2 described another child whom he transported to school together with his son every morning and whom he suspected to be on ADHD medication as the basis for his misgivings, saying:

There was a young boy that I was fetching in the morning and giving him lifts to school... I would like to think the boy is on medication because the boy the moment he gets into the vehicle, he sleeps until we get to the destination. To me, that proves to me that he is on medicine. I feel he's now behaving like a zombie, and he's being controlled by the medication. I wouldn't like my son to behave as such. I would like my son to express himself freely without being controlled by any medicines because I feel like I've robbed him his views, I've robbed him his expression. I feel it's unfair to control one not to express himself and experience his youth.

Participant P2 held a strong belief against pharmaceutical interventions for ADHD. Based on his narrative, it is apparent that he would have likely declined pharmaceutical interventions

and instead chosen non-pharmaceutical alternatives had he accepted his child's ADHD diagnosis.

Sharing the above similar fears of ADHD medications interfering with children's personalities, the other participants said, "but giving him medication...turns him into a zombie...he becomes a strange person. Without medication, he's able to express himself better" (P12), "The whole system [brain] gets re-wired in a very different way...I'm not gonna put my child through this torture. As much as it's good for her to have the best medication, I should not include making her a zombie...a stooge" (P16), and "the moods, temper, the crying become excessive, and he was not eating" (P4).

Moreover, apprehensions surrounding the potential labeling of a child who takes ADHD medication were raised by participant P2, who expressed concern that the child may be viewed as "having something wrong with them, leading to a loss of self-esteem among their peers." On the other hand, participant P16 voiced skepticism about pharmaceutical companies, suggesting that they may be promoting ADHD medication use for financial gain when he said, "The pharmaceuticals are gonna make money from our kids with ADHD because that is where the money is." As a result, these concerns raised by the participants further contributed to their dismissal of ADHD medical interventions for their children.

Considering the above concerns expressed by the participants about pharmaceutical interventions for ADHD, four participants (P2, P3, P16, and P19) decided to abstain from using medication as a means of managing their children's ADHD-related behaviors. On the other hand, the remaining three participants (P1, P4, and P12) had initially commenced ADHD medication treatments but opted to discontinue use due to the adverse side effects experienced by their children.

It is worth noting that concerning their gender group sizes, four out of the five male participants and three out of 16 female participants expressed concerns about administering

ADHD medication to their children. These observations could tentatively imply that Black male parents and caregivers in South Africa could be more inclined to decline or discontinue pharmaceutical ADHD treatments for their children compared to their female counterparts. However, as this study is not a quantitative design and the sample is very small, this generalized conclusion cannot be drawn.

Overall, on perceptions about ADHD medications, the findings suggest that the participants who had reservations about the medicinal interventions for their children with ADHD regarded the risks of side effects caused by ADHD pharmaceutical interventions to outweigh the benefits. Thus, they protected their children from those side effects by not subjecting them to ADHD medications. However, two-thirds of the participants were receptive to incorporating medicinal treatments as part of ADHD symptom management for their children.

### ***Hindrances to Intervention Pursuits***

The study uncovered the following obstacles that hindered participants from effectively implementing some recommended ADHD interventions for their children: a ‘lack of awareness and knowledge,’ ‘parental perceptions toward ADHD and its intervention,’ and ‘limited resources.’ The hindrances resulted in some children being unable to access certain or all of the recommended interventions, delaying intervention commencement and causing non-compliance and discontinuation.

***Lack of awareness and limited knowledge.*** The lack of awareness and limited knowledge about ADHD proved to be a considerable hindrance for the participants to access interventions for their children timeously. That lack of and limited exposure to ADHD initially caused diagnosis denial for many participants, as seen in Chapter 5. This led to delays in commencing ADHD interventions for the children as the participants were still processing the diagnosis. Encapsulating the narrative that represented the participants’

diagnosis denial experience that led to the delays, P20 said, “We were not ready to accept, and that delayed us or me getting help for my son.” However, for participant P2, the diagnosis denial, as expressed, “I don’t believe my son is sick,” led to the complete shunning of all interventions recommended by professionals. The analysis of the participants’ narratives implicitly signaled that due to their lack of awareness and understanding of ADHD symptomatology, the participants had struggled to accept that the ADHD behaviors exhibited by their children warranted a diagnosis and intervention. Thus, some children could not receive the prescribed interventions immediately upon diagnosis.

Additionally, limited awareness of alternative ADHD intervention options caused many participants to delay exploring different ADHD management strategies, as highlighted by participant P14, who expressed that “a lot of people don’t really know” alternative ADHD interventions except those recommended by professionals. Confirming this observation, participant P4 said, “People don’t even know what a remedial school is...When I chose the homeschooling, which was another world I didn’t know about...” This suggests that some Black parents and caregivers of children with ADHD may not access some ADHD interventions for their children that could suit their needs due to a lack of adequate information.

***Parental perceptions toward ADHD and its intervention.*** Earlier in this chapter, it was highlighted that seven participants expressed concerns about using medication to manage their children’s ADHD. As a result, four of those participants decided not to commence medicinal ADHD treatments for their children. The other three, P1, P4, and P12, had initially started the medication treatments for their children but discontinued them due to the side effects. However, participants P4 and P12 reported that they were open to reconsidering medication use, if necessary, with P4 saying, “it is better to take him off medication, and obviously when the real stuff [severe symptoms] starts coming out, then he’s gonna have to

go back on medication” and P12 saying, “I have stopped giving him medication, I only give him when he has serious tasks like exams.” It is important to note that parental hesitations towards a specific ADHD intervention method, in this instance, medication, can lead to intervention rejection or lack of adherence, preventing children from receiving the full benefits of the prescribed treatment modality.

The study findings based on three participants’ accounts indicated that disagreements between married couples regarding the perception and management of ADHD-related behavior in their child could prevent or delay the child from receiving necessary interventions. Participants P9 and P20, both mothers, reported that they delayed introducing ADHD medication to their children due to their spouses’ differing views on their children’s symptoms. Participant P9 shared that her spouse initially did not believe in the ADHD diagnosis, attributing the child’s behavior to a cultural cleansing ritual that required to be performed due to a miscarriage participant P9 experienced before the birth of their child with ADHD. As a result, the spouse “had to buy sheep and slaughter...doing so many rituals,” although the child’s concerning behaviors did not improve, leading the spouse to “slowly understand that it’s [ADHD] a medical thing and not a cultural thing.” Thus, the time taken during the process of perception shift for the spouse delayed the initiation of the prescribed intervention for the child.

Similarly, participant P20 shared that her spouse was against their child receiving ADHD medications and play therapy, as he did not perceive the child’s behavior as a cause for concern. Participant P20 reported that her spouse “did not want to hear of it [diagnosis and interventions].” Fear of being blamed if the child were to experience medication side effects led participant P20 to delay intervention for the child for “four years.” She said, “I was worried that if he [child] gets side effects from Ritalin, my husband would say it was my fault because I refused to listen to him.”

Although participant P2 alleged that his spouse was receptive to the ADHD diagnosis and the recommended interventions for their child, he dismissed the diagnosis as incorrect and refused the suggested interventions by professionals. He shared that had it been “her [spouse’s] decision alone, she would have put the boy on medications” long ago. The narration of participant P2 and the accounts of participants P9 and P20 reveal that when spouses differ in ADHD diagnosis perception, children in need of interventions are negatively affected when they do not receive interventions that could potentially improve their quality of life. Furthermore, the participants’ accounts suggest that some men seemingly have more influence in health decision-making for their children in some Black families. This is indicative that patriarchal hierarchies still prevalent in African societies impact the well-being of children.

**Limited resources.** According to the study, six participants reported encountering difficulties in obtaining ADHD interventions for their children due to inadequate and inefficient service providers caused by limited resources. Highlighting this plight, participants narrated that they encountered tremendous delays from the government service providers when their children were placed on lengthy waiting lists. Recounting the experience, participant P17 stated, “We went to Baragwaneth [hospital]...they said they will phone after three years because the queue is long.” The service providers were inundated with a backlog of service users, hindering timely service provision.

Furthermore, four of the participants described struggling to place their children in remedial or special needs schools as part of ADHD academic intervention strategies, saying, “remedial school is a process, the applications take time” (P8) and “for LSEN school...the District Office sent me from pillar to post” (P17). Also describing the frustration caused by the delay in placing the child at a special needs school, participant P5 said:

These special needs type of school, they don't respond. But if you follow up, there is nothing you can do. You can send ten emails a day, they don't respond. You wait how long for the Department of Education to respond to you in terms of school placement? And they don't respond...At some point you like okay, let me give up.

Additionally, participant P5 lamented about the lack of special needs schools in Black townships, saying:

Around Eastrand, Katlehong it's difficult to get her school...but around town, whether you go to the north or the east, there are many of these type of these special needs schools or special ADHD schools with proper psychologists at school, or whatever the case may be.

P11 shared a similar concern about the lack of resources available to provide interventions for children diagnosed with ADHD in townships when her child was referred for play therapy, saying, "And another disadvantage thing is that at my location, we do not have all those things. So it was going to be difficult for me to monitor my child." Participant P11's account underscored the lack of facilities due to limited resources as a barrier that Black parents and caregivers in townships face in seeking ADHD intervention for their children.

One participant experienced a lack of resources in the form of a shortage of Black professionals who would be a language and cultural fit to provide play therapy services for his niece. During the interview, participant P5 reported that he was waiting for a suitable African language-speaking psychologist to provide play therapy for his niece, saying:

I couldn't find the psychologist that speaks Zulu or African language around Joburg CBD. I think they called me after almost one year and a half to say you can come there's someone who is interested in doing this play therapy. But even then, they are not of African descent...because the problem is the language barrier. We would take her to a psychologist and so forth, but that language barrier, especially for play

therapy...Even the doctors who specialize in this, I went to Kempton Park, they are not African. Even the current doctor at Milpark Hospital, the psychiatrist...so it's difficult. Someone who is Black and will understand when I say we even went to do a cultural thing; they will understand where I am coming from.

From the excerpt, it can be seen that a language barrier can impede timely intervention commencement for a Black child with challenges expressing and communicating in English if there are limited professionals to meet the child's needs. Furthermore, participant P5 wished for a professional who would understand them from a cultural perspective and would not judge their decisions.

A lack of financial resources was another reason participants encountered as a hindrance to children receiving some of the recommended ADHD interventions. Participants shared narratives such as, "we only on medication now, we no longer do the therapy [family psychoeducation] sessions coz I don't have a medical aid" (P7), "The other struggle was money, those were going fine [behavior therapy], but I could only do three sessions...financial-wise, monetary-wise, I couldn't be able to afford... I ended up leaving that. I was unable to pursue it, continue it further" (P3), and "the doctor said I can take her for play therapy but...I need transportation, it's gonna cost me a lot to take my child for therapy" (P11). The above parents had to forego some interventions for their children due to the inability to afford the financial burden of the interventions. The narratives revealed the negative impact a lack of financial resources can have on a parent's or caregiver's ability to seek recommended interventions for their child.

Based on the study findings, 10 participants who could afford medical aid schemes also felt the financial strain and demand of pursuing ADHD interventions for their children. The participants were worried that their medical aid funds were getting depleted very quickly each year because the medical aid schemes did not consider ADHD medicinal treatments

under comprehensive chronic treatment coverage. Participant P8 expressed the participants' shared concern, saying:

They are saying that it is not chronic but my kids I'm telling you now, they inherited it from their grandmother, it means it's chronic. But then it does not fall under the prescribed premium benefits. From June onwards, you will be paying from out of your pocket. My daughter she's using Neucon. I think it's around 800 [Rands] something. The brother there is using Adderall and Risperdal. It's a lot that I'm paying a month with the money that we don't have...

Also emphasizing the impact of ADHD medication on financial resources, participant P12 said:

You worry about the cost of treatment. You would think how much it will be costing for you to go to a psychologist because some of these... most of these healthcare professionals they require cash and then the medical aids do not take this condition like something that they can pay for. All those things, I mean, the cost of seeing a pediatrician for your child can amount to thousands of Rands for just one session. Money is tight, you know.

Therefore, the children were likely at risk of treatment defaulting if the participants failed to afford the out-of-pocket payments.

Overall, the study findings gave insights that suggest that most Black parents and caregivers in South Africa are likely to exhibit a willingness to pursue interventions for their diagnosed children with ADHD despite the challenges they may encounter. That willingness is activated when parents or caregivers recognize and acknowledge that their children are experiencing difficulties that negatively impact their daily functioning.

### **Discussion: Decision-Making on Intervention Pursuits**

Parents and caregivers play a crucial function in the healthcare of their children. They are gatekeepers of their children's well-being (Saade et al., 2023). Consequently, they are responsible for making decisions about their children's health, including seeking ADHD interventions, ensuring intervention adherence, and offering the necessary support required by their diagnosed children. Therefore, the decisions and choices parents and caregivers make regarding their child's ADHD diagnosis significantly impact the prognosis of the child.

### ***Reasons for Intervention Pursuits***

***Seeking the best for the child.*** All the participants in the present study, except for one, reported that realization and acceptance that their children had challenges affecting their development, especially after the diagnosis, motivated them to pursue ADHD interventions for their children. These findings correspond with a South African-based study that explored teachers' experiences in supporting learners diagnosed with ADHD, which found that parents and caregivers who did not acknowledge their children's ADHD-related challenges were less likely to seek interventions (Dwarika & Braude, 2020). It is worth mentioning, as outlined in Chapter 5, that most of the participants in the current study did not initially consider their children's ADHD-related behaviors to be impairing. Instead, they believed that their children would eventually outgrow the ADHD-related behaviors, as found by Kediemetse's (2017) study on Black parents in South Africa. Extant literature reveals that often when parents perceive their children's ADHD-related as typical, they reject the ADHD diagnoses and recommended interventions (Alvarado & Modesto-Lowe, 2017; Evans, 2019; Kediemetse, 2017). However, this present study highlights new insights in understanding the phenomenon of ADHD within the South African context. Despite most participants' initial belief that their children's behaviors were typical, all except one eventually acknowledged that the children had challenges and pursued interventions. Contrary to the findings of the above extant literature, the participants did not reject seeking interventions, as may have been expected.

It is imperative to mention at this juncture that the parental perception shift regarding children's behaviors mentioned above was a result of gaining awareness and more understanding of the phenomenon of ADHD and its impact. This suggests that most Black parents and caregivers in South Africa are willing to be flexible in their beliefs regarding their children's behaviors and development if it is in the best interest of the child. Therefore, it can be said that awareness and understanding play an influential role in making parents and caregivers acknowledge their children's ADHD challenges, leading to intervention pursuits that support children's development.

***To End Perceived Social Stigma.*** A narrative review exploring various barriers faced by children with ADHD in Africa found that many African people misunderstand ADHD symptoms as misbehavior, intentional disobedience, or lack of discipline, leading to stigma toward the diagnosed children and their families (Olatunji et al., 2023). This narrative review highlights that due to the stigma associated with ADHD symptoms, Black families often reject the actuality of ADHD with the anticipation that it will disappear (Green, 2023; Olatunji et al., 2023; Wheeler et al., 2024). Consequently, the parents and caregivers may often avoid seeking interventions for their children for fear of being judged. However, this current study differed from the findings mentioned above. It showed that the perceived stigma did not deter some participants from seeking help for their children. Instead, the perceived stigma motivated the participants to pursue interventions for their children to minimize the negative behaviors that attracted the stigma. This finding from the current study sheds new light on the understanding of ADHD within the Black community in South Africa. Rather than hinder parents and caregivers from seeking help for their children, the perceived stigma is transformed into a positive action toward intervention pursuit.

Bronfenbrenner's bioecological systems theory (1977) claims that the influence of the microsystem impacts the child's development. Therefore, the decisions of the parents and

caregivers in the current study, operating within the microsystem level, to transform perceived stigma into a motivator for intervention pursuits opened an opportunity for their children with ADHD to benefit from interventions that could improve their quality of life.

### ***Motivations for Chosen Interventions***

As a recap, according to the findings of the current study based on Chapter 5 on the participant's ADHD management beliefs, almost all the participants (19 out of 21) reported utilizing more than one approach in the management of their children's ADHD, with some incorporating pharmaceutical treatments. The non-pharmaceutical interventions used by the participants varied from academic support and interventions, behavior modification at home and school, parental psychoeducation, a range of therapies (speech, occupational, play, and music therapies), dietary and herbal interventions, and physical exercise to divine and cultural interventions. The findings align with international guidelines advocating for multimodal approaches to treating ADHD (Drechsler et al., 2020). Multi-modal ADHD intervention approaches incorporate multiple intervention strategies, pharmaceutical and non-pharmaceutical, used in conjunction to manage ADHD.

***Professionals' Recommendations.*** The results of the current study indicated that all participants received prescribed intervention recommendations for children with ADHD from professionals upon diagnosis. According to Zysset et al. (2023), professionals should proactively educate parents and caregivers about various ADHD intervention options available before starting any treatment. This helps both parties to make an informed decision and choose the best intervention option that suits the child through collaborative decision-making. However, the current study suggests this was not the case with some participants.

Although 15 out of 21 participants in the current study followed through with the prescribed ADHD intervention recommendations for their children, some experienced a lack of comprehensive engagement regarding intervention choices highlighted above as an

indication that the interventions were imposed upon them. The participants perceived that the professionals excluded them from the intervention decision-making process. This finding from the present study is supported by NICE's (2018) study, which explored parents' and healthcare professionals' viewpoints regarding shared decision-making on ADHD. The study found that some parents perceived that ADHD interventions for their children were enforced on them. Therefore, the present study revealed that some healthcare professionals in South Africa do not always provide parents and caregivers with comprehensive information about ADHD intervention alternatives for shared decision-making. Instead, they may favor specific intervention options and may influence parents accordingly.

*Exercising decision-making autonomy.* It could be that due to feeling overlooked in the ADHD intervention choices for their children, as mentioned above, some parents and caregivers may not comply with management care plans set for them, as revealed by the participants in the current study who did not adhere to ADHD medications recommended for their children. Bronfenbrenner's bioecological systems theory (1977) claims that the interaction between parents and healthcare professionals at the exosystemic level impacts the child's development. Therefore, it is crucial that professionals provide parents with comprehensive information about ADHD and its treatment and also involve them in decision-making to encourage teamwork in the intervention compliance for the child.

It can be implicitly deduced through double hermeneutics "whereby the researcher is trying to make sense of the participant trying to make sense of what is happening to them" (Smith, 2011, p.10), that eight participants in the present study likely embarked on an experimental trial-and-error method in their search for alternative interventions for their children's ADHD to assert their decision-making autonomy. If these participants had received comprehensive information from healthcare professionals, they could have

collaborated with them and worked as a team to pursue their preferred interventions for their children without the added frustration of a trial-and-error process.

***Trusting the professionals.*** The present study revealed that some participants preferred to pursue interventions recommended by healthcare professionals for their children with ADHD because they trusted the professionals' judgment as they perceived them as experts and authoritative in their professional fields. This finding from the present study confirmed Dillion's (2011) claim that some parents and caregivers passively follow healthcare professionals' guidance because they perceive them to be authorities in their professions. While affirming Dillion's (2011) claim above, the present study differed in terms of the class of people who held this view. According to Dillion (2011), parents and caregivers who passively trusted and accepted the healthcare professionals' recommendations had lower educational levels than their counterparts.

In contrast, the two participants in the present study who identified with the claim came from the opposite end of educational background. One participant had an exit-level high school certificate, while the other held a master's degree certificate. Although the idiosyncratic experiences of the two participants may not be generalized to the broader community conclusively, their lived experiences suggest that some Black parents and caregivers trust healthcare professionals' expertise in recommending ADHD interventions for their children without inquiring about alternatives despite their educational levels. This finding may not be surprising, given the limited ADHD awareness and knowledge across educational levels among Black parents and caregivers in South Africa, as uncovered by the present study. Therefore, parents and caregivers seeking help for their children rely on the professionals to make the intervention decisions.

***Perception of nature of ADHD Influence on Intervention Preference.*** Parents' and caregivers' perceptions of the nature of mental health, including ADHD, play a role in their

pursuit of preferred interventions (Choudhry et al., 2016). The present study affirms the above claim, as evidenced by participants who aligned their intervention preferences for their children based on their understanding of ADHD etiology and nature. For instance, a registered nurse participant who viewed ADHD as a medical condition preferred medication as a management strategy. Conversely, a participant who linked the disorder's etiology to diet favored dietary interventions for their child. Therefore, these findings suggest that parents and caregivers of children with ADHD are likely to prefer interventions that are congruent with their understanding of the disorder, which can enhance intervention adherence and promote the well-being of children with ADHD.

***Religious Beliefs' Influence on Intervention Preference.*** Asare and Danquah (2017) argue that religion plays a crucial role in the lives of Africans, shaping their perspectives and decision-making processes. Furthermore, religion may also influence some individuals' attitudes toward mental health problems and the treatments they prefer. This is corroborated by two participants in the present study who declined pharmaceutical interventions for their children, as their Christian beliefs advocate the use of natural remedies and dietary interventions for health issues. Furthermore, the current study findings align with Rathod et al.'s (2017) study, which revealed that 40% of Indians rejected cognitive interventions for mental illness due to their cultural and religious beliefs.

The findings above can be understood from Bronfenbrenner's (1977) perspective that religion, located at the macro system level, plays a crucial role in shaping people's decision-making processes. As a result, some Black parents and caregivers align their preferences for ADHD interventions for their children with their religious beliefs rather than professional recommendations. This unveils a likelihood that some Black children in South Africa may not receive the full benefits of healthcare professionally prescribed ADHD interventions due to their parents' and caregivers' religious beliefs.

### ***Perceptions about ADHD Medications***

According to the findings of this present study, all participants received recommendations for medication as part of their children's ADHD intervention care plan upon diagnosis. These participants' experiences are consistent with the observations made by Danielson et al. (2018) that medications are often the first choice for treating ADHD. Healthcare professionals may recommend medication as a part of the initial ADHD management plan based on evidence that pharmacological interventions are highly effective in addressing the disorder (Lu et al., 2017; Sadock et al., 2015). However, some parents and caregivers may not be receptive to the idea of using medication for their child's treatment. The study showed that while 14 out of 21 participants embraced medication for their children and reported positive outcomes, seven out of 21 were not using the pharmaceutical treatment modalities at the time of the interviews.

According to Lu et al. (2017) and Danielson et al. (2018), many parents of children diagnosed with ADHD are hesitant to adopt medicinal treatments. However, the findings of this present study contradict this notion. The number of participants who were open to ADHD medications for their children compared to the participants who were reluctant to use medications was higher. This finding may imply that although many Black parents and caregivers may not initially consider the ADHD symptoms in their children as a cause for worry, upon perception shift through gaining awareness and knowledge about ADHD, many may be willing to pursue medicinal treatments to help manage their children's challenging behaviors.

In the present study, four participants who did not initiate ADHD medication administration to their children and three who did but later discontinued expressed concerns about the side effects of ADHD medications outweighing the benefits. Specifically, worries about medication altering their children's personalities (*zombifying*), disrupting sleep

patterns, causing mood swings, and suppressing appetite were among the cited concerns. Additionally, fears of perceived stigma and the perceived addictive nature of ADHD medication were expressed. These findings agree with existing literature on the caregiver and parental apprehensions toward ADHD medication (Gajria et al., 2014; Rashid et al., 2018; Ross et al., 2018; Taylor & Antshel, 2021). Therefore, the findings of the current study suggest that some Black parents and caregivers are cautious regarding interventions they perceive to do more harm than good. They would instead protect their children from the perceived harm associated with recommended ADHD interventions rather than adhere to the healthcare professionals' guidelines.

It should be noted that the side effects of ADHD medications can be effectively managed if monitored properly (Sadock et al., 2015). However, due to the perceived lack of shared decision-making between parents/caregivers and healthcare professionals brought to light by the present study, opportunities to try different medications at adjusted dosages to obtain the most medication are missed. This results in many children missing out on the benefits of ADHD medications.

### ***Hindrances to Intervention Pursuits***

It is vital to acknowledge that children with ADHD may often encounter obstacles in accessing interventions that could improve their quality of life. These hindrances could stem from parental and caregivers' lack of awareness and limited knowledge about ADHD and its interventions, parental and caregivers' attitudes and perceptions towards ADHD or its treatments, as well as a lack of or limited resources for accessing ADHD interventions, as evidenced by the present study.

***Lack of awareness and limited knowledge.*** As highlighted in Chapter 5, there is a limited understanding of ADHD among Black parents and caregivers in South Africa (Rajucumar & Paruk, 2020). Due to limited exposure and understanding of ADHD, most

participants interpreted symptoms of the disorder in children as normal childhood behaviors. Consequently, upon the ADHD diagnosis, the participants underwent a denial phase compounded by feelings of shock, anger, guilt, and sadness that delayed the commencement of interventions for the children. The participants' reactions to their children's diagnosis were similar to grief responses, which Godress et al. (2005) explained to be shared among parents and caregivers of children with ADHD upon diagnosis. Within the South African context, Dwarika & Braude (2020), whose study examined the teachers' experiences of supporting children with ADHD in 11 South African provinces, found that parents and caregivers of children exhibiting ADHD symptoms can be in denial for a prolonged time of over three years. This was similar to the findings of this current study, wherein one participant accepted the diagnosis after four years when she gained ADHD knowledge through her new career as an occupational therapist. One participant was still in denial and rejected the recommended interventions five years after the diagnosis at the time of the interviews.

The passage of time when parents and caregivers go through the grief response and denial phase as they process the diagnosis, leading to acceptance, can be perceived from the chronosystem level of Bronfenbrenner's bioecological system theory. According to Eriksson et al. (2018), the chronosystem refers to the dimension of time, focusing on the influences of changes over time that impact a child's development through their interactions with the environment. The parents' and caregivers' psychological adjustment and transition from denial and grief responses to acceptance of their children's developmental challenges and diagnoses happen over time (Mitchell & Holdt, 2014), as evidenced in the present study. In the interim, children's struggles with ADHD symptoms without interventions are prolonged as the gatekeepers of their health often may not pursue intervention during this psychological transitioning phase.

Therefore, this present study brings fresh insight into utilizing Bronfenbrenner's bioecological systems theory at the chronosystem level to understand hindrances to ADHD intervention pursuits that may emanate from intervention delays while the parents are in the psychological adjustment or transition period.

***Parental Perceptions toward ADHD and its Interventions.*** Differing perceptions in families about ADHD symptoms in children and its treatments contribute to obstacles that hinder some children from receiving interventions for the disorder, especially medical interventions. Two participants from the current study reported that disagreements with their spouses regarding the cause and management of ADHD-type behaviors displayed by their children led to considerable delay in initiating recommended medicinal interventions, while another participant ultimately rejected them. These findings are congruent with extant literature that highlights that parents of children with ADHD often disagree on how to deal with their child (Laugesen et al., 2016; Leitch et al., 2019; Mofekeng & van Wath, 2017; Spindler et al., 2017) leading to delays or ultimate rejection of recommended interventions. According to Mulisa (2019), marital disagreements between parents, who are elements of the microsystem in the bioecological system theory, are often a barrier to intervention for children with ADHD. Such impediments have a detrimental impact on the general functioning of the child.

It is imperative to highlight that of the three participants who experienced spousal disagreements about their children's ADHD, two of them were females who were willing to pursue the professionals' recommended intervention care plans for their children, yet their husbands were not ready to embrace the recommendations. On the other hand, the one participant who rejected the interventions for their child was a male whose wife, who did not participate in the study, was allegedly receptive to the diagnosis and the initiation of prescribed interventions. Based on the observation, it could be tentatively argued that Black

fathers in South Africa are possibly more likely to struggle with initiating medications for their children compared to Black mothers, given that other male participants in the present study, except for one, also had misgivings about ADHD for their children. However, further research is required to arrive at a conclusive position regarding this tentative argument.

**Limited Resources.** Economic challenges present a considerable hindrance in managing ADHD in children. Many people in Black communities in Africa are struggling to meet basic needs due to unemployment, poverty, and minimal living income (Chhibber et al., 2021). On the other hand, ADHD management strategies typically entail various therapies, pharmaceutical treatments, and specialized academic interventions that can be costly and financially demanding (Olatunji et al., 2023). The present study revealed that some participants discontinued pursuing recommended interventions, such as behavior therapy and family psychoeducation, because they could no longer afford the financial burden of the interventions. These findings from the present study support the assertions of Pearson (2015) and Zhao et al. (2019), who indicate that financial challenges may prevent economically deprived populations from accessing healthcare services.

Furthermore, the present study confirms other South African-based studies (Guler et al., 2018; Mazibuko et al., 2020; Mitchell & Holdt, 2014; Wetherston et al., 2017), which highlighted the financial burden that comes with the high costs of managing a child with developmental disorders. This results in intervention non-compliance due to the discontinuation of unaffordable interventions. The situation can be further exacerbated if traveling costs are required to access interventions, as unaffordable transport costs for some people may pose an added hindrance.

Ten (10) participants in the current study had access to medical aid scheme coverage. However, it is worth noting that the cost of ADHD management also poses a hindrance risk to ADHD intervention pursuits for parents and caregivers with medical aids. It may be argued

that the cost of managing ADHD may not negatively impact individuals who can afford medical aid schemes; however, the findings of the present study dispute that assumption. The findings indicated that Black parents and caregivers on medical aid were concerned by the potential risk of being unable to afford ADHD interventions because most medical aid scheme funding did not offer comprehensive ADHD coverage. This is because ADHD is often perceived as a treatable condition when it is a chronic disorder requiring long-term management.

Given that ADHD is a chronic disorder requiring diagnosed children to be on ongoing interventions, participants who are members of medical aid schemes reported that they were obliged to pay out of their pockets for interventions early in the year due to the allocated medical aid scheme funds being exhausted. The participants' narratives corroborate Botha and Schoeman's (2023) study, exploring 72 South African registered medical aid schemes' funding for ADHD, which found that the condition is underfunded in South Africa. The same study's statistics revealed that 41.17% of patients had to pay out of their pocket for ADHD medications and 62.20% for ADHD supportive and alternative therapies, despite having a medical aid scheme cover. The findings of the current study highlight a high risk of ADHD intervention defaulting should the individuals fail to afford the out-of-pocket costs for ADHD interventions required by medical aid schemes. Thus, despite the medical aid schemes, it is not guaranteed that all children with ADHD covered by the schemes will always be compliant with their interventions, given the pay-out-pocket financial burden some parents and caregivers may face. Therefore, the cost of ADHD management is a hindrance to individuals who cannot afford the cost, and it becomes a potential hindrance risk to medical aid scheme members who may fail to meet the pay out-of-pocket policy as stipulated by the medical aid schemes.

Another hindrance to effective ADHD management resulting from economic challenges affecting many Black communities in South Africa is limited access to unpaid or affordable mental health government services. According to Guler et al. (2018) and Wetherston et al. (2017), access to resources for neurodivergent and other mental health disorders in South Africa is limited and primarily privatized, leading to the scarcity of accessible and affordable services in public sectors. Consequently, the available government public sector service providers become overwhelmed and overburdened (Guler et al., 2018; Wetherston et al., 2017), as confirmed by the current study's findings, whereby some participants experienced considerable delays in accessing recommended interventions for their children. The delays were reportedly due to lengthy waiting lists in some healthcare sectors due to backlogs, ineffective service delivery, and delays at the educational offices for academic placements for children with special needs.

Furthermore, some participants in the present study experienced limited remedial and special needs schools that specialize in ADHD in Black communities and limited Black mental healthcare professionals who are a 'right' language fit for Black children who may struggle to communicate in English. Such narratives are consistent with assertions that economic challenges of a community result in a scarcity of resources (Paidipati, 2017) and limited availability of qualified mental health professionals (Olatunji et al., 2023), compromising the management of mental health challenges, including ADHD in children.

According to Bronfenbrenner (1977), the availability of resources and services, in terms of financial and geographic access, nested within the macrosystem of the bioecological structures indirectly influences the child's development. Applied to the present study, socioeconomic challenges led to limited resources, which played a significant role in limited and delayed access to interventions for children with ADHD. As revealed by the present

study, limited access to healthcare services due to limited resources beyond the participants' control resulted in poor ADHD management for children.

### **Summary**

Overall, despite the challenges Black parents and caregivers in South Africa may be facing regarding ADHD, the present study revealed a positive insight into their decision-making regarding an ADHD diagnosis for their children. It suggests that most Black parents and caregivers of children with ADHD are proactive in seeking solutions to support their children. Although some may disagree with the preferred interventions recommended by professionals, they are willing to explore alternative interventions they believe would benefit their children in managing ADHD symptoms. The next and final chapter will briefly overview the study's findings, strengths, limitations, and recommendations.

## CHAPTER 10: CONCLUSION

This chapter marks the conclusion of a study that focused on gaining insights into the perceptions of Black parents and caregivers about ADHD diagnosis for their children. The study explored how these perceptions impacted decision-making regarding intervention and preferences for the diagnosed children. To accomplish this, the Interpretative Phenomenological Analysis (IPA) approach was employed, allowing for a comprehensive exploration of the participants' lived experiences through generated extensive data. The findings of the study will be presented, revealing new insights gained. Additionally, the chapter will discuss the study's strengths and limitations, along with recommendations for practical application and future research.

### Summary of Findings

The overall findings of this study indicated an immense lack of ADHD awareness and knowledge about the disorder among the participants. Contrary to Dillion (2011), who states that lack of awareness and knowledge of ADHD is common among individuals from low socioeconomic backgrounds and educational levels, a different insight was gained from the study whereby a lack of awareness and knowledge was observed across all demographic backgrounds of the participants. Such lack of exposure to ADHD influenced most participants to perceive their children's ADHD-type behaviors from a cultural lens whereby such behavior may be tolerated as a developmental phase children would outgrow instead of viewing it through an ADHD symptomology lens. Due to this perception of children's ADHD-related behaviors, most participants experienced various adverse psychological responses to their children's ADHD diagnosis, including shock and denial.

At first, most parents perceived their children's behavior as typical, which caused some initial denial. However, all but two participants eventually acknowledged their

children's behavior as typical. The perception shifted through the realization and acknowledgment that the children had challenges. This finding highlighted a new insight into the knowledge of the participants regarding their children with ADHD. Previous literature (Alrahili et al., 2022; Dodangi et al., 2017; Fan et al., 2022; Kediemetse, 2017) states that when parents and caregivers perceive the child's behaviors as normal, they often reject the ADHD diagnosis. However, this study revealed that all participants, except for two, accepted the diagnosis, a new finding that differed from previous research. This underscores participants' cultural flexibility regarding their children's well-being on the interpretation of ADHD-related behaviors.

After the majority of the participants accepted the ADHD diagnosis, the study revealed their unreserved willingness to pursue interventions for their children with the disorder. The child's best interest was a considerable motivator for that decision. The extent of the participants' willingness to pursue ADHD interventions for their children was another noteworthy finding of this study.

The study revealed that participants had a varied understanding of the etiology and nature of ADHD. This understanding centered on heredity, diet, brain injury, substance abuse, chemical imbalance, neglect of culture, and the will of God as some of the causes of ADHD. Regarding the nature of the disorder, some participants perceived ADHD to be a chronic disorder. In contrast, others viewed it as treatable, including the medical aid schemes, highlighting a misconception of the nature of the disorder by some participants. Furthermore, some perceived ADHD as a mental disorder, others viewed it as a dietary condition, while others understood it to be a medical condition. Another participant regarded ADHD to be a social condition as it affected the diagnosed child's social functioning. For some participants, ADHD has a multiple nature; for example, it is both a social and dietary condition.

Participants differed in their belief in the management of ADHD, depending on their etiological understanding of the disorder.

The study findings showed that various influences shaped the participants' perceptions of an ADHD diagnosis for their child. Those influences were 'culture,' 'stigma,' 'awareness and knowledge,' and 'religious and spiritual beliefs.' Other influences identified were how the schools handled the child's concerning behaviors and the support participants received. A noteworthy finding was the role of the school in initiating a series of events that ultimately saw the children with ADHD-related behaviors receiving interventions that could improve their overall functioning. Those events began with the schools identifying atypical behaviors in children, communicating their concerns to their parents and caregivers, and making recommendations for assessments. Therefore, participants acknowledged the role of the school in precipitating events that resulted in their children obtaining help to manage challenging behaviors. However, some participants raised concerns that some mainstream schools lack supportive, conducive environments, willingness, and adequacy to accommodate children with ADHD, which exacerbated the symptoms of the disorder in children.

An ADHD diagnosis for their children had different implications for the participants. For most, it meant being judged as an incompetent parent raising an undisciplined child. This attracted stigma toward the parent and their child with the disorder. Interesting, fresh insights were drawn from this finding. Instead of stigma causing the shunning of ADHD interventions, some participants used it as a motivator to pursue the interventions to mitigate the perceived stigma. Other implications arising from the child's ADHD behavior experienced by the participants were the negatively impacted interpersonal relationships and social exclusion or isolation for both the parent and their child with ADHD. This study uncovered that in addition to the psychological negative impact of the disorder on the participants, one developed physical medical conditions as a result of the adverse

psychological effects of their child's ADHD behavior and lack of support from family members. This was a significant observation from this study that may require further exploration to ascertain its magnitude. However, on a positive note, an ADHD diagnosis for their children implied self-awareness, self-exoneration, and positive self-perceptions for some participants.

The study revealed an interesting discovery: most participants initially viewed their children's behavior as normal but ultimately embraced ADHD pharmaceutical interventions. However, some participants opted for alternative approaches. The majority of participants used a multi-faceted ADHD management approach. While participants faced obstacles such as delayed interventions, limited resources, financial strain, and perceived lack of collaboration from professionals, their proactive efforts in pursuing ADHD interventions for their children were noteworthy.

### **Strengths of the Study**

Several strengths of this study were identified:

- The study employed an Interpretative Phenomenological Analysis (IPA) approach, utilizing qualitative analysis to explore the participants' lived experiences. This approach enabled a thorough exploration of each individual's unique subjective experience. By providing a platform for the participants to express their subjective perspectives, the study not only valued but also acknowledged the importance of their voices in shaping the research.
- The study focused on the Black population, and demographic diversity, such as ethnicity, educational level, age, career, and socioeconomic status, was obtained within the target group. This diversity expanded the range of perspectives and experiences related to the phenomenon under study, ensuring a comprehensive exploration.

- It is important to mention that during the interviews with married participants, their spouses were not present. This meant that any potential influence from the spouse was eliminated, allowing the participants to express themselves freely when sharing their experiences.

### **Limitations of the Study**

The study had several limitations, as acknowledged below:

- Data collection for the study happened during the coronavirus pandemic, which saw both individual interviews (except for five) and focus groups conducted online and telephonically. Due to challenges with network connectivity with a few participants during the online interviews, there were some disruptions in the flow of the interviews. Nonetheless, the participants were patient, and the interviews were conducted successfully.
- Qualitative research findings are not meant to be generalizable by design. The scope of the study was limited to a sample pool of 21 Black parents and caregivers located in the Gauteng region of South Africa. Therefore, the findings of this study cannot be generalized to apply to the entire Black population in the country. However, the insights amassed from this study offer valuable insights to a diverse set of individuals, particularly healthcare professionals, educators, and policymakers.
- The study had a higher number of female participants compared to their male counterparts. Of the 21 participants, 16 were females, and 5 were males. This created a challenge in comparing perspectives between genders. However, the reason behind this difference is that in Black African communities, mothers are usually the primary caregivers for children. This explains the discrepancy in gender representation in the study.

- One of the participant selection criteria was the ability to communicate in English. However, this may have caused a sampling bias as it excluded Black parents and caregivers of children with ADHD who could not express themselves in English.
- According to Pietiewicz and Smith (2012), typically, IPA qualitative studies have small sample sizes ranging from one to 15 participants, while Turpin et al. (1997) recommend sample sizes of six to eight participants. This prevents the researcher from being overwhelmed by the data gathered, which could hinder in-depth, detailed analysis. On the other hand, Alase (2017) states that the sample size range could be 20-25 participants. This study had 21 participants, which generated overwhelming data. There could have been a likelihood of the research missing some engaging narratives as a single researcher who conducted all the interviews, data analysis, and coding. Nonetheless, the researcher endeavored to be as meticulous as possible in the data analysis and be cautious to remain within the parameters of the study's scope.

### **Recommendations for Practice**

The following recommendations for practice to the healthcare sector, education department, and relevant governmental policy-making entities are based on the in-depth interaction with the analyzed data:

- It is highly recommended that professionals take a collaborative approach with parents and caregivers during the decision-making process for interventions for children with ADHD. By working together as a team, parents and caregivers will have the autonomy to explore interventions that align with their religious and cultural beliefs. Additionally, this approach will allow both parties to consider alternative interventions that parents may be more comfortable with. When parents and caregivers perceive their opinions as valued and understood, they are more likely to adhere to and comply with the intervention plan.

- It is recommended that professionals offer increased support to family members who have a child with ADHD. This might include providing information to clear parents' confusion and concerns about the disorder and their child's future, resources to support groups or similar initiatives so parents and caregivers do not feel isolated, and effective academic interventions in schools.
- In African cultures, kinship is held in high regard, making it an integral part of the support system for families with children who have ADHD. To ensure the best possible outcomes for these children and their families, professionals must establish programs and initiatives that empower kin in managing the child's condition. This can lead to better outcomes for both the child and the family.
- The study highlighted a concern regarding the absence of empathy and sensitivity among some healthcare professionals and school staff. Professionals must show compassion and understanding when referring children for ADHD assessments, conveying the diagnosis, and implementing interventions. It is essential to bear in mind that parents and caregivers of children with ADHD may be experiencing a grief response to their children's condition and may require psychological support themselves.
- The study highlighted a significant lack of awareness and knowledge regarding ADHD among the participants. This indicates the need for solid efforts from the health and education departments, their respective sub-sectors, and policymakers to invest in ADHD awareness campaigns and strategies, with a particular focus on the Black population in South Africa to foster community awareness and acceptance regarding the disorder. These awareness campaigns should also address the stigma that appears to be widespread among the Black communities. It is commonly believed that being

more aware and knowledgeable about a topic can result in having a more positive attitude toward it.

- Traditional leaders, healers, and religious leaders are highly regarded in African communities, and their opinions carry significant weight. To combat the stigma and misconceptions surrounding ADHD, it is suggested that professionals and government officials engage with them and enlist their help as advocates for ADHD awareness campaigns. This approach could go a long way in dispelling negative beliefs about the disorder.
- Efforts to enhance ADHD knowledge among teachers and healthcare workers through rigorous training programs and ongoing professional development workshops are crucial. By staying current with the latest research and developments surrounding the disorder, these initiatives aim to equip and empower educators and healthcare providers to serve as valuable sources of information and support for parents and their children diagnosed with ADHD. The participants had raised concerns regarding the perceived lack of ADHD awareness and limited knowledge among some of the professionals.
- Policymakers at the Ministry of Health need to communicate information about the nature of ADHD, including that ADHD is a chronic disorder. This message should reach the public and all relevant sectors, including medical aid schemes. This is to ensure that the resources and funding allocated to managing the disorder are sufficient to provide ongoing support for children with ADHD.
- Given the high costs associated with ADHD treatments and limited resources within Black communities, it is recommended that the government partner with non-governmental, non-profit, and private organizations to establish subsidized or free ADHD management programs for both children and parents. This collaborative effort

would alleviate the strain on the public sector, often leading to service backlogs and subpar delivery. Additionally, the government should prioritize bringing mental health services closer to these communities, making it more convenient for families seeking assistance.

### **Recommendations for Future Research**

The findings of this study highlight the immense potential for future research and underscore the need for increased investment in research efforts to expand the body of ADHD knowledge within the Black population in the South African context.

- The study was carried out in urban communities. To gain a deeper insight into the perspectives of rural Black parents and caregivers in South Africa regarding an ADHD diagnosis for their children and how these perspectives may impact intervention-related decisions, it is suggested that the research be replicated in a rural setting. Doing so would facilitate a comparison between rural and urban Black parents and caregivers, expanding the existing body of knowledge on ADHD in the South African context.
- In light of the imbalanced gender distribution observed in the present study, it is suggested that future research endeavors expand and diversify their scope by emulating the study and concentrating on Black male parents and caregivers as the focal group. This approach will enable researchers to explore the phenomenon being studied from the perspective of Black males.
- This study highlighted the possible influence of parental personality on their perceptions of their children's ADHD diagnosis. However, the study did not extensively explore the effect of parent personality on their attitudes towards their child's ADHD diagnosis. Consequently, future studies should undertake a more

comprehensive investigation into this phenomenon to ascertain its magnitude and develop strategies to address it.

- The findings of the study highlighted marital tension and conflict due to differing opinions regarding the child's ADHD diagnosis and its management between some married couples. Some studies (Laugesen et al., 2016; Spindler et al., 2017) highlight that such conflict and tension could escalate to the collapse of marriages. Future research could explore the extent and impact of such conflict within the Black population in South Africa and how it could be mitigated.
- The findings of the study revealed the plight of the burden of care experienced by some parents and caregivers in Black communities due to a lack of support from immediate and extended family members. This results in affected individuals experiencing psychological and physical effects of the burden of care, which ultimately negatively impacts the child with ADHD requiring care. It is, therefore, recommended that potential future research explore the scope of the burden of care among Black parents and caregivers of children with ADHD within the South African context and explore possible solutions to address the challenge.

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## APPENDICES:

### Appendix A: Participant Information Sheet



PSYCHOLOGY  
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)



Dear Sir/Madam

Good day! My name is Beatrice Moyo and I am conducting a research study for the purpose of obtaining a Doctorate Degree in Psychology at the University of the Witwatersrand. I invite you to participate in my research titled “Black parents and caregivers’ perceptions and decision-making regarding an Attention Deficit Hyperactivity Disorder diagnosis: Implications for intervention pursuits.” Your participation will help me understand an area that has been under-researched in South Africa.

Participation in the study will involve you taking part in a semi-structured face-to-face individual interview of approximately 1 hour 15 minutes and a focus group interview of about 2 hours on a different day. The individual interview and the focus group will be scheduled at a place and time convenient to you. The South African Covid-19 pandemic safety regulations will be followed during the interviews. Participation in the study is strictly voluntary. Therefore, you have the right to withdraw from this study at any time. You also have the right not to answer any questions that you do not wish to, without any punishment. Taking part in the study will not advantage or disadvantage you or others in any way. Therefore, there are no expected risks to you or others, as well as no benefits to you or anyone else taking part in this study.

With your permission, the individual interview and the focus group interview will be audio recorded to facilitate collection of information. Your responses will only be accessed by my supervisor and I to ensure confidentiality of the information collected. After the study has been completed, the information you will share will be kept in password-protected computer and may be used for future analysis. Although I will have access to your name, I will ensure you will remain anonymous by not disclosing any of your personal information in my results or the final research report. During the individual interview, a name will be given to you, such as Participant 1, to protect your identity. However, kindly be aware that during the focus group interview all members will see each other. Therefore, confidentiality and full privacy during the group interview are not guaranteed. However, other than myself, I will request all the members of the focus group not to reveal their names or any other identifying information in an attempt to protect your identities. Furthermore, I will request all focus group members to keep the group discussion within the group in an effort to maintain confidentiality.

Kindly be aware that quotations from the individual interview and focus group interviews may be used in the research report but your name and other identifying information will not be mentioned anywhere in the report. With your permission, a follow-up interview and focus group interview may be requested for clarifying and validating collected information. The results of this study will be written up in the form of a research report. They may also be written up as a research article or presented at a conference. Your informed consent (permission) for this will be required. A summary of these results will be made available to you on request.

Before the interview can begin, I will ask you to read through and sign the attached consent forms to just confirm that you understand what is required of you and the confidentiality of the study. If by the end of the interview you feel the discussion has caused sensitive and emotional effects in you, then please make use of the free support and counselling that is available: Emthonjeni Community Psychology Clinic (Based at Wits University) – 011 717 6396 or Lifeline Johannesburg - 011 728 1347.

If you have any questions or concerns, please feel free to contact me on 0730038451 or contact me by email on [moyobeatie@gmail.com](mailto:moyobeatie@gmail.com). You may also contact my supervisor Dr. Mambwe Kasese-Hara on [Mambwe.Hara@wits.ac.za](mailto:Mambwe.Hara@wits.ac.za) / 011 717 4552.

Kind Regards,  
Beatrice Moyo.

## Appendix B: Informed Consent Form – Individual Interview



**PSYCHOLOGY**  
**THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)**



I, \_\_\_\_\_ (full name), agree to taking part in the face-to-face individual interview conducted by Beatrice Moyo for her research study entitled “Black parents and caregivers’ perceptions and decision-making regarding an Attention Deficit Hyperactivity Disorder diagnosis: Implications for intervention pursuits.”

As a participant in her study, I understand that:

- My participation is voluntary.
- There are no expected risks to me or others, as well as no benefits to me for taking part in the study.
- I may be requested to participate in a second interview on the same study.
- I am able to withdraw from the study at any time without punishment.
- I do not have to answer any questions I do not wish to.
- All my personal details and information will remain private and confidential, although I may be quoted in the final report.
- If however I am quoted, it will be under another name given to me during the interview.
- None of my personal information will be stated in the final research (I will remain anonymous).
- The information I share will be kept in a password-protected computer and may be used for future secondary analysis.
- This study will be approved by the Human Research Ethics Committee (HREC) at the University of the Witwatersrand. I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

Signed: \_\_\_\_\_

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

## Appendix C: Audio Recording Consent Form – Individual Interview



**PSYCHOLOGY**  
**THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)**



I, \_\_\_\_\_, agree to the audio recording of the face-to-face individual interview with Beatrice Moyo for her research study entitled “Black parents and caregivers’ perceptions and decision-making regarding an Attention Deficit Hyperactivity Disorder diagnosis: Implications for intervention pursuits”.

I understand and agree to the following:

- The tapes and transcripts (written records) from the individual interview will not be made available to anyone else except for the researcher’s supervisor.
- After the research study has been completed, the information I share will be kept in a password-protected computer and may be used for future secondary analysis.
- Although I may be quoted in the research report, it will be under another name given to me during the individual interview, thus my identity will be protected.

Signed: \_\_\_\_\_

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

## Appendix D: Informed Consent Form – Focus Group Interview



**PSYCHOLOGY**  
**THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)**



I, \_\_\_\_\_ (full name), agree to taking part in the focus group interview conducted by Beatrice Moyo for her study entitled “Black parents and caregivers’ perceptions and decision-making regarding an Attention Deficit Hyperactivity Disorder diagnosis: Implications for intervention pursuits”.

As a participant in her study, I understand that:

- My participation is voluntary.
- I am able to withdraw from the study at any time without punishment.
- I do not have to answer any questions I do not wish to.
- There are no expected risks to me or others, as well as no benefits to me for taking part in the study.
- I may be requested to participate in a second focus group interview on the same study.
- During the focus group interview, I will see and be seen by other group members.
- However, the researcher will try to protect my identity by asking other group members and I not to reveal our names or any other identifying information.
- To try to keep confidential (private) the information we will discuss in the focus group, the researcher will request all the focus group members not share it with another person who is not a member of the focus group.
- Although I may be quoted in the final report, all my personal details and information will remain private and confidential.
- If however I am quoted, it will be under a name given to me during the focus group interview.
- None of my personal information will be stated in the final research (I will remain anonymous).
- After the research study has been completed, the information I share will be kept in a password-protected computer and may be used for future secondary analysis.
- This study will be approved by the Human Research Ethics Committee (HREC) at the University of the Witwatersrand. I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

Signed: \_\_\_\_\_

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

## Appendix E: Audio Recording Consent Form – Focus Group



**PSYCHOLOGY**  
**THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)**



I, \_\_\_\_\_, agree to the audio recording of the group interview with Beatrice Moyo for her research study entitled “Black parents and caregivers’ perceptions and decision-making regarding an Attention Deficit Hyperactivity Disorder diagnosis: Implications for intervention pursuits”.

I understand and agree to the following:

- The tapes and transcripts (written records) from the group interview will not be made available to anyone else except for the researcher’s supervisor.
- After the research study has been completed, the information I share will be kept in a password-protected computer and may be used for future secondary analysis.
- Although I may be quoted in the research report, it will be under another name given to me during the group interview, thus my identity will be protected.

Signed: \_\_\_\_\_

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

## Appendix F: Sampling Site Information Letter



**PSYCHOLOGY**  
**THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)**



Dear Sir/Madam

My name is Beatrice Moyo and I am conducting a qualitative research for the purpose of obtaining a Doctorate Degree in Psychology at the University of the Witwatersrand. My study is titled “Black parents and caregivers’ perceptions and decision-making regarding an Attention Deficit Hyperactivity Disorder diagnosis: Implications for intervention pursuits.”

I hereby request permission to use your institution/practice/organization/social media platform as a sampling site for the study to invite Black parents and caregivers of children between the ages of 4-17 years old with a confirmed Attention Deficit Hyperactivity Disorder (ADHD) to participate in my study. I wish to request your assistance by way of informing your clients/patients/members of this study and facilitating the advertising of the study invitation flyer at your institution/practice/organization/Social media group.

My study will make use of individual interviews and focus group interviews that will be scheduled at a time and place convenient to the participants. There are no risks or benefits associated with participation in the study. Participation is strictly voluntary. All participants may withdraw from the study at any time without penalty. Data collected will be treated confidentially and only my supervisor and I will process it. Anonymity will be guaranteed as no identifying information of the sampling site or the participants will be put in the final report.

This study will be approved by the Human Research Ethics Committee (HREC) at the University of the Witwatersrand. Should you wish to give permission to be a sampling site for this study, please complete the attached consent form and email it to me at [moyobeatie@gmail.com](mailto:moyobeatie@gmail.com) or I can come and collect it. My contact number is 0730038451. For any further questions regarding the study, you may also contact my supervisor Dr. Mambwe Kasese-Hara at [Mambwe.Hara@wits.ac.za](mailto:Mambwe.Hara@wits.ac.za) / 011 717 4552.

Your consent in this regard will be appreciated.

Kind Regards,

Beatrice Moyo.

**Appendix G: Sampling Site Permission Letter**

I, \_\_\_\_\_, the Director/Health Practitioner/Administrator/  
Pastor/ of \_\_\_\_\_ hereby  
confirm that I understand the contents of this document and the nature of this research study.  
I give permission to Beatrice Moyo to advertise her research invitation flyer at our  
institution/practice/organization/social media group. I agree to assist Beatrice Moyo by  
informing our clients/patients/members of the study and facilitating the advertising of the  
study invitation flyer to Black parents and caregivers of children with confirmed Attention  
Deficit Hyperactivity Disorder. I understand that participation is strictly voluntary and that  
details will be kept confidential at all times. The institution/practice/organization/social  
media group's name will also not be mentioned in the study, further preserving the  
anonymity.

Name: \_\_\_\_\_

Signed: \_\_\_\_\_

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

## Appendix H: Research Recruitment Invitation Flyer

# ADHD

*Are you a Black parent/caregiver of a child with Attention Deficit Hyperactivity Disorder (ADHD)?*

*Would you like to contribute to valuable research in the field of ADHD?*



**Purpose of the study:** We would like to learn about the understanding and opinions of ADHD among Black parents and caregivers of a child with ADHD and how those opinions shape decision-making regarding intervention/treatment and preference.

**Eligibility:** To be able to participate in the study, you must be:

- A Black parent/caregiver of a child between the ages 4-17 years old with a confirmed ADHD diagnosis. (The child may / may not be in any ADHD intervention/treatment).
- Be over 18 years old.
- Able to speak and read English.
- Live within the Gauteng province.

**Activity:** You will be asked to:

- Participate in an individual face-to-face interview, and a focus group interview on a different day where you will be asked questions related to ADHD so that we can learn about your opinions.

**Researcher:** Beatrice Moyo, a Psychology postgraduate student at the University of the Witwatersrand.

### *Interested in participating?*

Contact Beatrice Moyo by 'sms', callback alert, phone call on 073 003 8451 or send an email on [moyobeatie@gmail.com](mailto:moyobeatie@gmail.com) for further information.

*(Please note that participation in the study is strictly voluntary. You will not be penalized in any way for not participating).*

## Appendix I: Demographic Information



**PSYCHOLOGY**  
**THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)**



Participant No.

1. Age: \_\_\_\_\_
2. Gender: \_\_\_\_\_
3. Ethnicity (Cultural Group): \_\_\_\_\_
4. Marital Status: \_\_\_\_\_
5. Residential Area: \_\_\_\_\_
6. Religion: \_\_\_\_\_ Practicing: \_\_\_\_\_ Not Practicing: \_\_\_\_\_
7. Highest Level of Education: \_\_\_\_\_
8. Current Employment: \_\_\_\_\_
9. Gender and current age of your child with ADHD: \_\_\_\_\_
10. At what age was the child diagnosed with ADHD? \_\_\_\_\_
11. Has the child ever received any form of ADHD intervention/treatment? \_\_\_\_\_  
 \*List interventions previously received: \_\_\_\_\_
12. List the ADHD interventions/treatments the child is currently on: \_\_\_\_\_  
 \_\_\_\_\_
13. How long has the child been on current ADHD intervention/treatment? \_\_\_\_\_
14. Apart from your child, are there other family members diagnosed with ADHD?  
 \_\_\_\_\_ Specify: \_\_\_\_\_  
 \_\_\_\_\_
15. Circle your average household monthly income:
 

i. R0 - R5 000	ii. R5 000 - R10 000
iii. R10 000 - R15 000	iv. R15 000 - R20 000
v. R20 000 - R30 000	vi. R30 000 - R 40 000
vii. R40 000 - R50 00	viii. R50 000 – R60 000
ix. Above R60 000	

## Appendix J: Semi-structured Individual Interview Guide



**PSYCHOLOGY**  
**THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)**



### **Research question 1: Parents/caregivers' understanding of ADHD**

- 1.1. Before your child was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), what information or awareness did you have on the disorder? (Expand on how you got this information/awareness).
- 1.2. Tell me what you understand are behaviors or signs that might suggest a child has ADHD.
- 1.3. Based on your understanding, what do you believe to be the cause of ADHD?

### **Research question 2: Black parents and caregivers' perceptions of an ADHD diagnosis for their child.**

- 2.1. Can you tell me how you received your child's ADHD diagnosis? (Acceptance/rejection).
- 2.2. After your child's ADHD diagnosis, what do you perceive ADHD to be?
- 2.3. Can you tell me how you perceive ADHD symptoms for your child can be managed?

### **Research Question 3: Factors influencing parental/caregivers' perceptions of an ADHD diagnosis for their child.**

- 3.1. What factors influenced you to accept/reject the diagnosis? (Elaborate).
- 3.2. How do you perceive family members and other people responded to your child's diagnosis? (If their response influenced your perception of the diagnosis, explain in what way?).
- 3.3. (*If applicable*) After your child's ADHD diagnosis, what was and continues to be your source of information regarding the disorder? (Elaborate how chose your information source).
- 3.4. Describe any experiences (positive/negative) you have encountered due to your child's ADHD symptoms and diagnosis.
- 3.5. (*Follow-up*) Can you reflect on how these experiences influenced your view of ADHD for your child, if they did?

### **Research Question 4: Meanings of an ADHD diagnosis: Implications for intervention pursuits.**

- 4.1. Tell me your feelings and thoughts when your child was diagnosed with ADHD.
- 4.2. (*Follow-up*) How did they impact your decision-making regarding intervention for your child?
- 4.3. Can you reflect upon your self-view as a parent when you received your child's ADHD diagnosis?
- 4.4. Can you describe how you perceive others view you as a parent since the ADHD diagnosis for your child?
- 4.5. (*Follow-up*) Elaborate how these views impacted on your perception of the diagnosis and decision-making towards intervention for your child, if they did?

**Research Question 5: Intervention pursuits and preferences.**

- 5.1 . (*If Applicable*) What made you pursue an ADHD intervention for your child?
- 5.2 . (*Follow-up*) Explain your motivation to choose the intervention you did over other options.
- 5.3 . (*If Applicable*) What factors influenced you not to pursue an ADHD intervention for your child?

**Conclusion:** Thank you so much for your time and sharing your thoughts on the topic. Is there anything else you would like to add? Should you have any questions or concerns, please feel free to contact me, or my research supervisor.

## Appendix K: Focus Group Interview Guide



**PSYCHOLOGY**  
**THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)**



1. What leads to parents' decision to have their children assessed for ADHD?
2. What do you think causes ADHD?
3. Can you share some of the reactions parents get when their child is diagnosed with ADHD? (Follow up questions to elaborate on the meanings attached to the diagnosis).
4. What are the reasons that make parents accept an ADHD diagnosis for their child? (Follow up questions relating to implications for intervention pursuits).
5. Can you share the reasons that may make a parent reject an ADHD diagnosis for their child?
6. How do you believe the ADHD symptoms in children are best managed? (Follow up questions relating to ADHD intervention preference).
7. How would you describe parents and caregivers' involvement in choosing the ADHD treatment/intervention for their child?  
*Follow-up:* What influences parents to settle for a particular treatment/intervention type to the others? (Probe).
8. Describe ways in which other people support or hinder parents/caregivers' management of their child with ADHD.
9. What influence does other people's attitude towards ADHD and its treatments have on parents and caregivers' willingness on seeking-help to manage ADHD symptoms in their child? (Ask probing questions)
10. In closing, what do you wish the professionals would take into account/consider when diagnosing Black children with ADHD?

**Thank you so much for your time and sharing your thoughts on the topic. Is there anything else you would like to add? Should you have any questions or concerns, please feel free to contact me, or my research supervisor.**

**Appendix L: Individual Interviews Data Collection Summary**

<b>PARTICIPANT</b>	<b>COMMUNICATION TYPE</b>	<b>VENUE/VIRTUAL PLATFORM</b>	<b>INTERVIEW DURATION</b>
P1	Face-to-face	Participant's Home	21 mins 53 secs
P2	Face-to-face	Participant's Work Office	24 mins 22 secs
P3	Face-to-face	Participant's Home	26 mins 57secs
P4	Online	Zoom	35 mins 8 secs
P5	Online	Zoom	46 mins 10 secs
P6	Online	Zoom	1hr 7 mins 28 secs
P7	Online	Zoom	20 mins 39 secs
P8	Online	Zoom	1hr 10 mins 38 secs
P9	Online	Zoom	30 mins 29 secs
P10	Online	Zoom	28 mins 23 secs
P11	Face-to-face	Participant's Church Premises	29 mins 08 secs
P12	Online	Microsoft Teams	42 mins 14 secs
P13	Phone Call	Mobile Phone	37 mins 13 secs
P14	Online	Zoom	15 mins 48 secs
P15	Online	Zoom	1hr 15mins 06 sec
P16	Online	Zoom	49 mins 37secs
P17	Face-to-face	Participant's Work Office	54 mins 50 secs
P18	Phone Call	Mobile Phone	23 mins 03 secs
P19	Phone Call	Mobile Phone	31 mins 17 secs
P20	Online	Zoom	44 mins 06 secs