Exploratory study of stigma as a potential barrier to accessing care for children with Attention-Deficit/Hyperactivity Disorder

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DECLARATION

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ABSTRACT

Attention-Deficit/Hyperactivity Disorder (ADHD) is a complex psychiatric disorder which affects approximately 5% of children worldwide. When left untreated, ADHD is linked to negative intrapersonal, interpersonal, and academic outcomes. In South Africa, while mental health services do exist in the community, many children with ADHD do not receive any treatment. Misperceptions regarding ADHD may cause children and their families to experience stigma due to their diagnosis, which may discourage families from seeking treatment. This study sought to address the knowledge gap which exists around stigma and ADHD in South Africa and explore the ways in which this affects help-seeking behaviour.

A mixed-method study was conducted consisting of three self-administered questionnaires and a semi-structured interview. Twenty-six parents of children screened by Goldilocks and The Bear Foundation (#gb4adhd) and 19 educators from schools where #gb4adhd has rendered services completed i) a demographic questionnaire, ii) The Knowledge of Attention Deficit Disorders Scale (KADDS) and iii) The Barriers of Access to Care Evaluation (BACE-3). Of these, 12 parents and six teachers participated in a semi-structured follow up interview.

Parents and educators showed poor knowledge of ADHD, scoring 37% of items regarding overall knowledge of ADHD correctly. Educators scored significantly higher than parents on all domains including knowledge of symptoms and diagnosis (64.30% *vs* 45.30%), treatment (48.70% *vs* 35.20%), associated features (43.20% *vs* 23.80%) and overall knowledge of ADHD (48.60% *vs* 28.40%). The most frequently reported barriers to accessing treatment were the financial cost involved, wanting to solve their/their children’s difficulties themselves, concerns about the available treatment and worries about seeming weak for accessing treatment. Instrumental barriers were found to be more significant than stigma-related barriers.

Participants described stigma as the recognition of difference and being labelled which leads to bullying, exclusion and being overlooked. Children with ADHD experienced lowered self-esteem and isolation. Families of children with ADHD expressed changing their day-to-to routine in order to avoid stigmatizing reactions from the community and increased emotional hardship. Financial barriers, lack of help, difficulties knowing where to access help, and lack of education about ADHD were highlighted as significant barriers to accessing treatment. Parents expressed a need for increased awareness and empathy in the community, and for ADHD to be normalised. Suggested methods for addressing the stigma included increasing awareness and education through using mass-media, role models and public health initiatives, and was thought to be the collective responsibility of government, educators, and parents.

Findings from this study indicate that stigma does play a role in the under-utilisation of treatment but does not account for all reasons that children do not receive help. Other additional factors such as financial constraints, poor awareness and lack of parental support pose significant barriers. Stigma could be viewed less as a barrier to treatment, and more as a barrier to overall wellbeing due to its extensive impact on the child and family’s lives. Recommendations for multi-stakeholder collaboration to identify effective culturally and contextually relevant initiatives to decrease stigma, increase awareness and enhance service provision are proposed to decrease barriers to accessing treatment.

OPSOMMING

Aandagtekort hiperaktiwiteitsteuring (ATHS) is ‘n komplekse psigiatriese diagnose wat wêreldwyd ongeveer 5% van skoolgaande kinders affekteer. Dit word aanvaar dat die prevalensie in Suid Afrika soortgelyk is. Indien ATHS nie behandel word nie, het dit ‘n negatiewe impak op intrapersoonlike, interpersoonlike en akademiese funksionering, sowel as die individu se lewenskwaliteit. Alhoewel psigiatriese gesondheidsorgdienste wel beskikbaar in Suid-Afrika is, is daar steeds baie kinders met ATHS wat nie die nodige behandeling ontvang nie. Dit kan moontlik as gevolg van ‘n gebrek aan bewustheid en kennis van die diagnose, of ‘n gebrek aan toegang tot die nodige gesondheidsorg wees . Alhoewel ATHS deeglik nagevors is, en wêreldwyd aanvaar word as ‘n erkende diagnose, bly dit ‘n omstrede onderwerp met vele wanopvattings. Dié wanopvattings mag veroorsaak dat kinders met ATHS en hul families stigma ervaar. Kinders kan as “stout”of “dom” beskryf word. Die vrees wat families vir moontlike negatiewe reaksies en moontlike diskriminasie het, kan hulle ontmoedig om behandeling te soek . Hierdie studie poog om die kennisgaping in Suid-Afrika rakendeATHS, en die gepaardgaande stigma, te ondersoek. Verder poog die studie ook om te bepaal hoe diè aspekte toegang tot psigiatriese sorg beingvloed.

Die “Goldilocks and the Bear Foundation” (#gb4adhd) is ‘n Suid-Afrikaanse welsynsorganisasie wat gratis psigatriese sifting (spesifiek gefokus op ATHS) en intervensies aan minderbevoorregtes lewer. Voorlopige navorsing wat deur #gb4adhd gedoen is, het bevind dat 2.7% van die kinders in die program aan die diagnostiese kriteria vir ATHS voldoen. Dit is laer as die aanvaarde internasionale prevalensie.

‘n Gemengde metode studie met vyf-en-veertig deelnemers is voltooi. Deelnemers het ses-en-twintig ouers van kinders in die #gb4adhd program, sowel as 19 opvoeders by die onderskeie betrokke skole ingesluit. Die deelnemers het drie vraelyste: ‘n demografiese vraelys, die *Knowledge of Attention Deficit Disorders Scale (KADDS)* en die *Barriers of Access to Care Evaluation (BACE-3)* voltooi. Verder het twaalf ouers en ses opvoeders aan ‘n semi-gestruktureerde onderhoud deelgeneem.

Beide ouers en opvoeders het gebrekkige kennis van ATHS gehad en het slegs 37% items ten opsigte van hulle kennis van ATHS korrek beantwoord. Opvoeders het opmmerklik beteras die ouers met betrekking tot kennis van simptome en diagnose (64.30% *vs* 45.30%), behandeling (48.70% *vs* 35.20%), geassosieëde kenmerke (43.20% *vs* 23.80%) en algehele kennis van ATHS (48.60% *vs* 28.40%) gevaar. Die mees algemene hindernisse tot toegang tot behandeling van ATHS was geopper: die finansiële kostes, die behoefte om die probleem self te wil oplos, kommer oor beskikbare behandeling, en kommer dat hulle as swak beskou sal word. Instrumentele (praktiese) hindernisse het meer gewig as stigma gedra.

Tydens die onderhoude is vier hooftemas bespreek: deelnemers se begrip van stigma, faktore wat die toegang tot sorg beïnvloed, onvervulde behoeftes en begeertes in die gemeenskap met betrekking tot ATHS, en die verwydering van hindernisse tot sorg. Deelnemers het stigma as die herkenning van ‘n afwyking en ook om geëtiketeer te word beskryf. Dit kan veroorsaak dat kinders geboelie en sosiaal uitgesluit word. Kinders met ATHS het dikwels‘n swakker selfbeeld en ervaar sosiale isolasie. Families van kinders met ATHS verduidelik dat hulle hul daaglikse roetine aanpas om sodoende stigmatiserende optrede van die gemeenskap te vermy. Hulle kry ook emosioneel swaar. Van die ander daarwerklike hindernisse tot toegang tot behandeling wat geopper is, is finansiele uitdagings, gebrek aan hulp, onkunde oor waar hulp bekom kan word, en ‘n gebrek aan kennis oor ATHS. Ouers het verduidelik dat daar ‘n groot behoefte in die gemeenskap is om bewustheid en kennis van ATHS te verbeter, om empatie te verbeter, en ook om ATHS te normaliseer. Voorstelle om stigma te verminder sluit in pogings om bewustheid en kennis deur die gebruik van die media, rolmodelle en openbare gesondheidsorg inisïatiewe te verhoog. Dié word as die gesamentlike verantwoordelikheid van die regering, opvoeders en ouers gesien.

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TABLE OF CONTENTS

List of figures

List of tables

List of acronyms and abbreviations

#gb4adhd	Goldilocks and The Bear Foundation (NPO/PBO)
ADHD:	Attention-deficit/Hyperactivity Disorder
BACE-3:	The Barriers to Access to Care Evaluation
DOE:	Department of Education
DOH:	Department of Health
KADDS:	The Knowledge of Attention Deficit Disorder Scale
LMIC:	Low-middle income country
MEED:	Metro East Education District
MNED:	Metro North Education District
SBST:	School based support team
WCED:	Western Cape Department of Education

CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

Attention-deficit/Hyperactivity Disorder (ADHD) is a complex psychiatric disorder characterized by a persistent pattern of inattention, hyperactivity and impulsivity (Shroff, Hardikar-Sawant, & Prabhudesai, 2017). Children and adults across all socio-economic, religious, cultural, and racial groups are affected by ADHD, which can have far-reaching negative educational, social and emotional consequences, particularly when left untreated (Barkley, 2016). It is estimated that ADHD affects 1 out of 20 school-going aged children in South Africa (Bakare, 2012). ADHD is linked to multiple negative intrapersonal, interpersonal, and academic outcomes. In a systematic review of 351 studies, Shaw et al. (2012) found that people with untreated ADHD had poorer outcomes in terms of academic performance, social functioning and self-esteem. They additionally had an increased risk of substance abuse and addictive behaviours, higher occurrences of accidents and traffic violations, and higher incidence of antisocial behaviour such as school expulsion and incarceration.

Children who exhibit behaviours related to ADHD can be unfairly labelled as “stupid’ or “naughty” (Geigel, 2017). This may lead to them being socially ostracised or bullied by peers or being treated differently to classmates by their teachers. This misattribution of behaviour to ill-discipline or intellectual difficulties is oftentimes rooted in the persistent stigma that surrounds mental illness. Children and their families face significant challenges in dealing with ADHD. They are faced with both the symptoms inherent in the disorder, as well as having to deal with the negative, and typically incorrect, perceptions about ADHD and its causes (Bussing & Mehta, 2013). This may lead those who need psychiatric intervention to avoid accessing mental health services due to fear of discrimination.

1.2 RESEARCH OBJECTIVES

The Goldilocks and The Bear Foundation (#gb4adhd) is a South African non-profit public benefit organization founded by psychiatrist Professor Renata Schoeman and entrepreneur/athlete Nic de Beer in 2017 and offers South Africa's first non-profit mental health screening (specifically also addressing ADHD) and early intervention services in underprivileged communities. An outline of what #gb4adhd offers within communities can be accessed online (http://gb4adhd.co.za/what-we-do/). During their first year of operation, #gb4adhd visited 18 schools (N=12447) of which 13 schools participated in the screening and intervention program (N=8780) (Schoeman, Enright, James, Vermeulen, & de Beer, 2018). Of this school population, 534 learners (6.2% of the school population) were referred and screened. Preliminary research found that 2.7% of children screened met the diagnostic criteria for ADHD. This prevalence rate of ADHD in children within their sample is lower than rates reported internationally.

Although there are mental health clinics in the public sector, many children do not reach the point of diagnosis and therefore do not receive treatment. There are multiple factors which may account for this including lack of awareness and knowledge of ADHD and lack of access to services. It is further hypothesised that stigma, as it relates to misperceptions of mental health disorders, may further cause those who are in need of psychiatric intervention to avoid seeking such treatment for fear of being judged and discriminated against (Corrigan & Nieweglowski, 2019).

1.2.1 Research aim

This study aims to address the knowledge gap which exists surrounding stigma and ADHD, and to explore the role that stigma plays in the ways in which people understand ADHD and how this, in turn, affects help-seeking behaviour and access to care.

Specific objectives included:

- To assess parents' and educators' knowledge of ADHD
- To explore factors acting as barriers to accessing care
- To determine whether stigma is perceived to be a barrier to accessing care
- To explore parents' and educators' understandings of stigma
- To explore parents' and teachers' experiences of stigma in relation to ADHD
- To better understand the barriers which parents and educators face in accessing care for children with ADHD
- To gain a deeper understanding of how stigma acts as a barrier to accessing care

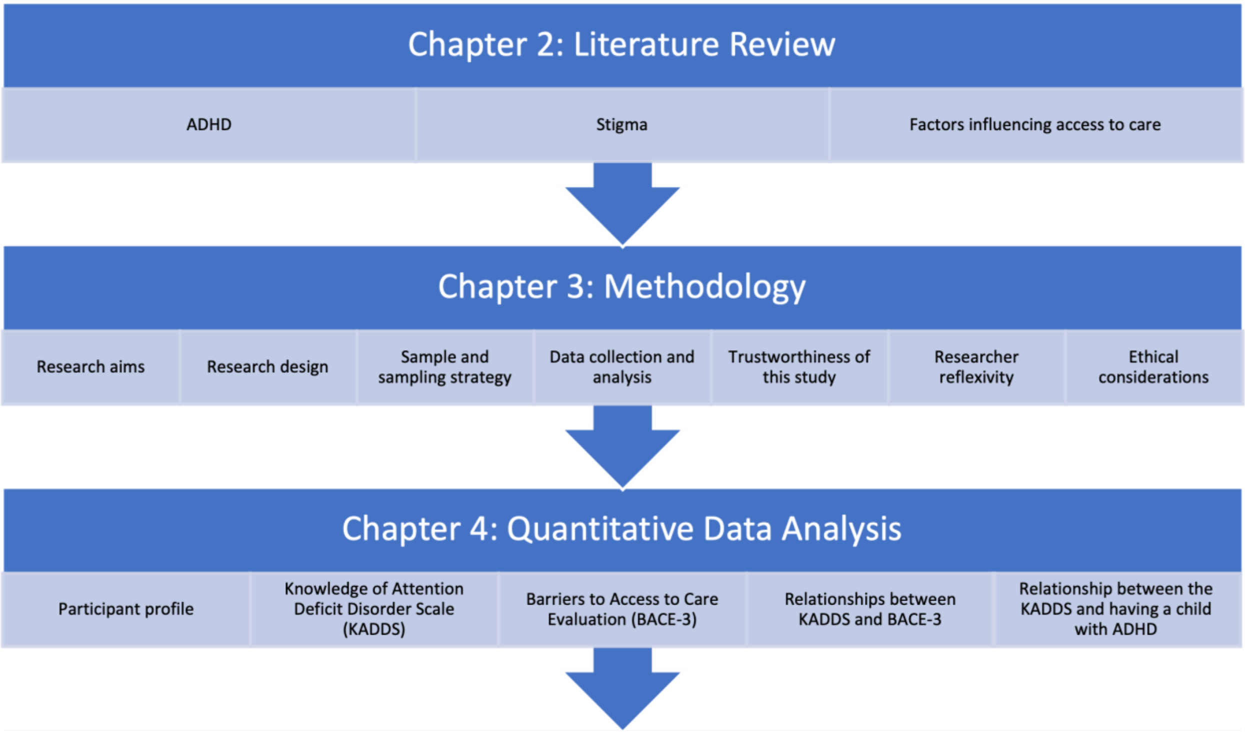
1.2.2 Research question

In South Africa, research regarding stigma associated with ADHD is lacking. I conducted a literature search across the Stellenbosch University library, Google Scholar, Sabinet, JSTOR, PubMed, ProQuest, PsycARTICLES and ScienceDirect using combinations of the terms "ADHD", "stigma", "South Africa" and "barriers to treatment". The search revealed a limited number of studies which investigated the perceptions of and attitudes towards ADHD in South Africa (Kern, Amod, Seabi, & Vorster, 2015; Perold, Louw, & Kleynhans, 2010; Venter, Linde, Plessis, & Joubert, 2004). There were however no existing studies which explored stigma as a barrier to accessing treatment for children with ADHD in South Africa.

Due to the lack of contextually relevant literature it is unclear how parents and educators in South Africa a) understand and explain mental health disorders and ADHD respectively; b) how their understanding and interpretation may lead to discrimination; and c) the impact of stigma in accessing care. Furthermore, the contribution of this potential discrimination or stigma faced by individuals affected by ADHD has not been explored. This study seeks to answer the following research question: Does stigma act as a barrier to accessing treatment for children with ADHD?

1.3 CHAPTER OVERVIEW

A visual framework for the study is provided in Figure 1.1.



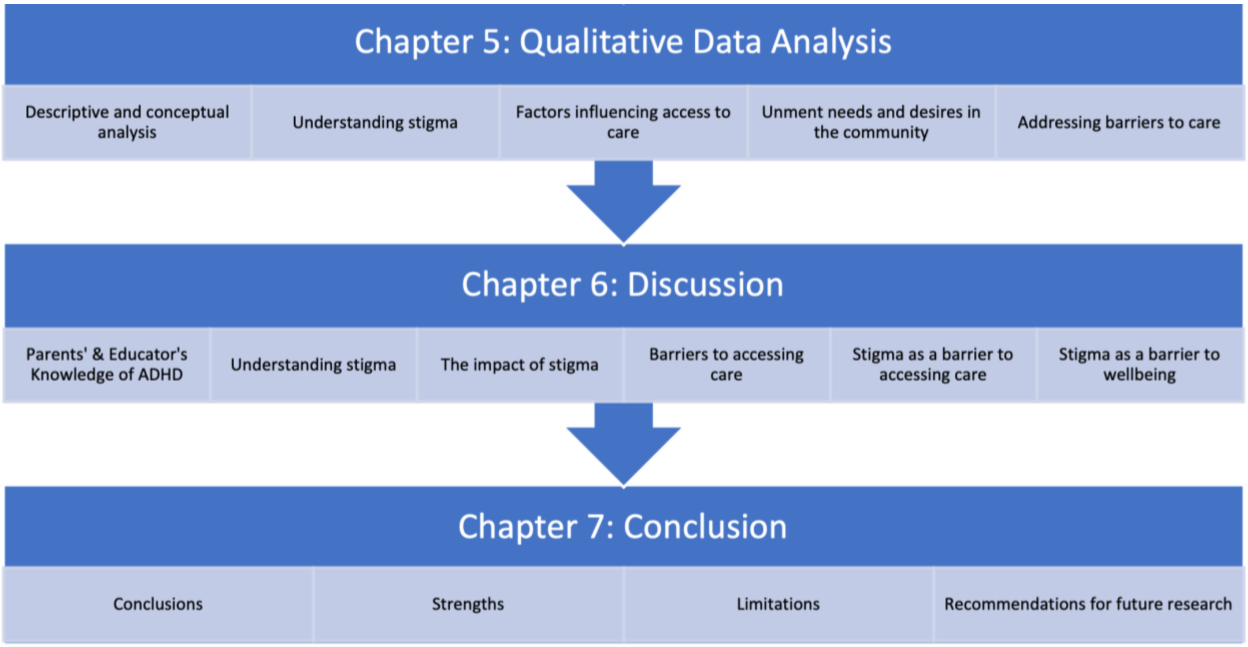


Figure 1.1: **Chapter Overview**

Following on from the introduction and stating of objectives, Chapter 2 provides a review of relevant literature. This will include an introduction to ADHD globally and in South Africa, a current theoretical understanding of stigma and the ways in which stigma relates to ADHD.

Chapter 3 outlines the methodology for the study including sampling procedures, data collection and analysis, and ethical considerations. Measurement tools are also discussed.

Chapter 4 reports on the quantitative findings of the study. The statistical methods that were employed are discussed and results from each measurement tool are presented.

Findings from the qualitative section of the study are discussed in Chapter 5. The data collected from semi-structured interviews are presented according to major emerging themes including understanding stigma, the impact of stigma, unmet needs and desires in the community and ways in which to address barriers to care.

Chapter 6 provides a discussion of the findings from the study by presenting a synthesis of the qualitative and quantitative findings and integrates these with relevant theory.

Conclusions drawn from the study are presented in Chapter 7, together with relevant strengths, limitations, and recommendations for future research.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The World Health Organisation defines mental health as a “state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community" (World Health Organization, 2014, para. 1). Mental health can also be viewed as “the springboard of thinking and communication skills, learning, emotional growth, resilience, and self-esteem” (U.S. Department of Health and Human Services, 2000, p. 4). A 2006 study based in the Western Cape estimates the prevalence rate for mental health challenges for children and adolescents as 17% (Kleintjes et al., 2006). ADHD is the most common childhood psychiatric disorder, yet it remains a controversial diagnosis clouded by misperceptions and stigma which impedes the abilities of families, teachers, and healthcare professionals to collaborate effectively in supporting children with this diagnosis (Moldavsky & Sayal, 2013). Danforth and Kim (2008) report that the vast range of understandings of ADHD available in literature reflect “ a general state of conflict and confusion, a cultural situation of high emotion and low clarity” (p. 50)**.** A systematic review of 3898 articles regarding attitudes, beliefs and experiences of ADHD in primary health care showed that lack of knowledge was a worldwide factor which hampered the effective management and treatment of ADHD (French, Sayal, & Daley, 2019).

This chapter provides an overview of the diagnosis and scope of ADHD globally and in South Africa, discusses ADHD in relation to education, outlines current theories of stigma and discusses factors which impact accessing treatment for mental health conditions such as ADHD.

2.2. ATTENTION-DEFICIT/HYPERACTIVITY DISORDER (ADHD)

ADHD is well-researched with more than 10 000 clinical and scientific publications. It is recognised worldwide by medical, psychological and educational organisations as a legitimate psychiatric diagnosis (Schoeman, 2017; Vrba, Vogel, & Vries, 2016).

ADHD is diagnosed using diagnostic criteria outlined in the American Psychiatric Association's (APA, 2013) *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) which describes the core and associated symptoms of ADHD (see Appendix A). The disorder is defined by persistent impairing levels of inattention, disorganisation, impulsivity and/or hyperactivity that interferes with functioning or development and which reduces the quality of social and academic functioning (Vogel, 2014). Symptoms may include failing to pay close attention to details and making careless errors, difficulty sustaining attention and staying on task, fidgeting and squirming, excessive talking and interrupting, and acting as if 'driven by a motor'. The symptoms need to be present over time and across different settings (APA, 2013).

ADHD can be understood as a bio-psycho-social condition, i.e., "it is medical in origin but it is affected and influenced by the environment, social and emotional aspects of the person and situation" (Schoeman, 2017, para. 3). The most consistently found risk factors associated with ADHD are both genetic and neurological. This includes very low birth weight, prematurity, exposure to tobacco smoke and alcohol in utero, and exposure to toxins (APA, 2013; Thapar, Cooper, Eyre, & Langley, 2013; Vogel, 2014). A hospital-based case-control study conducted in the Western Cape reported that birth complications, parental psychiatric disorders, maternal

ADHD and early traumatic life events are associated with children with ADHD (Van Dyk et al., 2015).

Studies have shown that there are specific neurochemical imbalances in individuals who display symptoms of ADHD, specifically dopamine and noradrenalin. This was explained by Schoeman and Liebenberg (2017, p. 7), who reported that "enhancing dopaminergic and noradrenergic neurotransmission in the pre-frontal cortex" is critical in the pharmacological treatment of ADHD. There are also differences in the development of the areas of the brain which manage attention, working memory and planning (Friedman & Rapoport, 2015).

The rate of psychiatric co-morbidity is high in ADHD, specifically with externalising disorders such as Oppositional Defiant Disorder (ODD) and Conduct Disorder (CD), and to a lesser degree with internalising disorders, such as Major Depressive Disorder (MDD) and anxiety disorders (APA, 2013). In South Africa, the comorbidity rates for ADHD with ODD, CD, MDD and Generalised Anxiety Disorder (GAD) are estimated at 17.86%, 21.43%, 17.86% and 28.57% respectively (Walker, Venter, Van der Walt, & Esterhuyse, 2011). Walker et al. (2011) reported that, of those who met the criteria for psychiatric co-morbidities within this sample, 42.28% met the criteria for three or more co-morbidities. It has also been noted that ADHD-like symptoms may be exhibited in children who do not have ADHD. For example, a child with anxiety may be fidgety and struggle to sit still. Similarly, a child who is depressed may appear to be inattentive, distracted or may lack the motivation to complete tasks. It is thus vital, when assessing for and diagnosing ADHD, that other mental health conditions (i.e., differential diagnoses) such as autism spectrum disorder, anxiety disorders, depressive disorders, substance use disorders, specific learning disorders and oppositional defiant disorder are also considered (APA, 2013).

2.2.1 Scope of ADHD

Research shows that ADHD is the most diagnosed psychiatric disorder in children in both the United States of America and Europe. The DSM-5 (APA, 2013) reports a prevalence of 5% of children and 2.5% of adults in most cultures. In a literature review, Bakare (2012) reported prevalence rates of ADHD to be between 5.4 and 8.7% in African children. The DSM-5 (APA, 2013) reports a gender prevalence ratio of 2:1 for male and female. However, it should be noted that ADHD is thought to be under-recognised and under-treated in females (Sayal, Prasad, Daley, Ford, & Coghill, 2018). Girls and women are less likely to be referred for assessment for ADHD, are more likely to have undiagnosed ADHD, and are more often misdiagnosed with another mental health or neurodevelopmental disorder (National institute for Health Care and Excellence, 2008; Sayal et al., 2018). Girls are often misdiagnosed as they are more likely to present with the inattentive sub-type of ADHD, and usually do not present with the hyperactive and disruptive behaviour commonly associated with ADHD. In addition, girls appear to be more aware of socially appropriate behaviour and to act accordingly, which leads to their behaviour not being perceived as problematic (Mowlem, Agnew-Blais, Taylor, & Asherson, 2019; Smith, 2017).

2.2.2 ADHD in South Africa

ADHD is highly prevalent, but is understood to be both under-recognised and undertreated, specifically in South African and other low and middle income countries (LMIC) (Vrba et al., 2016). Chinawa et al. (2014) described ADHD as a neglected health issue in Africa. Currently, there is a gap in the research and knowledge about the prevalence of ADHD in South Africa. It is, however, estimated that prevalence rates match those published globally, which state that 3% to 10% of children meet the diagnostic criteria for ADHD (Amod, Vorster, & Lazarus, 2013). An epidemiological and neuropsychological investigation amongst six cultural groups in the Limpopo Province in South Africa reported prevalence and gender ratios of ADHD as very similar to those in Western countries (Meyer, 2005). Schoeman et al. (2018) reported a prevalence rate of 2.52% in a community sample in the Western Cape. Despite ongoing prevalence studies, research regarding community perceptions and cultural understandings of ADHD in South Africa was not found.

2.2.3 The impact of ADHD

ADHD has the potential to impact all facets of life. In children, it can lead to educational failure, difficulty integrating socially, poor self-esteem, and increased and strained family relationships (Peasgood et al., 2016). Children with ADHD are also at a higher risk for being both bully victims and bully perpetrators (Keder et al., 2013; Winters, Blake & Chen, 2020). When left untreated, individuals with ADHD face an increased likelihood of becoming involved in crime-related activities. Young and Cocallis (2019) report a “five to tenfold increase of ADHD in the prison population versus the general population” (p. 2). Furthermore, Goksøyr and Nøttestad (2008) found that appropriate treatment of ADHD in childhood was associated with better psychological and social outcomes for adults across five domains: alcohol abuse, substance abuse, possessing a criminal record, level of psychological strain and social functioning. This highlights the importance of early identification and intervention which can protect against developing psychiatric co-morbidities such as anxiety and depression, and ameliorate social impairment (Goksøyr & Nøttestad, 2008).

2.2.4 ADHD and education

The right to education is enshrined in the Constitution of the Republic of South Africa (hereafter the "Constitution") (1996). According to the Department of Education (2007) the primary goal of any education system globally should be to "provide quality education for all learners so that they will be able to reach their full potential and will be able to meaningfully contribute to and participate in that society throughout their lives" (p. 10). Education is a cornerstone upon which other human rights such as the right to dignity can be built. Churr (2015, p. 2406) proposes that a "meaningful and significant existence is dependent on worldwide education" (p. 2406).

The Constitution is internationally recognised as forward thinking and an example of a truly democratic piece of legislation (Letseka, 2014). The guidelines for the right to education clearly state that every child is entitled to a learning environment which caters to their individual needs. In 2001, the Education White Paper 6 stated that "a broad range of learning needs exist among the learner population at any point in time, and that where these are not met, learners may fail to learn effectively or be excluded from the learning system" (Department of Education, 2001, p. 7).

One of the crucial learning differences not sufficiently catered for in education in South Africa is mental health disorders, with teachers reporting feeling overwhelmed by having to manage educational demands together with the expectations to improve their student's emotional and psychological wellbeing (Mfidi, 2017). In investigating the state of inclusive education for children with both physical and intellectual disabilities in South Africa, Human Rights Watch (2015) reported that "many students in mainstream schools face discriminatory physical and attitudinal barriers they need to overcome in order to receive an education" (2015, p. 2). Lund et al. (2008) reported that schools have the potential to act as important service providers for mental health in children, but that learner mental health was under-resourced and under-prioritised.

Symptoms related to ADHD, such as an inability to sit still and concentrate, difficulty in controlling behaviour, struggling to follow instructions, distractibility and inattention make it difficult for children to learn. During 2018, 13 307 830 learners were enrolled in the basic education system, who attended 29 749 education institutions and were served by 440 151 educators (Department of Basic Education, 2018). Based on international and South African estimates of a 3 to 10% prevalence rate of ADHD, there were potentially between 399 234 and 1 330783 learners within the school system who required additional support and accommodation from teachers, the Department of Education and the Department of Health in 2017 (Amod et al., 2013; CADDRA, n.d.). The classroom presents high demands on children with ADHD for sustained attention and self-control, and also creates an environment where children compare themselves to each other (Lauth, Heubeck, & Mackowiak, 2006). Furthermore, it has been found that there is overcrowding in South African classrooms which hinders teachers from offering the necessary individual support and compounds the already challenging circumstances resulting in sub-optimal learning environments (Letseka, 2014; Naude & Meier, 2019). In July 2019, parents at a school in the Western Cape went to extreme measures of locking the school principal in a classroom to protest against class sizes of up to 60 children per class (Lali, 2019). Children with ADHD face the significant challenge of managing the core symptoms of ADHD and associated emotional, academic and social difficulties, as well as challenges posed by the physical school environment such as inflexible curricula, unsafe buildings, inadequate support services and overcrowded classrooms (Department of Education, 2001). Thus, such physical constraints in the school environment could pose a significant barrier for learning amongst children with ADHD.

Based on the fact that ADHD is the most common psychiatric disorder in children, it is imperative that teachers are aware of the condition in order to provide children with the necessary support in order to mitigate its impact on educational attainment and quality of life (Schoeman, 2018). However, research shows low levels of awareness amongst teachers, as well as the presence of stigma in regards to ADHD (Akram, Thomson, Boyter, & McLarty, 2009; Perold et al., 2010; Sciutto et al., 2016; Topkin, 2013).

2.2.5 ADHD and families

ADHD is strongly heritable, which means that multiple family members may meet the diagnostic criteria for ADHD (Burke, Austin & Waldeck, 2011). This has implications for the ways in which ADHD is managed within families and can also increase the emotional burden associated with the condition. Childhood ADHD is associated with decreased wellbeing for the individual and their families, with families reporting lower quality of life in terms of family activities, and increased negative emotional impact experienced specifically by parents including elevated stress levels and increased rates of depression (Ahmed, Borst, Yong, & Aslani, 2014; Danckaerts et al., 2010; Peasgood et al., 2016). Additionally, siblings of children with ADHD report being less happy within their families and in life in general and experience more bullying within the family system (Peasgood et al., 2016).

Although ADHD was previously viewed as a childhood disorder, it is now understood as a condition which affects individuals across the lifespan (Smith et al., 2015). Parenting with ADHD creates additional challenges by placing high demands on attention, emotion regulation and the need for organisation and structure. Inattention, emotional dysregulation and impulsivity associated with adult ADHD have been linked to impaired family relationships, poorer marital functioning and parent-child difficulties (Chronis-Tuscano & Stein, 2012). In addition, parents with ADHD are confronted with the financial demands of managing their, and their children's, diagnoses and their own personal wellbeing (Cheesman, 2019). Therefore, the emotional burden of parenting a child with ADHD may be compounded by parental ADHD.

For children and their families, the difficulties associated with ADHD are exacerbated by social stigmatisation (Moldavsky & Sayal, 2013). Stigma is rooted in a lack of knowledge and underlying prejudice towards those who may appear to be different (Thornicroft, Rose, Kassam, & Sartorius, 2007). In mental illness in particular, a lack of understanding of the causes of disorders such as ADHD, can cause a child's behavioural difficulties to be attributed to acting out or to believing that a child is behaving a certain way due to insufficient parenting and discipline (Kern et al., 2015). Certain cultural and belief systems in South Africa may also attribute psychiatric symptoms to malevolent interventions such as bewitchment, sorcery, magic, or the influence of departed ancestors who wish to correct inappropriate social behaviour (Atindanbila & Thompson, 2011). Furthermore, the way in which individuals conceptualise and understand mental health conditions influences the ways in which they access care. In exploring community perceptions in the Limpopo province, Sehoana (2014) found that the Pedi community perception of mental illness is influenced by cultural and religious beliefs which in turn affects the choice of treatment, such as seeking traditional or spiritual healing rather than “mainstream” Western psychiatric treatment.

2.3 STIGMA

Stigma is a term which lacks a clear operational definition. This can be attributed to the fact that the concept of stigma is applied and researched in a multitude of circumstances and viewed through multiple lenses, based on which discipline the study is grounded in (Link & Phelan, 2001). In addition, Phelan, Link and Dovidio (2008) highlight an increasing “cross communication” in terms of stigma-related research, in as much as stigma is often used interchangeably with other terms such as prejudice.

The word “stigma” originates from the Latin “stigmat” meaning a mark or a brand (Merriam-Webster, n.d.). The Ancient Greeks used the term stigma to refer to “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (p. 10) which took the form of a physical mark that was burnt or cut into a person to expose something unusual or bad about the moral status of the individual (Goffman, 1963). The stigma indicated that the individual was ‘contaminated’ in some way and should be avoided. Presently, theories of stigma appear to incorporate two fundamental components: the recognition of difference and subsequent devaluation *(*Dovidio, Major, & Crocker, 2000).

In his seminal work, *Stigma: Notes on the Management of the Spoiled Identity*, Goffman (1963) defines stigma as an attribute which is deeply discrediting and which reduces a person in our mind “from a whole and usual person, to a tainted, discounted one” (p. 3). This process occurs when, through social interaction, a person is seen to be “different from others in the category of persons available for him to be, and of a less desirable kind” (Goffman, p. 11). Society holds preconceived ideas of how people ought to look, function or behave in various contexts, and when the expectations are not met, the individual is seen as “not quite human” and labelled with an “undesired difference” leading to experiences of shame and perceived (or experienced) rejections by the stigmatisers (Goffman, 1963). Referred to as a “pioneering treatise on stigma”, Goffman’s work was cited in 9939 articles published between 1963 and 2012 and made a significant contribution in the advancement of understanding stigma (Bos, Pryor, Reeder, & Stutterheim, 2013, p. 3). Stigma is widely recognised as a global phenomenon which poses a substantial threat to individual and societal functioning, operating at both macro and micro-sociological levels by discouraging individuals from accessing adequate health care, obstructing access to much needed social support, exacerbating social anxiety and hampering societal integration (Egbe et al., 2014; Hatzenbuehler, Phelan, & Link, 2013; Holder, Peterson, Stephens, & Crandall, 2018).

Thornicroft (2008) describes stigma as consisting of three related problems: a lack of knowledge (ignorance and misinformation), negative attitudes (prejudice), and excluding or avoiding behaviours (discrimination). Similarly, Corrigan (2018) describes stigma as being anchored by stereotypes, prejudice and discrimination. Both theories include prejudice and discrimination as key components of stigma. Prejudice refers to the process whereby people agree on a certain negative belief about a group, which results in an adverse behavioural reaction, also known as discrimination. Corrigan defines stereotypes as “knowledge structures framed as fact-based beliefs” (Corrigan, 2018, p. 48). It is possible, therefore, to see the intersection of Corrigan and Thornicroft’s theories where both highlight that misinformation and unsubstantiated assumptions form the foundation upon which negative attitudes are cultivated resulting in unfair and discriminatory treatment of people with mental illness. In summary, a stereotype is a belief, and prejudice is the cognitive and affective response to the stereotype which leads to discrimination, the resulting negative behaviour.

In conceptualising stigma, Link and Phelan (2001) describe four processes which occur, namely: distinguishing and labelling differences, associating human differences with negative attributes, separating “us” from “them” and status loss and discrimination. These four processes can be understood as follows:

Distinguishing and labelling differences. Individuals identify a difference in a person or a group and assign a label to that group.

Associating human differences with negative attributes. The assigned label is linked to a stereotype which is a set of undesirable characteristics, such as the belief that people with mental health conditions are dangerous.

Separating “us” from “them”. The label (and linked stereotype) implies a separation between the stigmatiser (us) and the stigmatised individual (them) and can lead to the perceived justification of maltreatment.

Status loss and discrimination. Having been identified as different and linked to unfavourable characteristics, the stigmatised individual experiences status loss and discrimination. This lowers their placement on the societal status hierarchy and negatively impacts their quality of life in terms of access to education, employment and medical treatment as well as affecting their overall physical and psychological wellbeing.

2.3.1 Stigma and mental health

According to Rusch, Angermeyer and Corrigan (2005), individuals with mental health disorders are faced with a "double problem". They not only have to deal with the symptoms and challenges of the disorder itself, but also with misperceptions within society which lead to stigma (Egbe, 2015). Thornicroft (2008, p.15) proposes that there is "no known country, society or culture in which people with mental illness with a diagnosis are considered to have the same value and to be as acceptable as people who do not have a mental illness". In reflecting on lessons learned from mental health campaigns, Corrigan (2018) emphasised that stigma should be viewed as primary health concern and should be afforded the same resources in terms of research and attention as psychiatry, saying:

> There should be no doubt that stigma is a major problem for people with mental illness and related behavioural health disorders. Stigma can be more harmful to people than the illness itself. It is not secondary to the more primary challenges of symptoms and should not be relegated to the back seat with public health focusing solely on symptom and disability management. It will not go away when mental illness is cured. (p. 188)

Different types of stigma have been conceptualised including public stigma, self-stigma, structural stigma, label avoidance, courtesy stigma, affiliate stigma, anticipated stigma and internalised stigma (Corrigan, 2018; Fox, Smith, & Vogt, 2018; Goffman, 1963). Public stigma is when the majority (those without a mental health disorder) endorse negative attitudes towards people in the stigmatised group (people with a mental health disorder) and behave in discriminatory ways towards them. This can include actively avoiding people with mental health disorders, creating segregation between groups or coercing those with mental health conditions to behave in certain ways such as staying out of public spaces, avoiding social situations or being institutionalised (Corrigan, 2018). Self-stigma is characterized by personal and subjective perceptions of devaluation, shame, secrecy and withdrawal which leads to profound psychological adversity, lowered self-esteem and increased hopelessness (Boyd, Adler, Otilingam, & Peters, 2014; Kellison, Bussing, Bell, & Garvan, 2010). Self-stigma occurs when a person with a mental health condition internalises negative public perceptions about themselves. The lack of appropriate infrastructure and services for people with mental health conditions may be informed by structural stigma. Structural stigma refers to both government and private institutional policies which either intentionally or unintentionally disadvantage a person or group based on their stigmatised status, leading to decreased opportunities and increased isolation (Elkington et al., 2012).

Many stigmatizing attitudes are based on physical or visible attributes such as skin colour, gender or whether someone is physically disabled. However, in many instances, mental health disorders may not be easily recognisable and may go unnoticed by the general public. In an effort to keep mental health challenges a secret, label avoidance may take place. Label avoidance is when a person avoids a certain place or institution where they could be recognised and labelled. Label avoidance has been linked to delays in help-seeking in order to avoid social disapproval and negative reactions from others (Van Zelst, 2009). For example, a mother might avoid taking their child to a community mental health clinic for fear that they or their child be labelled as mentally ill or “crazy”. Research shows that labels in themselves, separate from the behaviour of the individual with a mental health disorder, are a major signal which leads to stereotypes, prejudice and discrimination and encourages societal rejection (Corrigan, 2018; Hinshaw & Stier, 2008). Thornicroft (2008) reported that the average delay for accessing treatment for mood disorders is eight years, and nine years for anxiety disorders. One of the contributing factors to this delay was stigma. He further reported that “a strong reluctance to be seen as mentally ill appears to be a universal phenomenon” (p. 16).

Courtesy stigma, or stigma by association refers to a stigma which an individual possesses because of their close connection to a stigmatised individual (Quinn & Chaudoir, 2009). The nature of the prejudice experienced is informed by the nature of the relationship to the stigmatised person. Goffman (1963) describes that “the problems faced by stigmatised persons, spread out in waves, but of diminishing intensity” (p.42). In a family system, a child with ADHD may be actively excluded or bullied by friends, their mother may be blamed for causing the condition and their siblings may be viewed as ‘contaminated’ or ‘damaged’ due to their close proximity to the child.

An extension of the concept of courtesy stigma is affiliate stigma. Affiliate stigma refers to the process “when individuals perceive and internalise courtesy stigma” (Mikami, Chong, Saporito, Systems, & Na, 2015, p. 595). Thus, a parent, for example may recognise that they are being unfairly judged based on their child’s behaviour or stigmatised condition. This leads them to feel shame and embarrassment which, when internalised, has been linked to affective, cognitive and behavioural consequences including increased depression and anxiety, increased stress levels, excessive worry and self-blame and avoiding social interaction (Mikami et al., 2015). Mikami et al. (2015) describe a vicious cycle operating in parents of children with ADHD who experience affiliate stigma. In this study, parents displayed increased negativity in their parenting such as becoming overly upset, being too strict or over-correcting their child's behaviour. This was associated with poorer social skills, aggressive behaviour, and social withdrawal from their children, thus leading to on-going problem behaviour in their children which served to increase parental negativity. These parents were also less likely to seek social support or seek treatment for their children.

Anticipated and internalised stigma are associated with decreased help-seeking behaviour. Anticipated stigma refers to "the extent to which a person with mental illness expects to be the target of stereotypes, prejudice or discrimination in the future" (Fox et al., 2018, p. 15). Internalised stigma (also sometimes referred to as self-stigma) is "the extent to which people endorse negative beliefs and feelings associated with the stigmatised identity for the self" (Fox et al., 2018, p. 16). Internalised stigma can further be broken down into the internalised stigma of having a mental illness (e.g., I am unlovable because I have ADHD) or the internalised stigma of seeking treatment for the illness (e.g., I am weak because the doctor has to give me medication to control my behaviour). Internalised stigma negatively impacts self-efficacy, self-esteem and hope. This is associated with decreased empowerment, weakened social support and decreased quality of life, which in turn decreases the likelihood of seeking mental health care (treatment and counselling), as well as adhering to pharmacotherapy. Fox et al. (2018) found that internalised stigma of seeking treatment had a more profound effect on intention to access mental health support than internalised stigma of having a mental illness.

2.3.2 Conceptualising stigma and childhood

Stigma as it relates to child mental health and their families is assumed to play a significant role in the experience of mental illness as well as help-seeking behaviour. Despite the proposed significance of stigma in understanding child mental health, it's role has not been well-conceptualized and few stigma researchers have addressed the concept as it relates to child mental health (Mukolo, Heflinger, & Wallston, 2010).

When exploring ADHD as a potential barrier to care, it is important to take into account factors such as the ways in which parents, families and caretakers cope with a child's diagnosis and how this impacts their accessing care for the child (Mukolo et al., 2010). Parents of children with ADHD reported experiencing anger, frustration and helplessness, which they attributed to the difficulties of parenting a child with ADHD within families and communities who hold stigmatising attitudes towards ADHD (Mofokeng & van der Wath, 2017).

Given the paucity of literature on stigma in relation to child mental health, Mukolo et al. (2010) constructed a conceptual framework by reviewing literature on child mental health stigma and augmenting it with research related to adult mental health stigma. In order to understand what stigma is, Mukolo et al. (2010) posit that we need to know "*who* does *what* to *whom?"* (p. 6). The who, what and whom can be understood in terms of three interrelated constructs, namely the context of stigma, the dimensions of stigma, and the targets of stigma (Mukolo et al., 2010).

Context. Context refers to the "who" of stigma and can be broken down into three categories: public, self and institutions or service providers. Public stigma occurs when a large number of people accept a negative stereotype about an individual (or groups of individuals) based on the assumption that the person is in some way different and should be treated differently (Mueller, Fuermaier, Koerts, & Tucha, 2012). Individuals who experience stigma may turn the prejudice and negative attitudes towards themselves, resulting in self-stigma (Corrigan & Watson, 2002). Mental health patients may also experience institutional stigma at places where they access health services such as community clinics or hospitals. Additionally, children may experience institutional stigma at school.

Dimensions. Three important dimensions of stigma can be identified: stereotypes (or attitudes), devaluation and discrimination (Mukolo et al., 2010). These dimensions can elucidate the "what" of stigma. Negative stereotypes towards individuals with mental illness could lead to their devaluation within society and the community, and subsequently to discrimination.

Target. Stigma can be targeted at both the individual who is diagnosed with a mental health disorder, and/or their caregivers and families. In this regard, Goffman (1963) proposes courtesy stigma which refers to the experience of stigma based purely on an individual's association with a stigmatised person.

In studying ADHD and childhood mental disorders, this framework can be applied to untangle the complexity of stigma with regards to the ways in which it affects both children and their families and the level of care they are able to access.

2.3.3 Stigma and ADHD

Hinshaw (2005) claimed that there are four aspects of mental health disorders, relevant to ADHD, that may result in individuals with the disorder being stigmatised. Firstly, ADHD is not tangible or visible. Therefore, people may not have insight into why an individual with ADHD is behaving in a certain way, such as impulsively shouting out answers or being unable to follow instructions. Second, it is a chronic, long-term condition. Hinshaw contends that individuals with lifelong challenges experience greater stigmatization than those with short-term problems. Third, the media may portray ADHD in a negative light. However, Ray and Hinnant (2009) found that general media coverage of ADHD has become more sympathetic and less pejorative between 1985 and 2008. Although the diagnostic criteria do not include any reference to "dangerousness" as a potential characteristic of ADHD, certain stigma remains in the media; particularly stigma related to the marginalization of people with ADHD, as well as the overall "dangerousness" associated with having a mental health disorder. Research shows that perceived dangerousness of individuals with mental health conditions is a key contributing factor in experiences of stigma and discrimination (Kapungwe et al., 2010). The media has also portrayed ADHD as a myth and perpetuated the idea that psychopharmacological treatment is based on a hoax created by pharmaceutical companies for financial gain (Schoeman, 2017). Hinshaw's (2005) fourth reason why people with ADHD may experience stigma is that the types of behaviours associated with ADHD, such as interrupting, fidgeting or not paying attention, are often thought of as controllable. Research indicates that people tend to display greater stigma towards "abnormal" behaviour if they believe the behaviour to be under the individual's control. In other words, the behaviour is then interpreted as being deliberate or "naughty" rather than due to a psychiatric condition (Wiener et al., 2012). For example, people may assume that children with ADHD who wriggle and do not concentrate are doing so due to defiance or disobedience, rather than understanding that they are experiencing neurologically-based psychomotor agitation which makes it near impossible to keep still and pay attention. Thus, rather than feeling empathy towards a child who is struggling to perform academically, a parent, teacher or the community may label the child as a "problem child" and resort to harsh discipline or unfair punishment, because they are assumed to be able to control their behaviour. This in turn can have far-reaching consequences in terms of self-esteem, perceptions of competence, as well as making friends and maintaining social relationships (Moldavsky & Sayal, 2013; Thompson & Lefler, 2016) This could also link to courtesy stigma, where parents are blamed for failing to control their child's behaviour.

An additional impact of stigma as it relates to ADHD is the influence on perceptions of parents and teachers regarding academic performance. In a study of over 9000 grade 3 children, Eisenberg and Schneider (2007) found that parents and teachers perceived children diagnosed with ADHD to be performing more poorly in reading and mathematics than their peers, even though standardised measures of academic performance did not match this perception. Given that children's self-esteem and confidence is highly influenced by the perception and expectations of parents, teachers and peers, it is possible that being associated with a stigmatised label such as ADHD may affect a child's behaviour and academic achievement (Eisenberg & Schneider, 2007).

2. 4 FACTORS INFLUENCING ACCESS TO CARE

Despite the fact that mental illness is a leading cause of disability worldwide, only two thirds of people with mental health conditions in LMIC countries will receive treatment (Strumpher, van Rooyen, Topper, Andersson, & Schierenback, 2014). In a survey of six LMICs, between 76% to 84% of individuals with serious psychiatric conditions had not received any treatment in the previous year, pointing to a substantial treatment gap (Lund et al., 2012). Sub-Saharan Africa is among the most resource-constrained regions in the world, where up to 20% of children and adolescents suffer from a mental health problems in an environment with inadequate support (Atilola, 2017). Reported barriers to adequate care in South Africa include: socio-economic hardship, lack of knowledge and insight, lack of family support, embedded cultural beliefs about mental health, stigmatization, lack of health care resources and infrastructure and poor access to technology and information (Bimerew, Adejumo, & Korpela, 2015; Strumpher et al., 2014).

In South Africa, it was reported that 15% of children between the ages of six and 16, met the criteria for a mental health condition (Patel, Flisher, Hetrick, & McGorry, 2007). Despite this however, child mental health services remain “a relegated and obscure aspect of child health initiatives” (Atilola, 2017, p. 381). As a result of the lack of child mental health services in South Africa, one could hypothesise that many children who potentially meet the diagnostic criteria for ADHD are not timeously identified and diagnosed which in turn affects their opportunity to receive early intervention and maximise their abilities.

Mental health and subsequent access to treatment can be viewed as multi-layered, consisting of biological, psychological and sociocultural factors (Eriksson, Ghazinour, & Hammarström, 2018). Atilola (2017) and Eriksson et al. (2018) suggest using Bronfenbrenner’s (1979) ecological model of development in understanding and addressing the factors which influence access to treatment, because the model takes into account both individual development and the broader social context. According to Bronfenbrenner (1979, cited in Hook, 2009), a child's development (including their mental health) is equally influenced by intrapersonal, interpersonal, and environmental factors. These can be understood as a system of successive layers, comprised of a microsystem, mesosystem, exosystem, and macrosystem (Hook, 2009).

The microsystem refers to the immediate context that affects a child's development, which includes their interactions with and the influence of their primary caregivers, siblings, classmates and teachers. (Hook, 2009). Microsystemic barriers for children with ADHD can include lack of parental and teacher knowledge of ADHD. Parents are responsible for making treatment decisions for their children including choosing to consult a health professional, as well as decisions regarding treatment such as psychotherapy or pharmacotherapy. Taylor and Antshel (2019) report a significant delay in seeking treatment for ADHD, which may be influenced by negative parental attitudes associated with poor knowledge and understanding about the condition.

Teachers are often the primary source of identification of ADHD and play a vital role in the management of the condition. In a South African sample of 100 teachers, more than half of the participants expressed "no confidence in their ability to teach children with ADHD" (Amod et al., 2013, p. 224). In the same study it was found that teachers possessed very poor knowledge about the treatment of ADHD. Consequently, children may remain unidentified as needing additional assistance and being referred for treatment.

Multiple microsystems make up the mesosystem, and include a child's school, neighbourhood, and peer groups, as well as the interaction between microsystems, such as communication between parents and teachers (Hook, 2009). In South Africa, challenges within the education system may form a barrier to care. The Human Rights Commission (2015) reports that children:

> continue to be significantly affected by a lack of teacher training and awareness about inclusive education methodologies and the diversity of disabilities, a dearth of understanding and practical training about children's needs according to their disabilities, and an absence of incentives for teachers to instruct children with disabilities. (p.3)

In addition, educators are required to implement the Policy on Screening, Identification, Assessment and Support (SIAS) to determine which children need support, what type of support is required, and how it will be implemented (Western Cape Government, 2019). This process can be lengthy and time-intensive which may lead to children not being referred for help. Furthermore, children who are referred for support and who require specialised intervention may not receive it due to the historical barriers to access care and a lack of resources. South Africa continues to grapple with the aftermath of Apartheid which promoted and perpetuated exclusion on many grounds, including disability and special education needs (Amod et al., 2013). The Parliamentary Monitoring Group (2019) reported that 2352 children were on the waiting list for special education schools in April 2019. Thus, schools can pose a barrier to access due to being ill-equipped in identifying ADHD or managing the behavioural and academic challenges inherent to ADHD, despite the country following inclusive education policies (Amod et al., 2013; Human Rights Watch, 2015).

The exosystem represents the larger social context that affects the quality of care that a child can receive (Atilola, 2017). The under-resourced health system in South Africa, both financially and in terms of training, poses a significant exosystemic barrier to care for children with mental health conditions. A study in the Eastern Cape reported that professional nurses in a primary health care clinic did not have adequate knowledge and skills to manage mental health patients, which can lead to misdiagnoses or inadequate treatment (Strumpher et al., 2014). Furthermore, Docrat, Lund and Chrisholm (2019) report that:

> hospitals are outdated and in disrepair; there is an acute shortage of mental health professionals available to deliver this service; these facilities are unable to invest in the advancement of their scope of service (for example, child and adolescent psychiatry, neuropsychiatry and old age psychiatry. (Challenges to increased public and mental health financing section, para. 3)

Despite research demonstrating inadequate resources for mental health, less than $0.1 (±R1.47) per capita was spent on mental health in 2017 in South Africa (Statista, 2021).

The overarching institutional patterns of the culture and subcultures that surround an individual consisting of traditions, customs, values, ideologies, and policies form the macrosystem (Hook, 2009). Despite significant headway in economic transformation since 2000, South Africa remains plagued by inequality and poverty (Statistics South Africa (Stats SA), 2020). Poverty is a profound risk factor in children’s physical, cognitive and emotional development, and is strongly associated with mental ill-health (Lund et al., 2008; Stats SA, 2020). In reviewing childhood poverty, Stats SA (2020) found that 62.1% of children aged between 0 to 17 years are multidimensionally poor. Multidimensional poverty implies that an individual is deprived on multiple dimensions which can include housing, protection, health, information, WASH (drinking water, sanitation and waste disposal) and education/child development (Stats SA, 2020). Education, Housing, WASH and Health were found to be the major contributions to poverty in primary school children in South Africa (Stats SA, 2020).

Stigma, which is based on community perceptions, presents a notable macrosystemic barrier to care (Ilic et al., 2013; Wahl, 2012; Pepin, Segal & Coolidge, 2009). Although studies regarding mental health stigma in communities in South Africa are limited, the available studies indicate high levels of stigmatizing attitudes towards people with mental health conditions (Kakuma et al., 2010). In a community sample in Kwa-Zulu Natal, South Africa, Rajcumar and Paruk (2020) found that most parents accessing treatment for ADHD for their children has experienced stigma related to their child's illness and that many parents also endorsed popular misperceptions about ADHD. The South African National Mental Health Policy Framework and Strategic Plan (2013) highlighted stigma as a key barrier that needs to be addressed in order to improve the quality and access to care in mental health in South Africa. Semrau, Evans-Lacko, Koschorke, Ashenafi and Thornicroft (2015) highlighted that there is a lack of research regarding the efficacy of initiatives aimed to reduce stigma in LMICs such as South Africa. Further research to understand and address stigma is needed.

2.5 SUMMARY

This chapter outlined the nature of ADHD, stigma, and barriers to care, globally and in the South African context. The next chapter will discuss the methodology that was used in the study.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

This section describes the methodology that was used for this study. The research aims will be re-stated, followed by an outline of the research design, sampling strategy and data collection and analysis methods that were used. This will be followed by a discussion of the procedures used to increase the trustworthiness of this research and a critical reflection on my role as a researcher conducting this study. Finally, the ethical considerations for this study will be addressed.

3.2 RESEARCH AIMS

As highlighted in the literature review, stigma seems to act as a barrier to seeking treatment for mental health conditions due to fear of negative reactions and discriminatory behaviour from family and friends, and society in general. Hence, the aim of this study was to address the lack of knowledge regarding stigma as it relates to ADHD and how this in turn affects help-seeking behaviour.

The study was guided by the following aims:

- To assess parents' and educators' knowledge of ADHD
- To explore parents' and educators' understandings of stigma
- To explore factors acting as barriers to accessing health care
- To determine if stigma is perceived to be a barrier to accessing health care

- To better understand the barriers which parents and educators face in accessing care for children with ADHD
- To explore parents' and educator's experiences of stigma in relation to ADHD
- To gain a deeper understanding of how stigma acts as a barrier to accessing care

3.3 RESEARCH DESIGN

In this cross-sectional exploratory study, I used a convergent parallel mixed method research design to collect qualitative and quantitative data concurrently. After analysing the data, I interpreted and integrated the findings (Creswell, 2014).

Quantitative research is used for testing specific variables and investigating the relationships between them. Findings are presented in terms of numbers which can be statistically analysed (Creswell, 2014). A critique levelled against quantitative research is that it does not consider the common meanings created in social experience. The data collected is unable to explain the meaning underlying certain behaviour and rather provides an overall picture or snapshot of the variables which have been identified (Rahman, 2017).

Qualitative research, on the other hand, is an approach used to understand the meanings that people assign to a specific personal or social experience (Creswell, 2014). Data is collected through processes such as interviews and focus groups and presented in terms of words (rather than numbers). Qualitative research is primarily focused on individual meaning and has the ability to enrich the results of the quantitative data by "putting meat on the bones of the 'dry' quantitative findings" (Bryman, 2006, p. 106). It can assist to "test" the hypotheses generated by the qualitative investigation by offering an explanation as to the relationships discovered.

Yardley and Bishop (2008) suggest a pragmatic worldview as a guide in selecting a mixed method study. Pragmatism proposes that qualitative and quantitative methods complement each other, where quantitative enquiry provides norm-referenced data that can be compared to different people and populations, while qualitative enquiry provides rich information about individual experience (Yardley & Bishop, 2008). In adopting a pragmatic approach, I used self-administered questionnaires and semi-structured interviews in this study.

I asked participants to complete three self-administered questionnaires to capture their relevant demographic information, and to identify the key constructs and trends regarding the participants' knowledge of ADHD and the degree to which stigma exists as a barrier to care. I conducted semi-structured telephonic interviews to explore the participants' experiences of stigma in their communities, and the barriers which they have encountered. The qualitative portion of the study was conducted within a phenomenological paradigm. Phenomenological research "prioritizes and investigates how the human being experiences the world" (Given, 2012, p. 5). The interviews provided an opportunity to explore each participant's experiences of ADHD and stigma and how they make sense of the constructs which were investigated in the quantitative part of the study. In employing a mixed method design, I was able to collect empirical data which could be statistically analysed, while remaining attentive to the complexity of each participant's lived experience, the qualitative strategy enabled me to provide a comprehensive and rich analysis of the research problem being investigated (Creswell, 2014).

3.4 SAMPLE AND SAMPLING STRATEGY

I used convenience sampling to recruit participants for the study. Convenience sampling is a method of purposive non-probability sampling where "members of the target population that meet certain practical criteria" (Etikan, Musa, & Alkassim, 2016, p. 2) are selected for a research project. For the current study, selection criteria included that the participants needed to be able to complete the questionnaires in English, and they could either be a teacher at the selected schools, or a parent whose child has been screened by #gb4adhd at the chosen schools.

3.4.1 Context

Participants for this study were recruited from schools in the Western Cape where #gb4adhd currently renders free ADHD and mental health screening and early intervention services. Schools are assigned to #gb4adhd by the Department of Education. Most of the schools that #gb4adhd render services to are non-fee-paying schools. However, some schools have a stratified fee structure, i.e., depending on economic standing, some families are required to pay school fees.

Using the data from the most recent National Census conducted in 2011, the Information and Knowledge Department of the City of Cape compiled reports summarising the basic demographic, economic, dwelling and household data for specific areas in the Western Cape (Department of Information and Knowledge Management, 2013). Based on the afore-mentioned report, I used the data of the suburb Belhar as a proxy for the social context of the participants in this study. Using Belhar as an example of an area in which #gb4adhd has screened, the community statistics reflected that 79% of the labour force (aged between 15 and 64) was unemployed and

35% of households had a monthly income of R3200 or less. Furthermore, the report showed an average of 4.46 people per household, with 38% of people, aged 20 years or older, having completed Grade 12 or higher.

3.4.2 Participants

With reference to the practical criteria which this sample meets (as required in convenience sampling) for this study, the educators who participated have experience in teaching in low-income schools and under-resourced communities. As previously mentioned, 1 in 20 school-going aged children meet the diagnostic criteria for ADHD. In 2017, the Western Cape Government reported that the average learner-educator ratio in schools was 44:1 (Western Cape Government, 2017). Thus, it is likely that all educators have interacted with at least one child with ADHD in their classrooms and can therefore provide their insight on the experiences of teaching children with ADHD, as well as the possible challenges faced by the children and their families.

The parents in the sample have the experience of parenting a child who attends school in a low-income community, and was referred to #gb4adhd due to learning, behavioural or emotional barriers to education. All parents of children who were screened by #gb4adhd in the six participating schools were invited to take part, regardless of the outcome of the screening or whether their child/children met the diagnostic criteria for ADHD or another mental health condition.

3.4.3 Sampling procedure

As proposed by Caven (2012), a researcher relies on the goodwill of their participants to offer their time and insight for no gain of their own. I remained conscious of this by ensuring that I was flexible in my approach to sampling, and to the different protocols which the schools requested. By doing this I hoped to make sure that the school leadership, and subsequently the parents, felt comfortable and heard.

The Covid-19 pandemic and subsequent national lockdown coincided with the beginning of data collection for this study. Based on the Stellenbosch University Covid-19 research guidelines, I had to change the initial sampling procedure because face-to-face contact was prohibited and distributing paper-based questionnaires as originally intended was also deemed unsafe.

Having received permission from the Stellenbosch University Research Ethics Committee to conduct the study with adjusted methods based on Covid-19 restrictions (see Appendix B) and permission from the Western Cape Department of Education to begin the study (see Appendix C), I sent an email to the principals at the schools to request permission to conduct research at their schools (see Appendix D). Each email was tailored to the specific school principal and information regarding how many children were screened at the school and the outcome of the screening (e.g., number of children diagnosed with ADHD and other mental other conditions). I also sent an additional text message to the specific staff members with whom I had an established working relationship with. At the time of data collection, #gb4adhd was active in 26 schools within the Metro North Education District (MNED) and Metro East Education Districts (MEED). According to the Annual Report 2018/2019 of the Department of Education for the Western Cape, there are 189 school MNED and 175 schools in MEED (Western Cape Government, 2019). I approached the 26 schools where #gb4adhd has screened children, and six schools indicated that they would be willing to participate in this study. Of the six identified schools, two falls within MEED and four within MNED. Furthermore, two schools are non-fee-paying schools, and four schools have stratified fee structures.

Once permission was granted by the school principals to conduct the research, I made contact with parents and educators either via email, text message or WhatsApp message depending on the type of contact details available for the participant. I used the contact details which were collected during the #gb4adhd screening process to contact the parents, with a total of 451 parents being asked to participate.

Each of the schools presented specific procedures and guidelines which they requested I should follow when I contacted the teachers. For example, in one school, the learning support teacher indicated that she would send out a bulk email to the staff members asking if they would participate, while another school emailed me a list of staff members that I could contact. A total of 163 teachers were invited to participate. Of these, I contacted 34 teachers directly, and 129 teachers were invited via the school (either through the mass email or through staff WhatsApp groups).

The email/text/WhatsApp included a Google Forms link to the information sheet and consent form (see Appendix E). Those who indicated their willingness to participate in the research were sent a link to the questionnaire, which also included an option to indicate their willingness to take part in a follow-up interview. If they were willing to participate in the follow-up interview, they were contacted by their preferred method of communication. They were thanked for their contribution so far, and a suitable time to schedule an interview was requested.

A total of 26 parents and 19 educators completed the self-report questionnaires regarding their knowledge of ADHD and the barriers to access to care. This represents a response rate of 5.76% of parents, and 11.66% of teachers. Of those, 12 parents (2.6%) and 6 educators (3.68%) agreed to take part in a telephonic interview with the purpose of gaining a deeper understanding of their experiences regarding ADHD and stigma in their community. Although Nulty (2008) reports response rates ranging from 50% to 60% as acceptable, the Covid-19 pandemic presented significant challenges regarding recruiting participants. Covid-19 restrictions prohibited the use of paper-based questionnaires as originally intended, which necessitated the use of online questionnaires. Online questionnaires are reported to have lower response rates than paper-based questionnaires (Nulty, 2008). Furthermore, given the environment in which the participants live, namely under-resourced communities, relying on technological infrastructure to invite participants, as well as for them to complete the questionnaire and interview (where applicable) was a barrier. These factors may have contributed to a low response rate.

The Goldilocks and The Bear Foundation has had varied experiences working in the different schools since June 2017. In every school environment there is a complex interplay of factors which either hinder or facilitate a collaborative working environment between the school and #gb4adhd. These factors include school leadership, the level of functioning of the school-based support team, teacher “buy in” to the process, resources, literacy, and parental investment. These experiences were mirrored in as much as the schools who were willing to participate in the research, were also those in which the team members of #gb4adhd expressed anecdotal evidence of having had an “easy” working relationship. This was evidenced during screening and intervention through factors such as timeous return of documentation, teachers and principals who were eager to engage with the #gb4adhd team and a higher attendance rate of parental guidance meetings.

3.5 DATA COLLECTION AND ANALYSIS

I conducted a mixed method study to statistically investigate specific variables and relationships pertaining to stigma and ADHD, as well as to understand the meanings that individuals assign to their personal and social experiences regarding ADHD, barriers to accessing treatment and stigma (Creswell, 2014). I collected quantitative data with self-administered questionnaires, and qualitative data through semi-structured telephonic interviews.

3.5.1 Quantitative data collection

Three measurement instruments were used to gather relevant demographic information, investigate parents’ and educators’ knowledge of ADHD, and the barriers which they have experienced in accessing mental health care.

3.5.1.1 Demographic Questionnaire

For this study, I developed a brief demographic questionnaire to collect relevant information from participants including age, race, gender, highest level of education, current employment status and average monthly income. Participants were also requested to indicate whether they and/or their child(ren) had been diagnosed with ADHD or another mental health condition such as anxiety or depression (see Appendix F for the demographic questionnaire).

Stigma and discrimination are recognised worldwide as barriers to inclusion for people with mental health disorders, however the majority of research in this regard has been conducted in high-income countries (Semrau et al., 2015). It was therefore challenging to identify measurement instruments which were an “exact fit” for this study. In addition to the self-designed demographic questionnaire, I chose the Knowledge of Attention Deficit Scale (KADDS) and the Barriers to Access to Care Evaluation (BACE-3) as they measure important concepts related to stigma and ADHD and have been used in LMICs.

3.5.1.2 The Knowledge of Attention Deficit Disorder Scale (KADDS) **(Sciutto & Feldhamer, 2005)**

As mentioned previously, Thornicroft (2008) posits that lack of knowledge, which consists of misperceptions and ignorance, is a primary component underlying stigma. Hence, I used the KADDS to investigate the participants’ knowledge of ADHD. The KADDS has high internal consistency ($.80 < r, \alpha < .90$) and moderate to high test re-test stability ($0.59 < r < 0.76$) (Sciutto & Feldhamer, 2005). The KADDS has been used in studies in South Africa, as well as internationally (Flanigan, 2016; Rajcumar & Paruk, 2020; Shroff et al., 2017; Topkin, 2013; Topkin, Roman, & Mwaba, 2015). A cross-national study of nine countries reported good internal consistency across the total measure of knowledge, as well as across subscales (Sciutto et al., 2016)

In a South African study, Perold et al. (2010) reported a consistency of 0.81 for correct responses and higher for incorrect responses.

The KADDS is a self-administered questionnaire comprising of 36 items (see Appendix G). Educators and parents were asked to complete the KADDS, which measures specific issues related to ADHD such as its associated features, symptoms, diagnosis and treatment, as well as investigating common misperceptions that people have about ADHD (Sciutto & Feldhamer, 2005).

The rating scale uses a true (T), false (F) or don't know (DK) format. Examples of items include: "In order to be diagnosed with ADHD, the child's symptoms must have been present before age 7", "ADHD children often fidget or squirm in their seats" and "Current research suggests ADHD is largely the results of ineffective parenting skills". This format allows for differentiation between what parents and educators do not know about ADHD, versus the myths or misconceptions which they hold. The KADDS is scored using a standardized scoring procedure outlined in the *Test Manual for the Knowledge of Attention Deficit Disorders Scale (KADDS)* (Sciutto & Feldhamer, 2005). One point is allocated for correct scores, and zero points allocated for incorrect answers and "don't know" responses, which point to gaps in knowledge (Soroa, Gorostiaga, & Balluerka, 2012). Thus, a low score reflects poor knowledge of that specific dimension of ADHD.

3.5.1.3 The Barriers to Access to Care Evaluation (BACE-3) **(Health Services and Population Research Department, Institute of Psychiatry, King's College London)**

I used the BACE-3 to explore both stigma and non-stigma related barriers such as financial constraints, attitudes towards effectiveness of treatment, and knowing where to go to access help.

The BACE-3 is a 30-item self-administered questionnaire which is designed to assess the barriers that people experience in accessing proper mental health care (Silva et al., 2013) (see Appendix H for Bace-3 items). The measure is available online from The Indigo Network, a collaborative group of researchers based in 30 countries worldwide who aim to investigate the impact of stigma on people with mental health disorders (The Indigo Network, 2019)

The BACE-3, designed and validated by Clement et al. (2012), explores stigma-related barriers such as anticipated discrimination, social stigma, disclosure concerns, stereotypes, internalised stigma and stigma by association. The measure includes a 12-item treatment stigma subscale, which investigates the "stigma and discrimination that individuals believe to be associated with receiving care for a mental health problem" (Clement, Brohan, et al., 2012, p. 4). When completing the questionnaire, participants indicate whether the described item or issue has delayed or stopped them from seeking treatment for their mental health challenges. The questions are answered by selecting one of four possible answers: not at all (0), a little (1), quite a lot (2) or a lot (3).

Clement et al. (2012) demonstrated that the measure has acceptable test-retest reliability, validity, acceptability and readability, with an average 11 to 12 year old being able to understand the questionnaire. Using a Portuguese translation of the BACE-3, Miranda, Caetano and Madeira (2018) reported good validity, with an internal consistency of 0.961 for the full BACE-3 scale and 0.964 for the stigma subscale. The BACE-3 was adapted and used in Brazil in 2013. Silva et al. (2013) reported that the Brazilian version of the measure is able to provide critical knowledge needed to address inadequacies in mental health care in the country. No published studies using the BACE-3 in South Africa were found. Given that South Africa and Brazil are both classified as LMICs or developing countries, reflecting similarities in terms of poverty rates and low education and literacy levels (World Population Review, 2019), I deemed the BACE-3 as suitable to use in this study.

3.5.2 Quantitative data analysis

The statistical analysis was done in consultation with Professor Martin Kidd from the Stellenbosch University Centre for Statistical Consultation. Descriptive statistics and correlations were used to explore the participants' demographics, their knowledge of ADHD based on the KADDS, and the barriers which they experience in accessing care based on the BACE-3. The correlation between participants' knowledge of ADHD and their reporting of barriers to care was also investigated. In addition, Analysis of Variance (ANOVA) was used to investigate differences in terms of a) performance on the KADDS, b) reported barriers on the BACE-3 and, c) whether having a child with ADHD impacted participants' knowledge of ADHD.

3.5.3 Qualitative data collection

When completing their consent form, participants were asked if they would be willing to take part in a follow-up telephonic interview. I used a qualitative semi-structured research interview, " with the purpose of obtaining descriptions of the life worlds of the interviewee with respect to interpreting the meaning of the described phenomena" (Kvale, 2011, p. 8). I conducted a total of 18 interviews.

3.5.3.1 Semi-structured interview

A qualitative interview is a construction site for knowledge where the quality of the knowledge that is produced is dependent on the interviewers "ability to create a stage were the subject is free and safe to talk of private events for public later public use" (Kvale, 2011, p. 9). I used semi-structured interviewing, which is suitable when the "researcher knows enough about the topic or phenomenon to identify the domain (i.e., knows the limits of the topic and what is and is not pertinent to the research question) but does not know and cannot anticipate all of the answers" (Morse, 2012, p. 200). Semi-structured interviews allow reciprocity between interviewer and participants, provide a space for the participant to express their individual thoughts and feelings and have proved to be versatile and flexible by allowing the interview to improvise follow-up questions based on participant responses (Kallio, Pietilä, Johnson, & Kangasniemi, 2016)

I used an interview guide consisting of open-ended questions that I compiled by combining prior knowledge of ADHD and stigma based on my review of the literature combined with my experience of working in the community. Table 3.1 shows the interview questions that were informed by the research aims of the study.

I conducted the interviews in English. However, participants did at times answer questions in Afrikaans. I encouraged them to express themselves in whichever way was most comfortable. In instances where questions were answered in Afrikaans, I consulted with an Afrikaans-speaking peer who ensured that my transcription was accurate and assisted in translating those excerpts.

Table 3.1

Outline of Research Aims Guiding Interview Questions

Aims	Interview Questions
To explore parents' and educators' understandings of stigma	Can you describe what stigma means to you? How do you think stigma impacts someone with a mental health condition? Does stigma affect the family? In what ways? How do you think stigma can be addressed in your community? Whose responsibility is it to educate people about ADHD and mental health conditions?
To explore parents' and educators' experiences of stigma in relation to ADHD	How does it feel when your child/student is treated differently because they have behavioural, emotional, or learning difficulties?
To explore factors acting as barriers to accessing care	What are the biggest challenges in your community for children with ADHD and other mental health conditions? What do wish people knew about mental health conditions?
To better understand the barriers which parents and educators face in accessing care for children with ADHD	Do you know what help is available in your community for people with ADHD and mental health conditions? Have you accessed this help?
To gain a deeper understanding of how stigma acts as a barrier to accessing care	In what ways are people with mental health conditions discriminated against? Why do you think this is?

Due to Covid-19 and the associated risks, I conducted the interviews telephonically. Irvine, Drew and Sainsbury (2012) report a lack of empirical evidence regarding the impact of using telephonic interviews rather than face-to-face to interviews. However, available research shows that telephonic interviews have the advantages of widening geographic access, eliminating the costs associated with travelling to interviews, and enabling access to closed research sites, such as schools during the Covid-19 lockdown (Opdenakker, 2006). Furthermore, participants may be more willing to divulge information deemed too sensitive to disclose face-to-face (Irvine et al., 2013; Opdenakker, 2006). Disadvantages of using telephonic interviews are the lack of non-verbal data such as body language and facial expression, loss or distortion of verbal data through poor audio quality or technological failure, being removed from the interviewees' social context and increased mental fatigue and distraction (Irvine et al., 2013; Opdenakker, 2006).

In order to address the possible disadvantages, I ensured that I conducted the interviews in a quiet room and recorded the interview on two external electronic devices. In addition, I offered frequent verbal feedback and reassurance (e.g., "Mmhmm", "okay…", "can you say more about that?") to compensate for lack of face-to-face non-verbal cues such as nodding and eye-contact.

To enhance the feeling of safety and build rapport, I started each interview by making "everyday" conversation, checking in with the interviewees and thanking them for offering their time and for participating in this study. Following Kvale's (2011) recommendations, I briefed the interviewees at the start of the interview, and I provided a brief structure for the interview. I reminded the interviewees that the interview would be audio recorded and once again asked their permission to do so. I reminded the interviewees that they were free to only answer questions which felt comfortable for them, and I explained that they would have a space to ask any questions at the end of interview. At the end of the interview, I made time for reflection and created memos documenting my experience of the interview, what feelings I was left with, and noting salient points or moments during the interview.

3.5.4 Qualitative Data Analysis

I conducted a total of 18 interviews which ranged from 10 minutes to 71 minutes in length, with an average of 29 minutes. The interviews were audiotaped, and I transcribed the interviews verbatim (see Appendix I for an example of a transcribed interview). This was done to immerse myself in the data, to re-awaken the social and emotional experience of the interview, as well as to reflect on my own interviewing style and role in each interaction (Kvale, 2011).

Once the transcriptions were completed, they were reviewed by an independent colleague, who listened to the recorded interviews and checked the transcriptions for accuracy. The transcriptions were stored on a password protected folder on my personal laptop. I then uploaded the finalised transcriptions to ATLAS.ti, which is a computer-assisted qualitative data analysis software (CAQDAS) platform. In this way unstructured data contained in the interview transcripts can be broken down into smaller manageable pieces ("ATLAS.ti 8," 2019). I also uploaded the memos which I had made after each interview.

After I uploaded the data in Atlas-ti, I used Braun and Clark's (2019) six phases of reflexive thematic analysis which provides a rigorous and systematic approach to analysing qualitative data by uniting seemingly disparate pieces of data into meaningful patterns in order to generate codes and themes. Braun, Clarke, Hayfield and Terry (2019), state that reflexive thematic analysis aims to "provide a coherent and compelling interpretation of the data, grounded in the data" (p. 848) where "the researcher is a storyteller, actively engaged in interpreting data through the lens of their own cultural membership and social positionings" (p. 848). I used the following six phases to analyse the data from the semi-structured interviews:

Familiarising yourself with your data. To begin the data analysis, I re-read all the transcripts by employing active reading. This refers to engaged reading of the transcripts while searching for meaning and patterns in the data (Braun & Clarke, 2006). I also re-read the notes which I had made after each interview. In doing this, I was able to identify key issues that appeared across interviews and used these to generate the initial codes.

Generating initial codes. Generating codes refers to systematic and detailed engagement with the data in order to identify meaning throughout the dataset by attaching clear labels (codes) to 'chunks' of data as a way of organising and collating extracts from the around patterns of meaning (Braun et al., 2019). I applied an inductive approach of "line by line" coding, which is a process of open coding where one breaks down data into pieces and, in doing so, opens it up into all the possible ways in which the data can be understood (Lewins & Silver, 2007). Linneberg and Korsgaard (2019) posit that this process facilitates staying "close to the data, mirroring what is actually in them, rather than the ideas and prior understandings of the researcher" (p.263). I worked through each transcript thoroughly, which resulted in total of 90 codes.

Generating themes. I started this phase by creating mind-maps and other manual visuals in order to group initial codes into meaningful categories. Kvale (2011) suggests that a combination of computer-based and paper-based analysis provides the researcher alternative ways of making sense of the data (see Figures J1 and J2 in Appendix J for examples of paper-based analysis). Themes can be seen as interpretive and creative stories about data which are "produced at the intersection of the research's theoretical assumptions, their analytic resources and skill and the data themselves" (Braun & Clark, p. 594). In this second phase of coding, axial coding, one identifies relationships between open codes to develop overarching themes (Williams & Moser, 2019). Through grouping the initial codes into categories, and removing any redundant codes, I formulated ten subthemes. Table 3.2 provides an example of a coded transcription and demonstrates initial coding, axial coding, and the generating of categories which informed the subthemes.

Table 3.2

Example of a Coded Transcription

Transcript	Initial codes	Axial codes	Subtheme
R: Okay. Okay. All right. And how do you, do you think children with ADHD are treated differently by other people.			
AVA: Um, sometimes ja... like the school they don't give special attention to the children, who was diagnosed with ADHD. They treat them the same like the normal kids.	Diagnosed with ADHD Treated differently Being overlooked “Normal”	Stigma_difference Stigma_isolation	Defining stigma Individual impact of stigma
R: Okay.			
AVA: And I see that as very very unfair. That's very very unfair.	Emotion – unfair	Stigma_fam_emotions	Impact of stigma on the family
R: Okay, so it feels like maybe at school they should be treated in a different way.			
AVA: Yes, yes.			
	Treated differently	Stigma_difference	
R: And in what way do you mean?			Defining stigma
AVA: Um maybe extra classes for children who diagnosed. And then for the parents who wants to put the children in normal schools, so they can have maybe a class, just separately, they can put their children in that class that they can	Separated Need special attention “Normal” Feel included	Stigma_exclusion Stigma_isolation	Manifestations of stigma Impact of stigma on the individual

just get more attention. So that they can just feel a, a part of normal, not otherwise.			
…			
R: Okay okay. Does it, do you feel that at school that that's not happening that they are not sort of made to feel, like you say, "normal" like the other children?			
AVA: No, he's in like a normal school. The standards are very very high with that school and stuff, and I saw, because I've helped out in the school and stuff, and there are lot of kids who is diagnosed with ADHD, and they just give a tablet, and they go on like there is nothing wrong.	Need for academic support ADHD not taken Seriously Medication More support at school		
R: All right, and how does it feel for you as, as a mom when, when, you know, you feel like your child is being treated differently or is not being given the correct support?			
AVA: It makes me angry because the people that, the children at school is bullying my child, the children, because they are different from the others. Maybe they slower or they are something. It makes me angry, actually	Emotion_angry Bullying Being treated differently "slower"	Stigma_bullying Stigma_difference Stigma_fam_emotions	Manifestations of stigma Impact of stigma on the family

Note. Portions of the transcribed conversation which were not coded are omitted from the above example for brevity. Omissions are indicated with ellipses (…)

Reviewing themes. In honouring the iterative and cyclical nature of reflexive thematic analysis, I reviewed the subthemes by checking them against the dataset in order to determine whether they reflect the overall story of the data set (Braun et al., 2019). Through remaining open minded in looking for patterns and taking notes of any inconsistences or repetition, I refined the 10 subthemes and grouped them into four main themes. I then re-read the transcripts with these themes in mind and made necessary amendments. Figures J3, J4 and J5 in Appendix J provide examples of how I used the tools in Atlas.ti such at networks and links, in distilling the data into overarching themes.

Defining and naming themes. The purpose of defining and naming themes is to determine the scope of each theme and choose informative names which succinctly described the content of the theme (Braun et al., 2019). I reviewed the contents and subthemes contained within each main theme and named them as follows: 1) Understanding stigma, 2) Factors influencing access to care, 3) Unmet needs and desires in the community and, 4) Addressing barriers to care.

Producing the report. The final phase of reflexive thematic analysis involves revisiting your research questions, themes, subthemes and notes in order to "make connection to existing research and literature on the topic of interest, and weaving this into the written results and discussion" (Braun et al., 2019, p. 857). To report on the findings, I integrated relevant theory regarding stigma, ADHD, and barriers to care, together with quotations extracted from the interviews to illustrate and describe the experiences and insights of the participants, and how this relates to current existing theory.

3.6 TRUSTWORTHINESS OF THIS STUDY

Trustworthiness of a study can be enhanced by attending to four criteria: credibility, transferability, dependability and confirmability (Anney, 2014).

Credibility refers to the confidence that a researcher is able to place in the findings of the study (Anney, 2014). I used peer debriefing by seeking the support of colleagues at #gb4adhd and in the field of mental health, and I used these discussions as an opportunity to present my insights and receive feedback. I used data triangulation to enhance the consistency and accuracy of the findings which I presented (Creswell, 2014). I did this by comparing the results from the self-administered questionnaires with the categories, subthemes, and themes which I identified through thematic analysis of the interviews. This allowed me to confirm and corroborate the findings from the different arms of the study (Barnes, 2012). My experience working at #gb4adhd which involves providing mental health services in underprivileged communities has enabled me to build rapport and develop a sense of trust with parents and educators. Anney (2014) proposes that increased trust between researcher and participants lends credibility to a study by minimising distortion of information and increased understanding of the participants’ culture and context.

Transferability refers to the degree to which the results can be transferred to other contexts (Anney, 2014). To enhance the transferability of the study, I provided thick descriptions of the data to convey the findings, leading to a richer and more realistic presentation of results (Creswell, 2014). By using purposive sampling, I was also able to recruit participants who were knowledgeable about the topic and were able to provide in-depth insight.

I also established an audit trail which included systematically collecting and storing all raw data, notes and observations. This enhances the dependability of the study because I am able to account for and provide evidence for all the decisions that I made during the process of data collection, data analysis and compiling the report (Anney, 2014).

The degree to which the findings of a study can be confirmed by another researcher is known as confirmability. In analysing and interpreting data, Silver and Lewins (2017) describe a process of "noting observations and questions [which] will act as reflective ponderings, to return to later once you have pursued a line of inquiry and built on an idea, or noticed something else of salience" (p. 6). Confirmability of a study can be enhanced by maintaining a reflexive practice throughout the research process. I kept electronic memos and handwritten notes throughout the process, developed visual aids such as mind maps and flashcards with important themes and allocated focused time after each interview to document important moments or feelings that were evoked for me.

3.7 RESEARCHER REFLEXIVITY

Reflexivity refers to a disciplined self-reflection which aims to increase the richness and integrity of the findings and meanings derived from research by exposing any relational or ethical dilemmas (Finlay, 2012). Braun and Clarke (2019) highlight the importance of acknowledging that the meaning generated from research is always context-bound, positioned and situated, and reflects the researcher's interpretation of the truth. However, if the researcher is able to remain mindful of their potential influence on the research and remain reflexive, the researcher's subjectivity can be viewed as a resource for meaning-making, rather than a threat to the production of knowledge (Braun & Clarke, 2019).

In conducting this research, I aimed to remain aware of my role and influence on the research, particularly during the interviews. Factors such as class, gender, ethnicity and language influence the way we present ourselves during an interview, and the ways in which we interact with the interviewees (Finlay, 2012). I am a white, English-speaking 33-year-old woman who grew up in Gauteng in a middle-income household, with experience working in the mental health field. These characteristics set me apart from most of the participants in my study in terms of race, class, ethnicity and language. However, I also have a personal history of having a mental health condition, which led to some feelings of identification with the participants. Being cognisant of this fact, I set aside time at the end of each interview to write down my experience and feelings in an effort to disentangle “my stuff” from what the interviewee had disclosed.

My role at the Goldilocks and the Bear Foundation includes screening children for mental health conditions, providing psychoeducation to teachers, parents, and organisations, and providing feedback and interacting with parents. In my role, I have been exposed to the many ways that people make sense of ADHD and mental health, the difficulties the families encounter and the hope which comes with getting the necessary support. It was therefore difficult at times to separate my role as researcher from my role as service provider and psycho-educator. In anticipation of this challenge, I explained to interviewees that there would be time at the end of each interview where I could answer any questions related either to the services we provide at the school, specific information relating to a child I had seen, or general questions about ADHD or mental health. In many instances, the participants made use of this time – and in the case of one mother, even called her mother-in-law to join in the conversation for an additional 40 minutes after the interview ended.

In reflection, I feel that going into the interview situation with anticipatory anxiety regarding the dual role may have taken me out of the moment and lead me to hold back in moments where I could have offered more emotional containment or probed for clarification. I do however feel that I was able to build rapport and create a safe space to explore the participants' difficult feelings. More than one participant contacted me after the interviews to share photos of their children or share exciting achievements or latest school reports. This reflects the feelings which I felt during the interviews, which was that parents in particular just wanted someone to hear their story and to bear witness to their challenges.

3.8 ETHICAL CONSIDERATIONS

Potential ethical concerns should be addressed at every stage of research including design, data collection, data analysis and reporting (Kvale, 2011). Bless, Higson-Smith and Sithole (2013) highlight important guidelines which help to ensure the ethical principles of non-maleficence, beneficence, autonomy, justice , fidelity and respect for the rights and dignity of participants are upheld. The guidelines include, amongst others: an ethical review, informed consent and voluntary participation, confidentiality, anonymity, appropriate referral, and discontinuance (Bless et al., 2013). These guidelines were employed as follows:

Ethical Review. I submitted a detailed proposal outlining the intended research including the potential risks involved. I received approval for this study from the Stellenbosch University Research Ethics Committee, and the Western Cape Department of Education (see Appendix B and C). I also sought permission from school principals to conduct research at their schools, including inviting teachers and parents of children screened by #gb4adhd to participate (see Appendix D).

Informed consent and voluntary participation. Once permission had been granted, I invited participants to take part in this project. I provided each potential participant with information regarding the purpose of the study, the measures which would be taken to maintain confidentiality, and the ability to withdraw from the study at any time. Furthermore, it was stated in the informed consent documentation that participants would be provided access to free counselling with a psychologist if the study caused any emotional difficulties.

Confidentiality and anonymity. I stored all questionnaire responses, audio recordings and transcriptions on a password protected computer in order to ensure that the participants' information remained confidential. I also personally transcribed all the interviews. In order to ensure the participants' anonymity, I assigned each participant a pseudonym for the purpose of reporting the findings.

Appropriate referral and discontinuance. In the process of obtaining informed consent, participants were notified that they could be referred for free counselling with a psychologist if they experienced emotional distress during the interview process. During the follow-up interviews, two participants became emotional and began to cry while reflecting on their experiences. I allowed each participant time to express their feelings, allowed some time for silence in order for them to not feel pressured to continue talking, reflected on their emotions and challenges, and enquired as to whether they would be happy to continue with the interview. Both participants felt comfortable to continue and did not require referral to counselling.

3. 9 SUMMARY

This chapter outlined the research methods used in this study, the quantitative and qualitative data collection, data analysis, researcher reflexivity and ethical considerations. The following chapter will discuss the results of the quantitative component of the study including the KADDS, BACE-3 and demographic data.

CHAPTER 4

QUANTITATIVE RESULTS

4.1 INTRODUCTION

The aim of the quantitative section of the study was to investigate parents' and educators' knowledge of ADHD, the barriers which they have experienced in accessing mental health care and to gather relevant demographic data. This section presents the demographic profile of the participants, the findings regarding their knowledge of ADHD and their reported barriers of access to care.

4.2. PARTICIPANT PROFILE

Information regarding the participants' age, race, highest level of education, employment status and monthly income was collected. In addition, participants were requested to state whether they themselves had a diagnosis of a mental health condition, and whether their child had diagnosed mental health condition such as ADHD, anxiety, or depression.

A total of 45 (*n=45)* participants took part in this part of the study. Within the sample, 26 (58%) were parents, and 19 (42%) were educators. The demographic data is displayed in Table 4.1.

Table 4.1

Demographic Characteristics of Participants

Description	Educators		Parents	
	n	%	*n*	%
Race				
Black	0	0	7	26.92
Coloured	13	68.42	15	57.69
White	6	31.58	3	11.54
Highest level of education				
No formal education	1	5.26	0	0
Grade 9	0	0	1	3.85
Secondary school only	0	0	8	30.77
Secondary school with matric	1	5.26	8	30.77
Post matric	17	89.47	8	30.77
Employment status				
Unemployed	0	0	12	46.15
Employed	18	94.73	13	50
Employed in a temporary position	1	5.26	1	3
Current income				
No income	0	0	8	30.77
Up to R2500 per month	0	0	5	19.23
R2500 to R5000 per month	1	5.26	3	11.54
R5000 to R10 000 per month	1	5.26	5	19.23
More than R10 000 per month	17	89.47	5	19.23
Diagnosed with a mental health condition [a]	3	15.79	7	26.92
Child diagnosed with a mental health condition [a]	2	10.53	15	57.69

Note. *N* = 45. A total of 19 educators and 26 parents participated. Participants were on average 40.6 years old (*SD* = 10.50 years), with ages ranging from 22 to 64 years old. One participant chose not to disclose their race. One participant did not disclose their highest level of education.

[a] Refers to the number of people answering “yes” to this question.

The average age of participants was 40.6 (*SD* = 10.50 years) with ages ranging from 22 to 64 years old. Regarding their employment status, 31 (69%) were currently employed, 12 (37%) were unemployed, and two (4%) employed in a temporary position. The average monthly income was R8805.56 per month (*SD* = 6505.87). The 25th percentile was R1250.00, while the 75% was R15000.00.

In total, ten (22%) participants reported that they had been diagnosed with a mental health condition, while 35 (78%) participants had not. Participants were asked to specify their diagnosis. This was presented as an open-ended question to allow participants to describe their diagnosis in their own words. Based on these descriptions, seven (70%) participants' reported diagnosis falls within the diagnostic category of Mood Disorder according to the DSM-5 (APA, 2013). Of the remaining three participants, one reported having diabetes, while two participants elected not to disclose their diagnosis.

Regarding their children's diagnosis, 17 (38%) of the participants reported that their child had been diagnosed with a mental health condition, while 28 (62%) had not been diagnosed. In specifying the diagnosis, participants used a wide range of terminology. Based on their descriptions, 12 reported ADHD and two reported ADHD comorbid with a secondary psychiatric condition. Additionally, one participant indicated a diagnosis of Autism Spectrum Disorder, one parent reported their child had two previous suicide attempts, and one parent responded that *"she was diagnosed because she fell down at school with short breathing"*.

4.3 KNOWLEDGE OF ATTENTION DEFICIT DISORDER SCALE (KADDS)

The KADDS was used to investigate the participants' knowledge of ADHD. The measure examines knowledge of ADHD based on three domains: associated features, symptoms and diagnosis, and treatment. Ahmed, Borst, Yong and Aslani (2014) report that individuals have very limited knowledge of ADHD if they do not have a child with ADHD and that the knowledge they do have is often based on negative portrayals of ADHD in the media. It was therefore important to include both parents of children with and without ADHD to ascertain whether the knowledge of the condition was different. Participant scores are summarised in Table 4.2.

Table 4.2

Participant Performance on the KADDS

Domain	**Mean**	**SD**	**25th percentile**	**75th percentile**
Associated features [b]	0.32	0.21	0.20	0.47
Treatment	0.35	0.26	0.08	0.50
Symptoms and Diagnosis	0.53	0.22	0.44	0.66
KADDS total [c]	0.37	0.51	0.26	0.51

Note. Mean score refers to the percentage of items which participants answered correctly.
[b] Associated features refer to the nature, causes and prognosis of ADHD. [c] Refers to the overall score on all measures in the test

Participants scored highest on the symptoms and diagnosis domain, scoring an average of 53% (*SD* = 0.22) of items correct. The lowest score was found on the associated features domain, where 32% (*SD* = 0.21) of questions were answered correctly. The treatment domain had the greatest variability in terms of correct scores, with the 25th percentile being 8% and 75th percentile being 51%. In total, participants scored 37% (*SD* = 0.51) on the total measure correctly, with half of the participants scoring between 25% and 51%.

Each item on the KADDS was investigated in terms of percentage of participants who answered the questions correctly. Table 4.3 indicates the five items which received the highest and lowest scores.

Table 4.3

Highest and Lowest Scoring KADDS Items

Item	Item description	Percentage
	Highest scoring items	
KADDS3	ADHD children are frequently distracted by extraneous stimuli	*80%*
KADDS16	Current wisdom about ADHD suggests two clusters of symptoms: One of inattention and another consisting of hyperactivity/impulsivity	*73%*
KADDS26	ADHD children often have difficulties organizing tasks and activities.	*73%*
KADDS32	The majority of ADHD children evidence some degree of poor school performance in the elementary school years.	*71%*
KADDS13	It is possible for an adult to be diagnosed with ADHD.	*69%*
	Lowest scorings items	
KADDS18	Individual psychotherapy is usually sufficient for the treatment of most ADHD children.	*11%*

KADDS27	ADHD children generally experience more problems in novel situations than in familiar situations	*9%*
KADDS34	Behavioural/Psychological interventions for children with ADHD focus primarily on the child's problems with inattention	*9%*
KADDS23	Reducing dietary intake of sugar or food additives is generally effective in reducing the symptoms of ADHD.	*7%*
KADDS1	Most estimates suggest that ADHD occurs in approximately 15% of school age children	*4%*

Note. Percentage refers to percentage of participants who answered the question correctly.

Analysis of Variance (ANOVA) was used to investigate difference in performance on the KADDS between parents and educators. Research indicates that being exposed to children with ADHD in a classroom is associated with increased knowledge of ADHD (Kos, Richdale, & Jackson, 2004). It was therefore important to investigate if parents and educators scored significantly differently on the KADDS. The findings are summarised in Table 4.4.

Table 4.4

Comparison of Educator and Parent KADDS scores

Domain			Mean (%)	F	P
Associated Features	Total	(*N*=45)	32.00	(1, 43) = 11.41	< 0.01
	Educator	(*n*=19)	43.20		
	Parent	(*n*=26)	23.80		
Treatment	Total	(*N*=45)	35.20	(1, 43) = 10.80	< 0.01

	Educator	(*n*=19)	48.70		
	Parent	(*n*=26)	25.30		
Symptoms/Diagnosis	Total	(*N*=45)	53.30	(1, 43) = 9.68	<0.01
	Educator	(*n*=19)	64.30		
	Parent	(*n*=26)	45.30		
KADDS total	Total	(*N*=45)	36.90	(1, 43) = 14.37	<0.01
	Educator	(*n*=31)	48.60		
	Parent	(*n*=14)	28.40		

There was a significant variance between the mean scores for parents and educators on all domains. On all four domains of the KADDS, educators scored significantly higher than parents. In terms of total knowledge of ADHD, educators scored 48.60% (*SD* = 19.20%) correctly, while parents scored 28.40% (*SD* = 16.40%) correctly.

4.4 BARRIERS TO ACCESS TO CARE EVALUATION (BACE-3)

The BACE-3 was used to determine the factors which participants have experienced as barriers to accessing suitable mental health care. These barriers can be grouped into three categories – stigma-related, instrumental, and attitudinal barriers. Instrumental challenges refer to practical and logistical factors which prevent people from accessing care such as financial constraints or limited transport. Attitudinal barriers are thoughts or beliefs which discourage individuals from seeking help, such as believing that professional treatment would not help.

Stigma-related barriers reflect concerns and worries about what other people might think or how they may behave, based on a decision to access treatment.

Participants had to indicate whether a specific barrier has influenced their decision to access on a Likert scale, choosing either: 'not at all', 'a little bit', 'quite a lot' and 'a lot'. Participant responses are reported in Table 4.5.

Table 4.5

Participant BACE-3 Responses

Description	Barrier description	Mean	SD
1 (I)	Being unsure of where to go to get professional help	1.6	0.93
2 (A)	Wanting to solve the problem on my own	2.3	1.25
3 (S)	Concern that I (or my child) might be seen as weak for having a mental health problem	2.0	1.04
4 (A)	Fear of me (or my child) being put in a hospital against my will	1.6	0.94
5 (S)	Concern that it might harm my chances when applying for jobs	1.7	0.99
6 (I)	Problems with transport or travelling to appointments	1.6	0.96
7 (A)	Thinking the problem would get better by itself	1.7	0.94
8 (S)	Concern about what my family might think, say, do or feel	1.5	0.79
9 (S)	Feeling embarrassed or ashamed	1.5	0.87
10 (A)	Preferring to get alternative forms of care (e.g., traditional/religious healing or alternative/complimentary therapies)	1.8	1.00
11 (I)	Not being able to afford the financial costs involved	2.4	1.19
12 (S)	Concern that I (or my child) might be seen as crazy	1.7	0.95
13 (A)	Thinking that the professional care would probably not help	1.6	0.84
14 (S)	Concern that I might be seen as a bad parent	1.7	0.98
15 (I)	Professionals from my own ethnic or cultural group not being available	1.2	0.53

16 (I)	Being too unwell to ask for help	1.4	0.72
17 (S)	Concerns that people I know might find out	1.4	0.61
18 (A)	Dislike of talking about my feelings, emotions or thoughts	1.6	0.76
19 (S)	Concern that people might not take me (or my child) seriously if they found out I was having professional care	1.5	0.84
20 (A)	Concerns about treatments available (e.g., medication side effects	2.1	1.16
21 (S)	Not wanting a mental health problem to be on my (or my child's) medical records	1.4	0.81
22 (A)	Having had previous bad experiences with professional care for mental health	1.2	0.40
23 (A)	Preferring to get help from family or friends	1.4	0.72
24 (S)	Concern that my child may be taken into care or that I may lose access or custody without my agreement	1.6	1.02
25 (A)	Thinking that I (or my child) did not have a problem	1.6	0.83
26 (S)	Concerns about what my friends might think, say or do	1.4	0.53
27 (I)	Difficulty taking time off work	1.9	1.09
28 (S)	Concern about what people at work might think, say or do	1.6	1.84
29 (I)	Having problems with childcare while I receive professional care	1.7	0.96
30 (I)	Having no one who could help me get professional care	1.5	0.79

Note. Description includes the BACE item number with the bracketed letter indicating the type of barrier (A = attitudinal barriers, I = instrumental barriers, S = stigma-related barriers)

The most frequently reported barrier was not being able to afford the financial costs involved in accessing treatment (*mean* = 2.4, *SD* = 1.19), which represents an instrumental barrier to care. This was followed by participants wanting to solve the problems themselves (*mean* = 2.3, SD =1 .25) and concerns about the treatments available (*mean* = 2.1, *SD* = 1.16), which both represent attitudinal barriers. Concern that the participant or their child may be seen as weak for having a mental health problem was the most frequently reported stigma-related barrier (*mean* =

2.1, *SD* = 1.04). ANOVA showed no significant difference in terms of variation of frequency of reported barriers within the participant responses (F (29, 1248) = 6.51, $p<0.01$).

ANOVA was further used to investigate variation between the three subscales on the BACE-3, namely: instrumental barriers, attitudinal barriers and stigma-related barriers. Results showed a significant variation between subscales (F (2,68) = 2.54), $p = 0.09$). An LSD Post Hoc test indicated a significant difference between the instrumental and stigma subscales ($p = 0.05$). The mean scores for the instrumental and stigma subscales were 1.70 (*SD*=0.66), and 1.55 (*SD* = 0.67) respectively.

4.5 RELATIONSHIP BETWEEN KADDS AND BACE-3 MEASURES

Spearman's correlation was used to investigate correlations between reported barriers to care and knowledge of ADHD. Table 4.6 shows the BACE-items and KADDS domains which demonstrate correlation where the *p*-value for statistical significance is set at $p < 0.1$

Table 4.6

Correlation Between KADDS and BACE-3 Measures

BACE-item	KADDS domain	Spearman's	Spearman's p-value
Concerns that people I know might find out (BACE17)	S/D	0.33	0.03
Problems with transport or travelling to appointments (BACE6)	T	- 0.27	0.07
	K	- 0.25	0.09

Professionals from my own ethnic or cultural group not being available (BACE15)	A	- 0.26	0.09

Note. KADDS domains are as follows: S/D = symptoms and diagnosis, A=associated features, T= treatment, K= total knowledge of ADHD

The results show a weak positive correlation (*r* = 0.33, *p* = 0.03) between the barrier "concerns that people might find out" (BACE17) and knowledge of the symptoms and diagnosis of ADHD. Thus, participants who reported the fear of people finding out about their mental health condition as a barrier to accessing care (which is a stigma-related barrier), also demonstrated better knowledge of the symptoms and diagnosis of ADHD.

Participants who cited transportation as a barrier to care (BACE6), tended to have lower knowledge of the treatment of ADHD (*r* = - 0.27, *p* = 0.07) and lower overall knowledge of ADHD (*r* = - 0.25, *p* = 0.09). A weak negative association was found in participants who reported unavailability of professionals belonging to their ethnic or cultural group (BACE15) and reported knowledge of associated features of ADHD (*r* = - 0.26, *p* = 0.09).

Although not statistically significant, it is interesting to note that participants who reported thinking that the professional care would probably not help (BACE13) as a barrier, showed a trend towards lesser knowledge of the treatment of ADHD (*r* = - 0.24, *p* = 0.11). Additionally, participants who reported that they preferred to get help from family and friends rather than from a mental health professional (BACE23), showed lesser knowledge of associated features of ADHD (*r* = - 0.22, *p* = 0.14), lesser knowledge of treatment of ADHD (*r* = - 0.23, *p* = 0.13) and lesser overall knowledge of ADHD (*r* = - 0.21, *p* = 0.16).

Pearson's correlation was used to compare the domains of the KADDS (associated features, treatment, symptoms/diagnosis and total KADDS) with the BACE-3 subscales (instrumental barriers, attitudinal barriers, and stigma barriers). No significant correlations were found.

4.6 RELATIONSHIP BETWEEN THE KADDS AND HAVING A CHILD DIAGNOSED WITH ADHD

ANOVA was used to determine whether participants who have a child diagnosed with ADHD scored significantly differently to participants whose children do not have ADHD in terms of their knowledge of the disorder. Findings are summarized in Table 4.7 where the mean refers to the percentage of questions answered correctly. The overall mean is reported for the domain (Total), participants whose child is not diagnosed with ADHD (ADHD No) and participants whose child is diagnosed with ADHD (ADHD Yes).

Table 4.7

KADDS Performance of Parents With or Without a Child Who Has a Diagnosis of ADHD

Domain			Mean (%)	F	P
Associated Features	Total	(N=45)	32.00	(1, 43) = 0.49	0.83
	ADHD No	(N=31)	32.47		
	ADHD Yes	(N=14)	30.95		
Treatment	Total	(N=45)	35.19	(1, 43) = 0.25	0.62
	ADHD No	(N=31)	33.87		

	ADHD Yes	(N=14)	38.10		
Symptoms/Diagnosis	Total	(N=45)	53.33	(1, 43) = 2.07	0.16
	ADHD No	(N=31)	50.18		
	ADHD Yes	(N=14)	60.32		
KADDS total	Total	(N=45)	37.00	(1, 43) = 0.18	0.67
	ADHD No	(N=31)	36.00		
	ADHD Yes	(N=14)	39.00		

Although not statistically significant, findings indicate that participants who have a child diagnosed with ADHD scored higher with regards to their knowledge of symptoms and diagnosis. Here, the total percentage of correct answers for all participants was 35.19% (*SD* = 21.06%). When analysed separately, those whose children had a diagnosis of ADHD answered 60.32% (*SD* = 16.72%) of questions correctly, while those whose child did not have ADHD scored 50.18% (*SD = 23.18%)* correct. These findings should be interpreted with caution due the small sample of participants who reported that their child had ADHD. Analysis of the associated features, treatment and Total KADDS domains, did not show any significant difference between the two groups.

4.7 SUMMARY

This chapter reported on the results from the quantitative measures used in this study. Demographic data was reported, as well as performance on the KADDS and BACE-3. In addition, correlations and analysis of variance were reported in comparing performance on the KADDS and BACE-3. The next section provides an overview of the results from the qualitative interviews.

CHAPTER 5

QUALITATIVE FINDINGS

5.1 INTRODUCTION

This section reports on the themes which were identified during the semi-structured interviews. Interviews were conducted with 18 participants from the Western Cape: twelve parents and six educators who indicated during the surveys that they would be willing to be interviewed. This represents 46.15% of the parents and 31.58% of educators who completed the questionnaires. Each interviewee was assigned a pseudonym for the purposes of reporting.

The guidelines regarding anonymising interview data outlined by Saunders, Kritzinger and Kritzinger (2015), were used in selecting pseudonyms. The aim, as per the guidelines, is to select a name which does not reveal too much cultural or ethnic information, while still resonating with the interviewee in some way. Table 5.1 provides a brief description of the participants.

Table 5.1

Participant Description

Interviewee	Description
Parents	
1: Elana	31-year-old mother of twins diagnosed with ADHD, and a personal history of Bipolar Mood Disorder. Currently employed in the accounting field.
2: Ava	32-year-old mother of a child diagnosed with ADHD and a personal history of depression. Currently unemployed.
3: Samantha	43-year-mother with a child diagnosed with ADHD. Currently employed as a police officer.

4: Faith	33-year-old mother of a child diagnosed with ADHD. Currently unemployed.
5: Maria	40-year-mother of child diagnosed with ADHD. Currently employed in a temporary position as a domestic worker.
6: Stella	42-year-old mother, currently employed as an electrician. No known diagnosis.
7: Beverley*	44-year-old mother of a child diagnosed with Major Depressive Disorder with psychotic features and ADHD.
8: Aletta	46-year-old mother of a child diagnosed with ADHD. Currently employed in the accounting field.
9: Mia	54-year-old mother of a child diagnosed with ADHD. Currently employed in quality control.
10: Liam	46-year-old father of a child that is on the autism spectrum and a second child currently being assessed for ADHD. Currently employed in complaints management.
11: Enzo	44-year-old father of a child with Autism Spectrum Disorder. Currently employed as a lecturer.
12: Lucas	47-year-old father with a personal history with depression and anxiety, and family history of chronic depression and suicidal ideation. Currently unemployed.
Educators	
13: Audrey	40-year-old educator. No personal history or family history of mental health conditions.
14: Klara	36-year-old educator. No personal history or family history of mental health conditions.
15: Ella	42-year-old educator (learning support teacher). Mother of a child with ADHD, (predominantly Inattentive Type).
16: Rose	55-year-old educator. No personal history or family history of mental health conditions.
17: Justine	63-year-old educator (learning support teacher). Mother of a child with ADHD.
18: Christelle	64-year-old educator. No personal history or family history of mental health conditions.

Note. * Beverley is a non-academic staff member at a school. Her child was not screened by #gb4adhd. However, it was decided that she would be included in the study due to the insight she was able to provide as a parent of a child with a psychiatric diagnosis and of being a staff member at one of the participating schools.

5.2 DESCRIPTIVE AND CONCEPTUAL ANALYSIS

The final code list consisted of 32 codes which represented 296 quotes. See Appendix K for the code book which outlines the list of codes as well as the frequency with which each code occurred. The codes were then grouped into 10 subthemes. These subthemes are reported in terms of four key themes which emerged across the interviews. Figure 5.1 summarises the themes and subthemes.

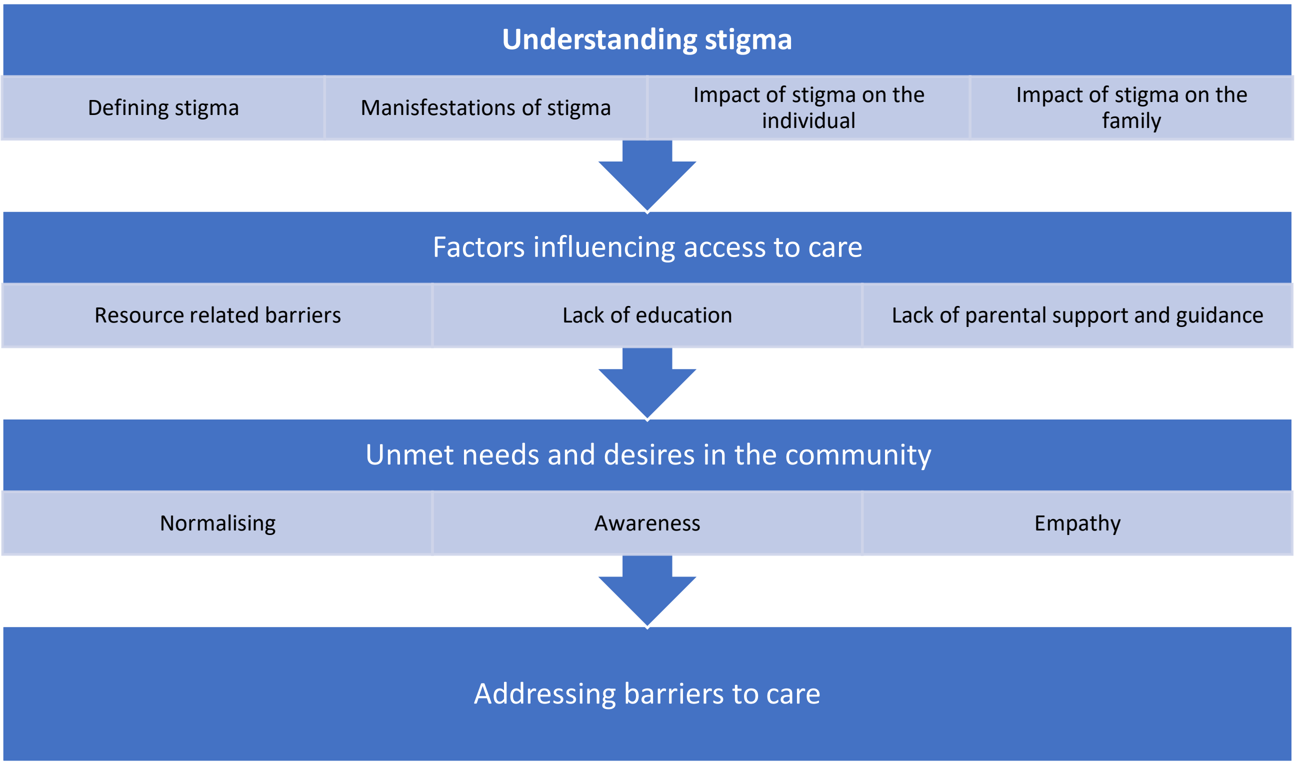


***Figure 5.1:* Themes and subthemes**

5.3 UNDERSTANDING STIGMA

Stigma is a term which has been investigated across many disciplines but remains a concept which is not clearly operationally defined leading to cross-communication in stigma research (Link & Phelan, 2001; Phelan et al., 2008). To understand if stigma acts as a barrier to accessing care, it was important to first investigate the ways in which parents and educators experience and make sense of stigma. The discussions centred around four subthemes: defining stigma, manifestations of stigma, the impact of stigma on the individual and the impact of stigma on the family. Table 5.2 presents a thematic map of the subthemes and categories.

Table 5.2

Thematic map: Understanding stigma

Subtheme	Category
Defining stigma	• Difference • Being labelled • Being stripped of your individuality
Manifestations of stigma	• Bullying • Exclusion • Individual needs not being met • Behaviour interpreted through a lens
Impact of stigma on the individual	• Decreased self esteem • Isolation
Impact of stigma on the family	• Day-to-day-living • Emotional hardship

5.3.1 Defining stigma

During the interviews, interviewees were asked to describe what the word stigma means to them. Responses centred on three core characteristics: difference, being labelled, and being stripped of individuality.

5.3.1.1 Difference

Instances of stigma rest on the premise of recognition of an “undesired difference”, which results in feelings of shame and experiencing lack of acceptance (Goffman, 1963, p.14). Many of the participants described experiences of difference related to stigma, either related to their child in particular, or to experiences in society in general.

Enzo, a father of a child who is on the Autism Spectrum described stigma as:

> *Okay, it's seeing them differently. People might think like "no, that person is not normal". People look at a different angle, like he's crazy maybe. People might say that people are not intelligent. So it is things like that. So those are the things, like ...we label, we label people.* (11:8)

Lucas, a father who has recently dealt with his own diagnosis of depression and anxiety, explained:

> *So to me, stigma is where, you know, somebody's either labelled or treated differently because there's something that people don't understand about them. It could be something physical, it could be something behavioural, but it’s just there will be a difference somehow*. (12:9)

5.3.1.2 Being labelled

In the context of human interaction, a label is defined as "" a word or a phrase that is used to describe the characteristics or qualities of people, activities, or things, often in a way that is unfair" (Cambridge Dictionary, n.d.). By applying a label to a person, a connection is made between that person and one or many stereotypes (Link & Phelan, 2001). Klara, an educator described stigma as follows:

> *"Umm, well obviously, I'd say like a label…umm... that gets put on you because of either something that you have or something that you're going through. So it's a negative label".* (14:1)

In describing stigma in her own words, Elana, a mother of a child with ADHD explained:

> *Stigma... that is like, it's a label that they use, like usually stereotyping about what ADHD is and you know, saying that they're dumber. Using that word, that they dumb. Or their parents don't give them enough attention, that is why they that way. That's, that is the stigma behind ADHD and its sad. It really is because many of these children, they are just looking for someone to listen and to understand.* (1:13)

Here, Elana describes the process where the label "ADHD" is linked to devaluing characteristics or stereotypes. A stereotype refers to a negative belief about a group (Corrigan, 2018). In this instance, the stereotype is that children with ADHD are unintelligent or that their behaviour is a result of poor parenting. Her definition of stigma also points to two different types of stigma: self-stigma and courtesy stigma. Self-stigma occurs when an individual accepts the negative beliefs which others hold of them, while courtesy stigma refers to stigmatisation based on affiliation with a stigmatised individual (Bussing & Mehta, 2013).

In reflecting on her experience of having a child dealing with a dual diagnosis of Major Depressive Disorder with psychotic features, and ADHD, Beverley became very emotional and tearful during the interview, explaining:

> *It's like people mark you like, like for me, in Zane's case, people mark him already, he's a problem child. And that is not right. That is what I told the principal like… he's already labelled as a problem child. But for me, you mustn't just label the child according to his behaviour, what he's doing, what his background is. But for me, I think the school labelled my child as a problem and I'm actually getting emotional…*(7:17)

She went on to describe the ways in which she believed her child has been treated differently because of being labelled. Beverley gave an example of an instance where the principal spoke badly of her child in a staff meeting and another instance in which the principal had told other children not to associate with her son due to his problematic behaviour.

5.3.1.3 Being stripped of your individuality

In the process of acknowledging difference and labelling (as described above), a person is categorised or grouped according to the attributes linked to that label. By doing this, individual characteristics and nuances are lost. A theme which emerged during the interviews reflected that the process of stigmatization leads to a loss of identity or individuality. Aletta, a mother, described how she felt that the label of ADHD had been attached to her daughter, leading to loss of individuality, in that she is no longer seen as a complex individual:

> *Stigma is something that is attached to you. So for me, it is, like, the ADHD would be like an attachment to her, which umm, people would, would seem to think that, that is just, that is who she is. They... you don't, you don't look deeper into the person, you do not see the person per se, without attachment.* (8:9)

Ella, an educator, echoed these sentiments, saying:

> *It means that, to me, that generally people put a name or categorizes someone in a group, instead of looking at people individually. So, they will judge according to a sickness or disorder or whatever. Instead of looking at people individually.*

In making sense of stigma, the interviewees outlined three processes which take place. Firstly, a difference is recognised. Subsequently, based on this difference, a label is applied. Finally, once this label has been attached, the person loses their uniqueness and instead is represented by the label.

5.3.2 Manifestations of stigma

Conceptualisations of the stigma remain broad and encompass many different experiences and potential consequences. These factors may be influenced by the underlying cause or reason which someone is treated differently (i.e., a mental health condition), or the context in which it takes place. While experiences were varied, common themes emerged including bullying, exclusion, being overlooked and misunderstood, individual needs not being addressed and having behaviour interpreted through a lens.

5.3.2.1 Bullying

In reflecting on ways in which their children or learners have experienced stigma, parents and educators highlighted many instances of bullying. Bullying is a proactive aggressive behaviour that is: a) intended to harm, b) repetitive and c) reflects a power imbalance (Winters et al., 2020). It can take on many different forms including physical, verbal, and relational victimization (Fite, Evans, Cooley, & Rubens, 2014).

During the interviews, I posed the question: in what ways are children with ADHD discriminated against? Samantha and Ava, both mothers of children with ADHD, mentioned bullying:

> *By bringing him down. Umm, how can I say? Like bullying him, calling names, and so on*. (2:13)

> *The children at school is bullying my child, the children, because they are different from the others….Because of the bullying...because of the constant bullying and the name calling and you know? All that. It's very difficult for her*. (3:11)

In that moment during the interview where Samantha reflected that "it's very difficult for her", the tone of the interview seemed to shift, reflecting what I interpreted to be sadness and a sense of helplessness. Instances where parents reflected on the emotional impact of their child's experiences were found through the interviews. These will be reflected when discussing the familial impact of the stigma.

Research shows that mental health conditions lead to stigma based on four factors, including intangibility, chronicity, negative media portrayal and controllability (Hinshaw, 2005). The symptoms and behaviours linked to ADHD map onto Hinshaw's theory of mental health stigma as follows: ADHD is a chronic, neurodevelopmental disorder which is not physically visible to an outside observer. The symptomology of ADHD - inattention, hyperactivity and impulsivity – are often interpreted as something which is controllable. This can lead people to believe that a child is deliberately acting out or choosing not to listen. Thus, children with ADHD are candidates to experience stigma (Hinshaw, 2005).

Children with ADHD are at a higher risk for becoming victims of bullying (Winter *et al.*, 2020). This has been linked to the idea of "provocative victims", in which the behaviour of the victim leads to an increased risk for being bullied , as well as for being bullies themselves (Keder, Sege, Raffalli, & Augustyn, 2013). In the case of children with ADHD, behaviour such as speaking out, acting inappropriately, missing social cues, being boisterous and loud, having trouble waiting for their turn, and difficulties with emotional regulation are more likely to make them an easy target for bullies. Winters et al. (2020) report that children with ADHD are chronically targeted by bullies, and have higher rates of depression, anxiety, aggression, and interpersonal difficulties because of the bullying.

5.3.2.2 Exclusion

Exclusion in relation to mental health conditions occurs in various ways such as exclusion from social activities, exclusion from opportunities for self-development and being excluded in decision making regarding their treatment (Corrigan & Watson, 2002; Ilic et al., 2013). Elana described:

> *I think they are socially excluded because they are different. They think differently. You know, when... not everyone pops the same. So if you put kernels in to pop and they all pop at different times. So, that is just my opinion on people with ADHD, they just take a little more time, you know? To absorb information and once it's in, it sticks. So, I think people that learn a little bit slower they are, they are umm, you know, labelled as stupid or ignorant or they, it's just, they are given labels as no, they're poor or, you know? And it's not always that. People just need some understanding. They need a support system. A lot of the time, it's social exclusion and people that are bullied, children that are bullied, for being different.* (1:7)

Elana used the metaphor of popping popcorn to describe the reason her child has been socially excluded. When popcorn is made, the kernels are all placed in the same pot, at the same temperature, but some kernels become popcorn more quickly than others. In her metaphor, children with ADHD “pop” a little bit later which causes people to label them as “stupid” or “ignorant” which then leads to social exclusion and bullying.

Samantha was very emphatic in her response when asked if children with ADHD are treated differently, exclaiming:

> *“EVERYTHING! EVERYWHERE! Even children. And that's one of the reasons she don't have friends…a few years back, they invited her for a party, and she said "you can bring my cake. I don’t want to go”.* (3:19)

In this example, her daughter declined an invitation to a birthday party because of ongoing bullying and exclusion.

The findings from this study indicate that exclusion can also manifest as being overlooked by various members of society including teachers, peers, and institutions. Children are excluded from educational opportunities through being overlooked and misunderstood. Interviewees described that:

> *"if they don't attend the right school, they fall out of school, they can't go to work. They not getting work when they done with school"*. (16:1)
>
> *"what I experienced with my child, she didn't get attention at school."*(3:13)
>
> *"they basically just overlooked, all the time because they're not the brightest in the class. And children with ADHD are actually very bright"*. (1:16)

In investigating the perceptions of the academic skills of children with ADHD, Eisenberg and Schneider (2007) found parents and educators expected lower performance in reading and mathematics than was indicated on performance measures. Teachers' perceptions of academic skills were also found to be significant in predicting academic success of children with ADHD (DuPaul et al., 2004). This points to the idea that educators may underestimate the abilities of a child with ADHD, and in doing so negatively impact their performance.

5.3.2.3 Individual needs not being addressed

A theme of individual needs of children with ADHD not being addressed was evident in the interviews. An interesting tension was observed where some parents felt that their children should be treated differently for the special needs to be accommodated, whereas other interviewees felt their children's emotional needs would be better accommodated by being treated the same as the other children in their class.

> *Um, sometimes ja... like the school they don't give special attention to the children, who was diagnosed with ADHD. They treat them the same like the normal kids… there are lot of kids who is diagnosed with ADHD, and they just give a tablet, and they go on like there is nothing wrong.* (2:4)

> *"they kind of just throwing them in with the rest, and they need to just roll with the punches"*. (1:45)

Children's needs may also be neglected where ADHD is not recognised as a disorder or not taken seriously. Faith, a mother reported:

> *I also don't think there's a lot of help with children with ADHD, because, how can I say? Most people take it, your child is normal, they don't see it as a disorder. So yes, I don't think there is lots of help for children like that.* (4:24)

Justine described:

> "*most of the parents tell me "no, my child is naughty, he's not listening" and then it's not a really a problem because he is having ADHD"*. (17:6)

As an educator, Justine's experience in schools is that parents sometimes attribute their children's behaviour to intentional acts of defiance, rather than a psychiatric diagnosis such as ADHD. In this instance, a child's needs cannot be met because they are blamed for their behaviour, rather than receiving psychopharmalogical or psychological support to manage their condition. Ella, a learning support teacher reported:

> *"It's more like people don't really believe...they think, like children, they would just think, well they're just naughty, you know?..., but they would just think but, "Just get yourself together. You can manage it", if that makes sense".* (15:5)

A father described:

> *Well, let's say for instance... let's say just for learning purposes, the person has already ... that disability. So for instance, let's say they have to perform a task. He's not going to perform the task in the same, in the amount of time that the normal person...okay, they're also normal, but the amount of time with that person having that handicap, is not going to be same as the person that hasn't. So let's say you have to complete the task in five hours, that person might need an extra hour to complete that. So, in that regard... So if I'm not aware then I'm not going to take that into consideration. I'll just think, no, you're not able to do that task, but where that person who umm, has that ummm... that ability. He just needs extra time to complete it because the thinking could have been maybe slower. You see?* (11:4)

Referring to his experience as a lecturer, Enzo highlighted that when educators are not aware of the challenges their students are facing, then their individual needs cannot be catered for.

5.3.2.4 Behaviour interpreted through a lens

Stigma is a process whereby a larger population accepts a discrediting stereotype about a group, often based on falsely assumed associations (Mueller et al., 2012). Interviewees provided examples where their children's behaviour was interpreted negatively because of their ADHD diagnosis:

> *I would say like umm, mostly people that is around us because of Aaron snapping, Aaron is hyper. So lots of people actually think like, he is just a rude boy. But it's not that it's rude, it's that it just comes out wrong and it comes out fast".* (4:17)

Aletta explained that her daughter struggles with emotional regulation and a tendency to retaliate when confronted. While this maybe be viewed as typical behaviour for a teenager, Aletta felt that due to her child's diagnosis of ADHD, her behaviour is viewed more negatively than those of neurotypical children without a diagnosis:

> *... if anybody says anything negative to her, she would retaliate and I don't want that, because it's going to be perceived as her being rude. And I do remind her of that, I regularly remind her that that is why people will say that you are rude. Because of the way you're saying things. They don't know that you just voicing your opinion or things like that. Whereas with per se a normal person, they would say a normal child, they would take that child is just straightforward… if it's even rude for a child that is, that has a mental health disability, that it's regarded as rude for that child, then why can't it be regarded as rude for... that is also another thing where stigma comes in - a child that that has mental health disability or some condition, that child is rude, but a child that is per se classified as normal, that child is, umm, that, it's not said that child is rude, it's said that child is just straightforward and the child just states, speaks their mind.* (8:28)

Both Faith and Aletta's examples describe instances where the way in which their child voices their opinion influences the way in which it is interpreted. Faith mentioned that her child's opinion "comes out wrong and it comes out fast", which may be an expression of impulsivity and difficulty with emotional regulation associated with ADHD. Mia, a mother, acknowledged that oftentimes her son was involved in socially unacceptable behaviour such as fighting, but she felt that people tend to be harsher on him than on the other children:

> *When there is trouble, he's always the one that... he's part of it but they usually see that he's the one who actually started these things, or he's the culprit. And most of the time he is. I don't, I don't pick sides or excuse what he's doing, but sometimes I feel they a little bit too harsh on him.* (9:4)

5.3.3 Impact of stigma on the individual

Stigma impacts individuals with mental health disorders emotionally, psychologically, and materially. Findings indicate that stigma leads to decreased self-esteem and self-worth, increased isolation and acting out behaviour.

5.3.3.1 Decreased self-esteem

Self-esteem is an individual’s overall feeling about themselves and is related to emotions such as worthiness, value, likeableness and acceptance (Searcy, 2007). Lower self-esteem has been reported in children with ADHD and learning disabilities (Bussing & Mehta, 2013; Wiener et al., 2012). In discussing the impact of stigma on her child, Elana described:

> *“he told me the other day actually, that he's...he's dumb. And I felt so terrible about it. And I told him "my dear, you are not dumb. You just think differently, and you know, differently. You are very. And you tell me clever things all the time". So, I just feel that he feels that he's not good enough. And because everyone else is learning so fast, and he's like still, you know, really trying to pick up the pace. And because he's trying to pick up the pace, children notice that he's slower and then make fun.* (1:18)

Research indicates that self-esteem influences decision making that can affect a person throughout their life span, including school attendance, crime involvement, use of alcohol and illegal substances, age of first sexual encounter and peer group selection (Searcy, 2007).

In discussing the impact of stigma, Beverley described:

> *It affects his self-image, because you treating me [referring to her son] like that, now I'm going to give you more problems. You understand? So I don't want…. That's why Zane don't go to class sometimes. And I think that is… so she's [son's teacher] actually the main reason also why I think that's why a lot of children don't… bunk classes and that. Understand? Because he already labelled as a problem.* (7:34)

In this example, labelling and the subsequent poor self-image is seen at the reason for the child (and other children) not wanting to attend class, which can have long-term consequences for their educational attainment and future employment opportunities. This may also point to the cyclical nature of stigma where the experience of stigma causes an individual to react in a way that is further stigmatizing. For example, in the above scenario Zane is labelled a problem and treated differently, which causes him to skip classes which reinforces the idea that he is a "problem", which creates a self-perpetuating negative cycle.

5.3.3.2 Isolation

The interaction between social isolation and stigma is bi-directional in as much as experiences of stigma may lead people to isolate others who are different and conversely, people may isolate themselves for fear of being stigmatised or discriminated against (Hatzenbuehler et al., 2013; Wahl, 2012).

When reflecting on the impact of stigma on his son who is on the Autism spectrum, Enzo explained:

> *Yes. Yes. It's going to have an impact on him because he can start isolating himself because people think you are on different levels, you learn different.... Because [they] are not aware and then him seeing the way that people are reacting towards him, then he's gonna change.* (11:6)

Enzo feels that once his son becomes aware that people are treating him differently, that his behaviour could change, causing him to isolate. This illustrates Corrigan, Watson and Barr's (2006) conceptualisation of self-stigma which proposes a process of stereotype agreement, self-concurrence and self-esteem decrement. In this process an individual first recognises and endorses the stereotype about themselves (stereotype agreement). This is followed by self-concurrence in which the individual comes to believe that the negative stereotype applies to them. If the individual concurs with the belief, then this can lead to self-esteem decrement, where their self-esteem is lowered because they believe and endorse the negative stereotype (Corrigan et al., 2006).

Maria, a mother of a child with ADHD described a similar process in which a child's behaviour or demeanour will change due to their experience of being bullied and treated differently:

> *The person would get very distant as soon as people start with you know, these bully things and name calling and stuff like that. It hurts. So the next child will start to get very distantly, he will became quiet. If you knew the child that was like a child that was always smiling*

> *and happy and talkative, even if he had ADHD... He will definitely, they will definitely became very distantly they became quiet. You see?* (5:13)

5.3.4. Impact of stigma on the family

Two conceptualisations of stigma are relevant to the families of children with mental health conditions such as ADHD, namely courtesy stigma, and affiliate stigma. Courtesy stigma occurs when an individual is mistreated due to their relationship with a stigmatised person (Corrigan, 2018). Affiliate stigma takes place when "individuals perceive and internalize courtesy stigma" (Mikami et al., 2015, p. 2). For example, a parent may feel shame due to their child's diagnosis. Interviewees described that stigma affected them in terms of their day-to-day living and heightened feelings of inadequacy.

5.3.4.1 Day-to-day living

Mia and Liam, when asked about ways in which stigma affected themselves directly or their family, responded:

> *Aaah, I think so yes. Yes. It definitely does. Because we would rather sit at home than to go out to people or rather we as a family do things. So I would say definitely…. sometimes his behaviour is a little bit out of hand, and I will tolerate things where other people might not. You know? So we just say we stay at home, we can do things at home rather than by other people. Even if they are sometimes family.* (9:9)

> *Yes, it does. It does have an impact on the family. It definitely impacts the family from you know, especially for us, umm, having a son that has special needs, it definitely does impact us when we walk around or when we go to shops. We generally don't go to shops if it's busy, we generally try to avoid busy areas, or busy shopping centres or certain, even going*

> *to religious establishments, for example, because you need to be quiet, you need to you need to meet certain requirements to be able to sit through a service, you understand what I'm saying? And that is why we tend to just rather stay at our home and rather go at peculiar times to the shop so that we can avoid people looking at us in a certain way."* (10:5)

Both parents chose to avoid common scenarios such as shopping, spending time with families or attending a religious service due to their fear of judgement or recrimination based on their child's behaviour.

5.3.4.2 Emotional hardship

Parents of children with ADHD are at an increased risk for depression, anxiety and social isolation which has be attributed to challenging behaviour of a child with the condition, which is compounded by courtesy stigma (Norvilitis, Scime, & Lee, 2002). In a recent study conducted in Kwa-Zulu Natal, South Africa investigating the knowledge and misperceptions of parents of children with ADHD, 75% of parents reported experiencing stigma due to their child's diagnosis of ADHD (Rajcumar & Paruk, 2020). Elana explained:

> *It affects me emotionally because I'm a single mom, and I'm taking care of my kids alone, and I'm trying my best to get them to do well. It's already a struggle that they have ADHD. And when I, when I hear that they were be mistreated, it really, really agitates me.* (1:20)

In describing the emotional hardships, Faith described feeling alone and unsupported:

> *You're exhausted of the day and then you don't want to show them you crying, because then you look so weak, [nervous giggle]…but when I get into bed, it's like, you know, I just*

> *feel for crying, I just feel like… sometimes I'm washing up and then my tears just roll down. Because there's no one to help you, there is no one to support you, there is no one"* (4:22)

In alluding to the stigma-associated shame which parents encounter, Ella, an educator, explained:

> *Yes, I'm sure it [stigma] does affect family and friends as well. And probably also see, some... I don't know, shame in their child not being able to, you know, perform as they should.* (15:11)

Interestingly, Maria, who has a daughter with ADHD reported that stigma affects mothers and fathers differently:

> *It will affect the family. If you look at it in that way, it will affect the family. Maybe not the father but the mother. The mother will feel bad. It will, like I said now, it will affect the child and it will affect the parents also. For the stigmas that is in the community because of the name calling and stuff like that, maybe not the father so much. You see? But in rural communities, it will affect the mother. She'll feel bad for her child also.* (5:14)

Bussing and Mehta (2013) report that while the entire family may be affected by courtesy stigma, it is usually the mothers who carry the main responsibilities of caring for the child with ADHD, and are thus more strongly affected by the stigma, as well as "mother-blame".

5.4 FACTORS INFLUENCING ACCESS TO CARE

An aim of this study was to explore factors which act as barriers to accessing mental health care in general, and challenges which parents and educators face in relation to treatment for ADHD. The interviewees presented multiple barriers which will be discussed in three broad themes: resource-related barriers, lack of education and a lack of parental support and guidance. Table 5.3 presents a thematic map of the themes.

Table 5.3

Thematic Map: Factors Influencing Access to Care

Subtheme	Category
Resource related barriers	• Financial barriers • Lack of help • Uncertainty regarding available help
Lack of education	
Lack of parental support and guidance	

5.4.1 Resource-related barriers

Resource-related barriers refer to instances where lack of resources such as financial means, availability of help and knowing where to access help acted as barriers to receiving treatment.

5.4.1.1 Financial barriers

To better understand the difficulties which people encounter, interviewees were asked: "What do you think the biggest challenge is in your community for children with ADHD?" Lack of financial means was commonly reported as a major challenge. Responses included:

> *I think people that are, first of all, number one, financial situation.* (1:1)
>
> *The ones, where I work in Ruyterwacht, they have to get it [medication] from the clinic, they can't afford it. So the ones who don't go to the clinic and they've got a medical aid but, so they're not qualified for the clinic. They can't afford it. So they don't, the medical aid is only a hospital plan or doesn't allow you know that sort of medication. And then the kids go without it, they go with without it and then they never reach their full potential those children, I think.* (18:5).

A mother, Beverley, reflected on her experience of having her child treated as an inpatient at a psychiatric ward:

> *I'm lucky in that sense, I have insurance. I have medical aid. And then like I'm telling my principal, imagine I didn't have medical aid, where would my son have been? Because he's been suicidal, because he was on the verge of suicide… So imagine he wasn't also in that clinic, where would Zane would be? Because his stay was almost R70,000. Just his stay. So that is what I'm saying. Not all of us is fortunate enough to have medical aid. And within the poor communities, that is why children go into drugs and that, because there is no help at all.* (7:14)

Klara, an educator explained that:

> *Because I know a lot of parents they don't earn a salary they earn wages, so if they are not at work, they don't receive their salary, they don't receive their wage, so they're not actually going to take the time out to take a day off work to sit at a hospital or sit at a clinic. So you don't get an appointment perhaps because you first need to be screened and those kinds of things, you have to actually take off the whole day to start the process. And that might also be daunting because a day lost is money lost. And also transportation maybe, they need to pay because they don't have their own transport. So I think they are contextual*

factors surrounding the different types of people in communities, would also be a barrier. (14:13)

5.4.1.2 Lack of help

A vast treatment gap exists in the treatment of mental health conditions in LMICs such as South Africa. One reason for the immense gap is the lack of available services. When asked about services available in the community, the interviewees' responses included:

No, there is nothing. (3:21)

I don't think there is any help in the community. Not at all. (7:30)

We don't actually get help through the community because here isn't a place where you can get a facility like that. (2:16)

These parents were unable to mention any community services to support children and families. A mother described her recent attempts to access help at the clinic:

Umm, I don't think there is enough help…I've been to the clinic for three full weeks now to find out if I can get appointment for Ryan. And the lady hasn't been there, I haven't met her yet…. But I also think that every clinic must have someone there that constantly work there….You see… like she's is only there on a Monday, I think that maybe we can get somebody that comes in three days in a week or so…. And maybe for parents that's looking for help with children with this, umm, with the ADHD because, I mean, I've got a handful. (4:4)

The promotion of mental health care has been called a humanitarian and developmental priority, and is said to be the core of sustainable development globally (Docrat et al., 2019). However, despite it being a priority, provision of mental health services has weakened due to lack of finances and personnel, high level of stigma and insufficient information collection to fully understand the burden of mental health disorders (Docrat et al., 2019). Audrey, an educator, provided an illustration of the interplay of the above-mentioned factors:

> *Firstly, the biggest challenge in my opinion would be to remain undiagnosed, for the child, not knowing what is 'wrong' with him or her, as well as for parents and family for peace of mind and starting to educate themselves. Other challenges would then include being treated differently or discriminated against. Then also strain in relationships between child and family members. Not receiving the necessary medical or psychological treatment. And then kids who eventually resort to substance abuse or crime, become dropouts due to not being diagnosed.* (13:9)

5.4.1.3 Uncertainty regarding available help

During the interviews, parents and educators explained that they are aware that there is help available in the community, but their challenge was knowing how or where to access that support:

> *With the twins, I literally had to go to the school and explain to them that the twins have ADHD. And then they mentioned that they do have a program with the Goldilocks and The Bear Foundation. So they introduced me to it. But otherwise, outside of school, I don't think there is anything like that.* (1:24)

> *I think the program that you're [#gb4adhd] doing, if we hadn't come through [the school], then we wouldn't have a solution…. So, there is no support that I know of. At all.* (12:18)

A common sentiment from educators was that they were aware of mental health services because of their role as an educator. Ella, a learning support teacher, laughed while explaining

> *That is my job. Mostly. Well, part of it. So I've been, I've been Googling, and looking into, and approaching, a lot of people.* (15:14)

Klara mentioned different resources in her community such as community health centres and state hospitals but added:

> *I think I probably wouldn't have known that if I wasn't also involved with kids in the school… So I wouldn't possibly off the bat have known about the different avenues that there are. If I didn't have to research it, if there wasn't a reason for me to research, I probably wouldn't have known, if I can put it that way.* (14:11)

An additional concern for interviewees indicated a lack of trust in the quality of help that is available. Enzo explained that:

> *It's quite difficult because even if you go there, the nurses and the people who are working there, they don't know about it. So, I think it's more uhh, specialized institution or a specialized doctor or psychiatrist or something like that, who need to tackle that…. Because ja, in the day hospital it's quite difficult…., the person receiving you, doesn't even know what are you trying to tell them.* (11:12)

5.4.2 Lack of education

ADHD remains a controversial topic clouded by misinformation which hampers the effective identification and management of the condition (Danforth & Kim, 2008; French et al., 2019). The interviewees similarly reported a lack of awareness and knowledge of ADHD as a significant barrier to accessing care, stating:

> *People don't have enough information about it. That's the biggest challenge. People are not aware about really what is that"* and *"People aren't educated about ADHD. They don't know what it is or what the symptoms are, they're not educated on what children need"*. (11:2)

As a barrier to care, lack of education is compounded by misinformation and myths. Many myths exist regarding the cause and treatment of ADHD including attributing the behaviour to sugar and food additives or poor parenting skills or believing that ADHD is only a childhood disorder (Akram et al., 2009). Likewise, the participants reported:

> *Sometimes they would assume that a child maybe has foetal alcohol syndrome...and then it's maybe not that, maybe that wasn't the issue and rumours that are made up about children with ADHD.* (1:5)

> *That whole pathway of diagnosing a child, getting a child diagnosed, getting him onto Ritalin getting the parents to agree... Because normally it's the fathers that say no… they say, we know someone.... you know the old story of "look at the cousin he was on Ritalin and now he's a drug addict" or now he's a zombie or nonsense like that".* (18:1)

Lack of knowledge is also associated with increased stigma. Thornicroft (2008) posits that a lack of knowledge (ignorance and misinformation), together with negative attitudes and avoiding behaviour, act as a "powerful force for social exclusion" (p. 14).

5.4.3 Lack of parental support and guidance

Parents play the role of gatekeeper in terms of treatment for children with mental health conditions (Taylor & Antshel, 2019). In this role, they make decision regarding whether to seek treatment and what types of treatment will be utilised. Poor recognition of symptoms, negative attitudes about ADHD and its treatment, as well as fear of stigma have been cited as factors influencing treatment seeking behaviour (Taylor & Antshel, 2019).

An educator explained:

> *The thing is some of the parents, they don't have the knowledge, they don't have the insight. As soon as you explain, explain it to them, so they can understand, I think they will be more....they will be more concerned about the children and try to help them*. (17:3)

A mother also described that parents need to be taught how to identify and manage their children's challenges to respond appropriately:

> *And they slap them, so that they listen. Now a lot of people are quite old-school so they will not want to work with a child who has this problem… it is almost they are constantly looking for attention… and perhaps in an ugly manner. That woman may not know how to help that child. She's going to either scold that child or slap the child or something. Understand? Our moms and dads need to learn how to work with the child so that they do*

> *not vent their aggression on the child.* (4:7) *(Note: this excerpt was translated from the respondent's original response given in Afrikaans).*

The interviewee went on to suggest that education about child mental health should be incorporated into ante-natal care, saying:

> *So I think that parents, when you pregnant, and you going to this, where you have to go maybe every month or every week or so, to the clinic that they will always be like someone just to help the parents explain if your child has ADHD or if your child has a disorder, how to face it.* (4:18)

5.5 UNMET NEEDS AND DESIRES IN THE COMMUNITY

In designing this study, the interview questions were based on an extensive review of current literature and my experience working in the community. However, Cook (2012) highlights that interviewing participants who fall within marginalised groups can emphasise asymmetrical power dynamics and perpetuate stigma. With this in mind, the question "What do you wish people knew about ADHD and mental health?" was added to the questionnaire. This was done to mitigate any preconceived ideas of the challenges experienced by the interviewees in regard to mental health in their communities. Three common themes emerged from the interviews, namely the wish for normalisation of mental health conditions, awareness, and empathy.

5.5.1 Normalising

In investigating psychiatric stigma, Egbe (2015) describes that discriminatory behaviour and negative attitudes are based on society's perception of a mental health care user as "being divergent from group norms" (p. 2). Thus, normalising mental health conditions could potentially lead to a decrease in stigma. Interviewees expressed their wish for mental health conditions to be more normalised, with sentiments like

> *That having it is as normal as having other illness like diabetes, and that it can be managed that it's very normal and I think probably everybody goes through it at some point in their lives.* (18:11)

> *What they should know is that the people with mental disability or mental health issues are just as normal and are also just as much human as the person that is perceived as normal.* (8:31)

> *I wish people knew is that it is real, that it's something that people struggle with and maybe more, more people than you actually imagine with it and that it happens to older people, it can happen to younger people, it can happen to you at any age. And also that there is help and that it's not something that you need to be embarrassed about. And also for families to know that if there is someone in the family that it's not something that should be embarrassed about or something that should be hidden.* (14:20)

5.5.2 Awareness

Regarding the barriers to care (as discussed in section 5.4.2), a lack of knowledge of ADHD and mental health conditions is a significant hurdle in receiving appropriate care. This need for awareness was prominent in the wishes of interviewees.

> *For me it is always sad that there is little acknowledgement in society about mental health conditions, since we by nature tend to focus more on the physical. So my wish would be for greater acknowledgement and awareness on mental health. Also, these conditions are often 'spiritualised' by society, especially in the church. For example, irrational behaviour would be seen as demonic or the work of the devil. In our community, people are more keen to*

> *accept the views of the church than psychologists or science. So another wish would be for these two diverse fields, religious leaders and psychologists to engage on these issues. In this way, I believe, more opportunities for awareness on these conditions can be created*. (13:11)

> *People don't know. They are not informed. They don't know. They are not aware. So people would have treated people differently if there was more information available for them… They don't understand, they don't understand. And it will take quite some time for people to get to that stage.* (11:13)

5.5.3 Empathy

Empathy enhancement has been cited as a key component of successful and long-lasting stigma reduction strategies (Hinshaw & Stier, 2008). In discussing their wishes regarding societal understandings of mental health, three mothers described an increased need for empathy and understanding:

> *People just needs to be a little sensitive in talking or dealing with a specific person. Sometimes people will say and do things that is really hurtful.* (9:18)

> *I wish they, they knew that those people are actually really, really special. They're actually the greatest artists, the greatest engineers, because they think differently... There was so many great artists and scientists that had dyslexia, that had ADHD…And it's usually those people that are looked down on because they think differently, they develop differently, that actually become really, really successful, and they are very dependable*. (1:34)

> *Don't treat the children differently and treat them like normal kids, and so on, just be softer on them, and gentle on them… You mustn't just breaking them down and stuff, you must pull him up. Because they are feeling they are going down, they don't go up.* (2:21)

The participants' responses regarding their wishes and desires reflect a need for intervention in the community on multiple levels to enhance the lives of children and families who are living with ADHD.

5.6 ADDRESSING BARRIERS TO CARE

Many different barriers to care were highlighted throughout the interviews based on individuals' experiences and roles in society. However, when asked how they felt society could address the barriers, the overwhelming response throughout the interviews was awareness and education. Different methods to create awareness were suggested including:

> *A community centre… where people could be invited to hear someone talk about mental health issues.* (1:28)

> *Maybe put it on social media or something like that. Post it on the communities groups, and so on.* (2:20)

> *Maybe a role model that has been stigmatised, alright? ....and he has to be open and say " hey, you know what. I actually used to go through this kind of stigmatization" and people can just share. Just some kind of communication, you know?* (12:14)

One father, Liam, explained how information about mental health needs to be made more visible and prominent in society. He highlighted how society has embraced the practice of printing health warnings on cigarette boxes, but that the same level of exposure is not afforded to mental health:

> *The biggest thing for me is educating people, creating awareness, and really just pushing it out in the media. Not celebrating it on one special day, but making it more of a thing that everybody can see consistently. You see advertisement boards, you see it everywhere. It's in your face. If it's on an advertisement, on a bread packet or the milk carton….because I mean, you can do the cigarettes, you putting cigarette advertisements, we saying what the health issues are...you use that so nicely, but you can't do it on other things like advertising boards, radio, news, all of those things to cover it? ….Because if that gets talked about by a famous actor, or famous singer, singer, it lets it gets traction…, the influencers, for example. You know, those are people that you can really generate that understanding of the different or special needs, ADHD, mental illnesses, those are things I think, I think are people that can really push those agendas for us that doesn't have a voice.* (10:8)

Following a similar approach, Klara, an educator explained that mental health education should follow models used to address highly stigmatised conditions:

> *I think if it was given the same type of exposure as AIDS or TB or teenage pregnancy was given then I think people would know more. Because those are things that are spoken about all the time, often, it's advertised everywhere on TV, radio and its spoken about and it's okay to do talk about. I think if the same type of education is attached to those, it might stop being a taboo, it might be okay even to admit that I have one of these things And that I need help for it. Or that I'm getting help for it.... It's not anymore where you are crucified but people empathise with you so...And that only came with education. Something else had to drive that, so I think education and knowledge is the key.* (14:15)

Exploring the need to create awareness necessitates a discussion as to whose responsibility it is to facilitate the education. Both parents and educators felt that everyone has a role to play including parents, educators, and government.

> *So, then I would feel that it is each and everybody's own responsibility to...how can I say... To educate themselves. Where, where mental health disabilities or mental health comes into, because even you as the per se "normal person" will also deal with mental health issues issue. So we need to educate ourselves about all these things, so that we can be, we will be able to educate our children…. it is up to us parents, to educate ourselves so that we can educate our children so that they can one day continue the chain to educate their children. And in that way, everybody will be educated enough to be able to make decisions for themselves where mental health and things like that is concerned.* (8:21)

The role of government was highlighted by both parents and educators:

> *I think it falls on the government really. It falls on the government because it affects the entire society. People who can afford, people who cannot afford. People who are educated, people who are not educated. And it's only an organization such as the government which can reach out to people at such a large magnitude. I think it's a mammoth task for private organizations to do.* (12:6)

The role of educators and schools was also discussed:

> *I think it starts at school. They are mostly at school, during the day. It starts there….Maybe talk to the children, that children with glasses, children with lisps or with disabilities are still children, can still be their friends, you know?* (3:16)

> *From my side obviously as a teacher because when I identify something I discuss it with the people so that is my, my responsibility, my role, to try and make a change, and help parents also understand that it's not a bad thing, if it is identified and it's not that anything's wrong with a child, it's just something that needs to be, something that your child needs help with.* (14:19)

> *Well, I think it starts probably with us, the teachers. If you want… well, not to educate specifically but maybe to just get them to, you know, lead them in the right direction. Towards places where they can be educated.* (15:18)

5.7 SUMMARY

This chapter presented the findings from the qualitative interviews. The discussion centred around four major themes: understanding stigma, factors influencing access to care, unmet needs and desires in the community and addressing barriers to care. The next section provides an integration of the quantitative and qualitative results.

CHAPTER 6

DISCUSSION

6.1 INTRODUCTION

In this chapter, I discuss the findings from the mixed methods study by integrating the results presented in Chapter 4 and Chapter 5.

6.2. PARENTS' AND EDUCATORS' KNOWLEDGE OF ADHD

Parental and educator knowledge of ADHD is essential for children with ADHD as their insight (or lack thereof) influences the identification, treatment, and management of their condition. When left untreated, ADHD can lead to long-term negative educational outcomes, development of co-morbid psychiatric conditions, poor self-esteem, and higher incidences of risky behaviour (Barkley, 2016; Shaw et al., 2012). Parental knowledge and attitudes directly affect access to care, adherence to treatment and psychosocial support at home (Rajcumar & Paruk, 2020). Furthermore, educators are regarded as essential sources of information for parents, play a key role in referral and diagnosis, and are responsible for creating a conducive learning environment for children (Perold et al., 2010; Topkin, 2013). Parental and educator attitudes towards mental health conditions can be influenced by cultural practices or belief systems. In the multicultural context of South Africa, cultural and religious beliefs may lead individuals to attribute symptoms to the influence of departed ancestors or bewitchments, which may in turn impact the type of treatment sought – turning to traditional healers rather than accessing Western-based medicine (Atindanbala & Thompson, 2011; Sehoana,, 2014). .

The findings from the quantitative component of this study indicate that both parent and educator knowledge of ADHD (including cause, symptoms, diagnosis, and treatment) is poor. In response to the KADDS that measured overall knowledge of ADHD (i.e., associated features, treatment and symptoms and diagnosis), participants answered 36% of questions correctly. The statement which was answered most correctly (80%) was "ADHD children are frequently distracted by extraneous stimuli". This is similar to the findings of Rajcumar and Paruk (2020), who reported that 88.6% of their participants answered this question correctly. The question in this study which had the lowest number of correct responses (4%) was "most estimates suggest that ADHD occurs in approximately 15% of school age children". This matches the findings that parents, and educators scored highest on measures of symptoms and diagnosis, and lowest with regards to associated features such as the nature and causes of ADHD. Perold et al. (2010) similarly reported that a substantial number of their participants showed lack of knowledge regarding the causes and long-term outcomes and risks (nature) of ADHD.

In the current study, educators scored 48.60% of all items correct. In comparing the parents' and educators' knowledge of ADHD, the educators consistently scored higher than parents. These findings are similar to those reported by Perold et al. (2010). In their study of educators' knowledge of ADHD in 35 schools in Cape Town., their sample reported 42.6% correct responses regarding their knowledge of ADHD. Perold at al. (2010) also found that educators were more aware of the symptoms and diagnosis of ADHD than of the treatment and associated features. In their cross-national study of educator' knowledge of ADHD, Sciutto et al. (2016) found a range of correct responses: Czech Republic (57%), Germany (54%), Greece (47%), Iraq (455), Republic of Korea (39%), Saudi Arabia (15%), South Africa (52%), United States of America (62%) and Vietnam (33%) (Sciutto et al., 2016).

The idea that limiting sugar intake is effective in reducing ADHD-related symptoms is a commonly held misperception. In investigating teacher's perceptions of ADHD, Topkin et al. (2015) and Perold et al. (2010) reported that 63.3% and 65.2% of the teachers in their samples endorsed this belief, respectively. Rajcumar and Paruk (2020) reported that 92% of parents in their sample agreed with this statement. In the current study, 93% of participants endorsed this belief. The current study found no significant difference regarding the overall knowledge of ADHD, and whether the participant did or did not have a child diagnosed with ADHD.

The need for more education regarding ADHD was a prominent theme throughout the interviews with parents and educators (see Sections 5.3.2, 5.4.2 and 5.5). Educators expressed a wish for more involvement from the Department of Health and Department of Education. They also suggested that there should be workshops available for both educators and parents. This aligns with suggestions posed by Topkin et al. (2015) that once-off training on ADHD should be replaced with continuous knowledge development regarding both the symptoms and management of ADHD, as well as classroom intervention strategies. Furthermore, educators indicated that increasing knowledge amongst parents would lead to better outcomes for children as parents would be able to attribute difficult behaviour to ADHD rather than to misbehaviour and that they may be more open to psychopharmacological treatment for their child. Parents highlighted the need for educators to be more equipped to manage the specific needs of children with ADHD and for platforms where parents could learn how to support their children (see Section 5.3.3). This echoes

Perold et al. (2010) who state that the education system has a responsibility to ensure that educators have sufficient knowledge of ADHD in order to successfully manage their behaviours in class, as well as to aid children in achieving social and academic success. The findings of this study support those of Mofokeng and van der Wath (2017) who reported the need for multi-disciplinary interventions aimed at empowering parents and encouraging communication between parents and the educational system to support children with ADHD. Furthermore, parenting skills training was recommended to encourage effective authoritative, as opposed to authoritarian parenting, which was related to decreased levels of depression in parents of children with ADHD (Mofokeng & van der Wath, 2017).

6.3. UNDERSTANDING STIGMA

Stigma as it relates to mental health has been shown to be a major contributing factor to poor access to care. Furthermore, research shows that the impact of stigma can outweigh the impairment of a mental health condition, leading to poorer prognosis (Hinshaw & Stier, 2008).

In their conceptualisation of stigma, Link and Phelan (2001) describe four components: distinguishing and labelling differences, associating human differences with negative attributes, separating “us” from “them” and status loss and discrimination”. This framework will be used in discussing the participants understanding of stigma.

6.3.1 Distinguishing and labelling differences

In defining stigma in their own words, the parents and educators highlighted the notion of recognition of difference and labelling, which leads to a loss of individual identity (see Section 5.2.1). Participants used phrases such as “it’s seeing them differently”, “people mark you” and "it's a negative label" to describe stigma. This concurs with Goffman's (1963) notion of stigma as a signal of 'contamination', leading to a label of undesired difference, in which a person is reduced to something 'not quite human' based on an attribute they possess (p. 14). aligns with Dovidio, Major and Crocker's (2000) conceptualisation of the fundamental components of stigma where a) recognition of difference, leads to b) devaluation. Children's symptoms of hyperactivity, impulsivity, and inattention lead to exhibiting behaviours which deviates from the norm and thus lead them to be seen as different from their peers or family members (Link & Phelan, 2001).

6.3.2 Associating human differences with negative attributes

Associating human differences with negative attributes involves two components - a label and a stereotype. In this process, a label links a person to a collection of characteristics that constitute that stereotype. A stereotype is a socially constructed belief about a group of people which acts as a "shorthand" to describe that specific social group (Corrigan, 2002; Hinshaw & Stier, 2008).

Both parents and educators described situations in which the recognition of difference was linked to negative attributes (see Section 5.2.1.2). One participant described stigma saying, "stereotyping about what ADHD is… saying that they are dumber". In this instance, the label "ADHD" is linked to a negative attribute, namely poor intellectual ability. Participants also made a link between ADHD-type behaviour and stereotypes about parents, including that the child's behaviour is caused due to alcohol use during pregnancy or to lack of attention from parents. In this case, the behaviour, often referred to by parents as "hyper" in this study, is linked to a stereotype, rather than the actual label of ADHD. Additional misperceptions regarding stimulant treatment of ADHD leading to substance abuse were also mentioned. Through the process associating human difference with a negative stereotypes, two types of stigma were experienced or observed by the participants in this study. Participants described instances of public stigma in which the societal majority endorses negative attitudes about a stigmatised group of people (Corrigan, 2018). Instances of courtesy stigma where people closely associated with the stigmatised individual (e.g. parents or siblings) are poorly treated due to their involvement and proximity with the individual were also reported (Quinn & Chaudoir, 2009).

6.3.3 Separating "us" from "them"

A distinct separation between "us" and "them" is an important feature of understanding the stigma process. Stereotypes in themselves are not harmful i.e., individuals may be aware of a stereotype regarding a certain gender or culture, but this does not mean they endorse this belief. When an individual endorses the negative stereotype, a negative affective response takes place (e.g. being fearful or disgusted by an individual with a mental health condition) which results in prejudice (Rüsch et al., 2005).

Link and Phelan (2001) propose that after a difference has been labelled, and that label has been associated to a negative stereotype, individuals are categorised into what society believes are fundamentally distinct groupings. This is a result of prejudice. Importantly, this separation between "us" and "them" appears to dehumanise the individual in the stigmatised group and in doing so, justify discrimination and mistreatment in the eyes of the stigmatiser. Participant responses where children or students had been classified as "them" include "that person is not normal" and "he's crazy maybe". The word "normal" was used often throughout interviews to refer to children or adults who do not have mental health difficulties. Parents in this study described that they felt their children's behaviour was always viewed in a negative light, or through the lens of ADHD. This led to the behaviour of children who were in the "them" (ADHD) group to be seen as rude or unacceptable and for them to be judged more harshly than similar behaviours seen in children in the "us" (non-ADHD) group (see Section 5.3.2.4). In these instances, the children's label or grouping justified unfair treatment from others.

6.3.4 Status loss and discrimination

Link and Phelan (2001) posit that "when people are labelled, set apart and linked to undesirable characteristics, a rational is constructed for devaluing, rejecting and excluding them" (p. 371). Based on the dehumanising effect of being assigned to the "them" group, the stigmatiser can assign any number of negative attributes to a group, which leads to a diminished moral status (Goffman 1963) or devaluation (Dovidio et al., 200), that subsequently allows the stigmatiser to justify their discriminatory behaviour. Discrimination is the behavioural component of stigma and leads to excluding and avoiding behaviours (Hinshaw & Stier, 2008; Thornicroft, 2008).

In this study, the participants reported many instances of devaluation, rejection, and exclusion. This manifested as bullying and name calling, exclusion from social events and educational opportunities, children having their individual needs disregarded and being overlooked (see Section 5.2.2). Furthermore, some parents felt that their child's behaviour was always interpreted negatively by peers, family and educators even if the behaviour was a symptoms of their ADHD or when behaviour was benign or typical of children in similar environments and developmental stages. Parents felt that these negative reactions were underpinned by stigma.

6.4 THE IMPACT OF STIGMA

Research indicates that experiencing stigma has a negative influence on both mental and physical health by affecting social relationships and self-esteem, as well as the adaptation of maladaptive coping strategies and decreasing access to material resources and support (Hatzenbuehler et al., 2013; Holder et al., 2018). The negative impact of stigma affects both individuals with ADHD and their families.

6.4.1 Impact on the stigmatised individual

The views expressed by participants in this study suggest that stigma in relation to ADHD could negatively affect self-esteem and increase isolation (see section 5.2.3). Parents and educators described how children viewed themselves as “dumb” or were cognisant of being labelled a “problem”. Moldavsky and Sayal (2013) reported that children with ADHD felt as if they had a bad reputation amongst peers, teachers and parents of peers, which resulted in differential treatment. Parents and educators further felt that as a result of being labelled, children would either be excluded (see Section 5.2.2.2) or withdraw and isolate themselves (see Section 5.2.3.2). This is corroborated in the findings of Moldavsky and Sayal (2013) where parents expressed concerns that receiving a label of ADHD would lead their child to being socially isolated or rejected. This demonstrates experiences of self-stigma or internalised stigma, where individuals accept and endorse the negative public perceptions about their stigimatised identify and turn them towards themselves, leading them to feel disempowered, hopeless, devalued and shameful (Boyd et al., 2014; Rusch et al.,2005; Kellison et al., 2010; Fox et al., 2018). Self-stigma has been shown to increase emotional impairement and negatively impact self-image (Kellison et al., 2010) as well as decreased help-seeking behaviour (Fox et al., 2018). Thus it appears that children not only have to contend with the challenges of ADHD, but that they also have to deal with the social and emotional experiences that accompany the stigma-based reactions from peers, teachers, family and society. This is similar to findings reported by Rusch et al., (2005) indicating that individuals with mental health conditions are disadvantaged by both the symptoms of their condition, as well as society's negative or prejudicial reactions, which can lead to internalised stigma that has both intrapersonal and interpersonal consequences.

6.4.2 Impact on the family

In my study it became evident that stigma impacts the family both practically and emotionally. Practically, participants described avoiding certain places or planning activities to avoid situations with crowds, due to fear of how society may respond. These changes in behaviour could be attributed to anticipated stigma, which refers to the degree to which an individual expects to be the target of stigma, and experience subsequent discrimination (Fox et al., 2018). Responses indicate that parents anticipated a negative reaction from society because their child could not or would refuse to behave in a manner which is deemed socially acceptable (see Section 5.2.4.1). As noted by Link and Phelan (2001) (see Section 6.3), behaviour which is viewed as 'abnormal' or 'different' is often labelled and associated with negative attributes which creates stigma and leads to separation, exclusion, loss of status within the community, and discrimination. Choosing to exclude themselves and their children from certain places or activities may be the result of courtesy stigma, which is a stigma a person possesses due to their proximity or connection to a stigmatised individual (Quinn & Chaudoir, 2009). Thus a combination of anticipated and courtesy stigma may have a substantial effect of the whole family.

Emotionally, parents reported feeling exhausted and alone. Parents also described feeling bad for their children or feeling agitated due to their mistreatment (see Section 5.2.4.2). The findings of this study match the findings of Mofokeng and van der Wath (2017) who reported increased parental stress levels from managing their children's challenging behaviour, which is compounded by stigmatising attitudes from families and communities, leading to social impairment and emotional distress. Similarly, in both studies, parents reported feeling emotionally unsupported and fatigued. Increased stress-levels, depression and self-blame may reflect the parent's experience of affiliate stigma, in which an individual notices and accepts the courtesy stigma they have experienced due to their connection to their child who has been discriminated against, leading to increased anxiety and withdrawal, decreased social functioning, and heightened negativity towards themselves and their children (Mikami et al., 2015). Lack of emotional support for parents, due to society's negative reactions to a diagnosis of ADHD was reported by Cheesman (2019) who highlighted the need for improved societal knowledge of ADHD to increase support and reduce isolation. The ways in which stigma affects the family of a child with ADHD appears to be multi-layered – the child may experience public stigma, leading to family members experiencing anticipated, courtesy and / or affiliate stigma which has substantial emotional consequences that may exacerbate family discord and distress within the family system.

6.5 BARRIERS TO ACCESSING CARE

Accessing healthcare in South Africa is fraught with many challenges including lack of resources, deeply entrenched beliefs about mental health and poor awareness of mental health conditions and treatment (Strumpher et al., 2014; Bimerew et al., 2015).

Based on the results from the Barriers to Care Evaluation (BACE-3) (see Section 4.4), participants in this study most frequently reported the following as barriers to accessing care:

- Not being able to afford the financial costs involved
- Wanting to solve the problem on their own
- Concerns about available treatments (e.g., medication side effects)
- Concern that they (or their child) might be seen as weak for having a mental health problem.

These represent instrumental, attitudinal, and stigma-related barriers to accessing care. Analysis of the participant's responses to the BACE-3 showed that overall, participants rated instrumental barriers as the primary barrier to accessing care. This was followed by attitudinal barriers and then stigma related barriers. The presence of instrumental barriers was corroborated by the interviewees who mentioned financial constraints, lack of available help and uncertainty regarding where to access help, as barriers to treatment in their communities (see Section 5.3.1). Parents and educators highlighted the challenges of taking a day off from work to go to a community health clinic, and the cost of transport to get to the appointment as important instrumental barriers. This aligns with international findings which indicated that concerns about cost of treatment, transportation to appointments and beliefs that the symptoms they were experiencing were normal and not due to a mental health condition, were perceived as greater barriers than stigma (Pepin et al., 2009). Locally, Strumpher et al. (2014) reported that the cost of travelling to appointments, and lack of insight into the fact that mental health conditions can be treated, pose major barriers in the utilisation of mental health care in the Eastern Cape province of South Africa.

Throughout the interviews, participants highlighted lack of awareness and knowledge, compounded by misinformation and myths about ADHD, as a primary barrier to accessing care (see Section 5.4.2). As reported in Section 4.3 and discussed in Section 6.2, parents' and educator's knowledge of ADHD in this study was poor, with educators performing slightly better than parents. Statistical analysis of correlation between the BACE-3 and KADDS measures found participants who had more knowledge of the symptoms and diagnosis of ADHD were more likely to avoid seeking treatment due to fear of other people finding out, which implies a fear of being stigmatised. This finding in my study contradicts existing research which suggests that increased knowledge of mental health conditions is positively correlated with treatment seeking (Rajcumar & Paruk, 2020). Choosing to not access professional care, despite being aware that a behaviour or symptoms may be due to a legitimate psychiatric condition, may be an enactment of label avoidance. Label avoidance is the choice of individuals or family members to avoid certain places or institutions such a mental health clinic, where they might be recognised and labelled, and subsequently mistreated, and has been linked to delays in seeking help and support (van Zelst, 2009; Corrigan, 2018; Hinshaw & Stier, 2008).

Lack of parental support and guidance was a prominent theme during interviews (see Section 5.3.3). Educators indicated that increased parental education about ADHD could lead to better long-term outcomes for children. Parents expressed a need to be taught how to manage ADHD-related behaviours in a healthy manner. This echoes the findings of Mofokeng and van der Wath (2017) who explored the challenges of parenting a child with ADHD, and suggested case-specific psychoeducation to lessen the burden of care and to encourage consistent and effective parenting styles. Participants in my study suggested the use of support groups or learning from parents who have had similar experiences would be beneficial in helping them understand ADHD, parent effectively and develop coping mechanisms to manage the frustration they felt towards their children. This aligns with the findings of Ahmed et al. (2014) who reported that parents strongly supported the idea learning from “real life” experiences of other families in similar situations. In addition, parents felt that the information they received focused on treatment, and lacked information regarding the causes of ADHD and the role which parents can play in managing the condition (Ahmed et al., 2014). In investigating factors associated with parental treatment attitudes and information seeking for childhood ADHD, Taylor and Antshel (2019) reported that while increasing parents’ knowledge about ADHD is important in treatment seeking attitudes, that this should be accompanied with efforts to decrease stigma, foster self-efficacy, and bolster resilience. Mofokeng and van der Wath (2017) additionally highlighted the importance of effective communication between health professionals and educators, as well as managing any psychopathology that a parent may be experiencing. By combining education with social and psychological support, parents may be more likely to access treatment, be more resilient towards inevitable stigma and be more equipped to manage the stress of parenting a child with ADHD.

6.5.1. Ecological model of barriers to care

The development of both neurotypical and neurodiverse children is influenced by many factors, which according to Bronfenbrenner (1979) operate in a system of layers and include a child’s immediate contact such as interactions with caregiver, their neighbourhood and peer group and school, as well as their larger social context which includes cultural influences as well as community resources and infrastructure (See Section 2.4).

In investigating challenges to access to treatment, Bronfenbrenner's (1979) ecological model of development is helpful in understanding the ways in which a child's milieu has an impact of their mental and physical health (Atiola, 2017; Eriksson et al, 2018). The participants in this study identified many intrapersonal, interpersonal and systemic challenges which impact the process of getting adequate care for ADHD. Microsystemically, the low levels of knowledge of ADHD (See Section 6.2), increased parental stress, as well as heightened emotional pressure and family discord (See Section 6.4.2) are factors that could influence the development of a child with ADHD. If caregivers are unable to recognise a child's behaviour as being caused by ADHD, or properly know how to manage the condition, the child may lack the necessary emotional and physical support they require and may also not receive any formal medical intervention. In addition, an unhealthy family environment may compound the neurodevelopmental challenges the child is already contending with.

School environment and peer groups (mesosystem) are instrumental in a child's development. This study found many scholastic and interpersonal barriers for children with ADHD. Participants felt that children with ADHD were often bullied and excluded which led to decreased self-esteem and isolation which in turn stripped them of their individuality and led to their individual needs not being met (See section 5.3.2). This aligns with research that found that many children still continue to face both physical and attitudinal barriers in the classroom which influences their ability to fit in at school and to receive the necessary physical and psychological support they require to reach their potential (Human Rights Watch, 2015; Lund et al, 2008; Letseka, 2014; Naude & Meier, 2019, Department of Education, 2001).

Both teachers and parents in this study highlighted the implications of financial barriers and lack of community health resources as substantial barriers to accessing care (See Section 5.4.1). Challenges relating to infrastructure and available resources which may aid in a child's development reflect exosystemic barriers. As a country, our state health system remains under-financed and in some cases, health professionals are not sufficiently trained to manage mental health difficulties (Strumpher et al., 2014; Docrat et al, 2019; Statista 2021).

The society and culture within which a child grows up may serve to nourish their development or impede it. The participants in this study lived and/or worked in underprivileged communities and were thus facing macrosystemic barriers such as poverty (See Section 5.4.1). Parents and teachers highlighted the fact often the nature of employment the parents had (those who were employed) involved daily wages. Thus, taking a day off of work (and thus forfeiting a daily salary) was not feasible for caregivers, and therefore created a barrier in accessing treatment (See Section 5.4.1.1). Stigma is an additional macrosystem barrier faced by both the children with ADHD and their parents. Stigma as a barrier to care will be discussed in the Section 6.6.

6.6 STIGMA AS A BARRIER TO ACCESSING CARE

Thornicroft (2008) proposes that rather than relying on an operationalised definition of stigma, it should be viewed as an "amalgamation of three related problems: a lack of knowledge (ignorance and misinformation), negative attitudes (prejudice) and excluding or avoiding behaviour (discrimination)" (p. 14). The current study found that all three of these problems affected the participants. In the interviews, participants highlighted three key unmet needs in the community: the need for ADHD and mental health conditions to be normalised, the need for increased awareness and need for increased empathy. These unmet needs may reflect the way in which stigma currently operates in the community. Figure 6.1 demonstrates this reflection by showing how the needs of the community identified in this study can be mapped onto Thornicroft's conceptualisation of stigma.

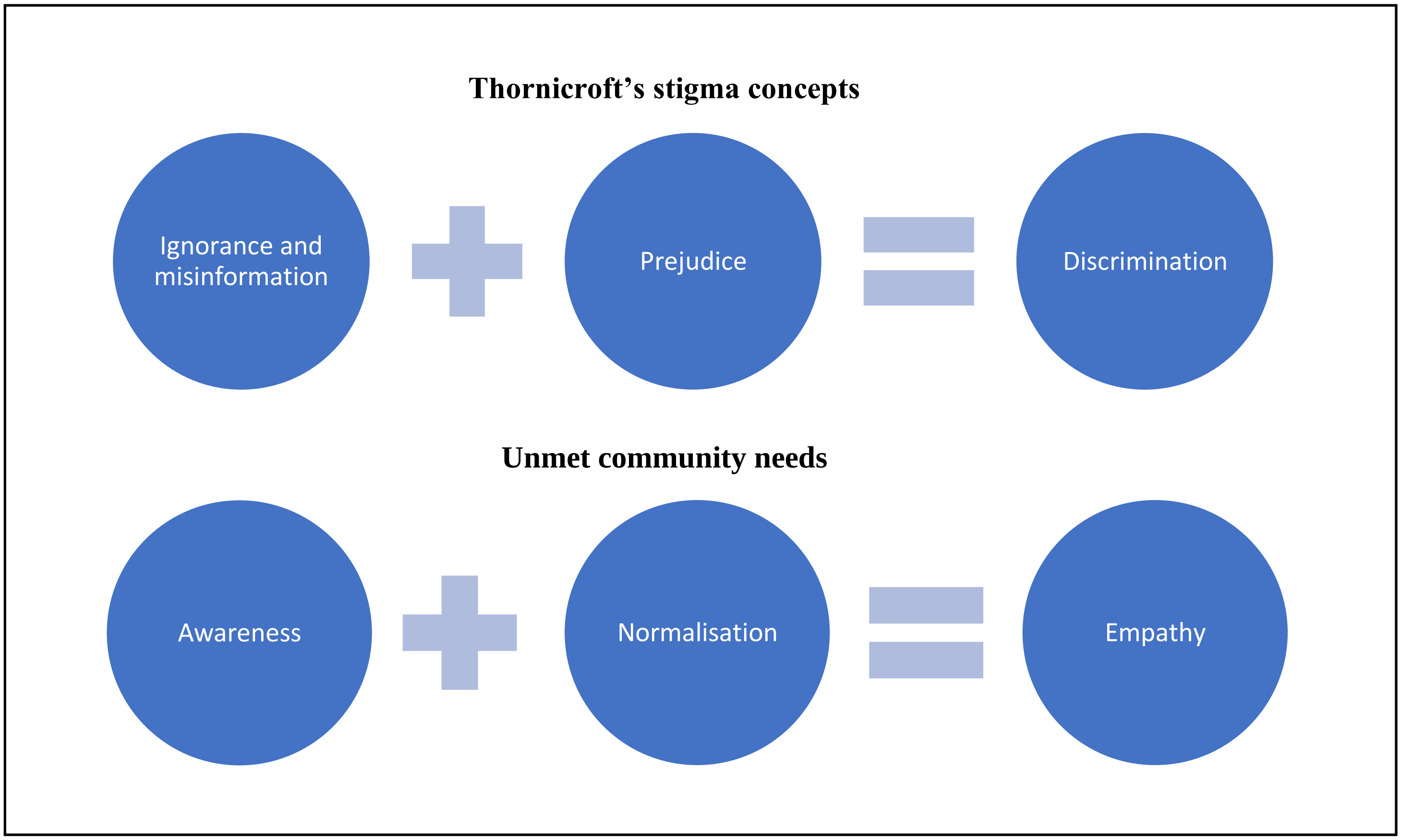


Figure 6.1. **Unmet Community Needs as a Reflection of Stigma in the Community**

The current needs in the community can highlight the ways in which stigma impacts the lives of community members. In addition, the unmet needs provide insight into possible ways in which to structure stigma-reduction strategies – namely, that by increasing awareness (and reducing misinformation), ADHD may become more normalised (and prejudice could be decreased), which could lead to more empathy (and less discrimination). Participants proposed various ways to target stigma in the community including psychoeducational workshops about mental health and using role models and social media influencers to create awareness. Furthermore, participants suggested that awareness initiatives for ADHD should be similar to those targeted at other stigmatised conditions such as teenage pregnancy and HIV/AIDS, where they felt that stigma-reducing initiatives have been effective, leading to normalisation and reduced stigma. In a review of anti-stigma campaigns related to mental health in South Africa, Kakuma et al. (2010) found that numerous campaigns were in place, but that these activities were seldom systematically monitored or evaluated leading to lack of clarity regarding reach and effectiveness. International research highlighted the efficacy of using mental health patients in anti-stigma campaigns (i.e. using their stories as an example of how mental health stigma may be overcome or demonstrating hope), and the importance of directing anti-stigma initiatives amongst youth (Kakuma et al., 2010; Ilic et al., 2013). Likewise, participants in the current study proposed learning from the experiences of people who have overcome stigma, and teaching children about mental health at school as practical means of tackling societal stigma.

6.7 STIGMA AS A BARRIER TO WELLBEING

While stigma does appear to act as a barrier to accessing care by virtue of various types of stigma – public, courtesy, and affiliate – as well as due to label avoidance, the findings from this study also indicate that the effect of stigma permeates all aspects of living with ADHD. A child with untreated ADHD symptoms may be treated differently due to the behaviour which they struggle to control and might be labelled as naughty or lazy. Hinshaw (2005), as discussed in Section 2.3.3., proposes that four characteristics of ADHD make it particularly prone to evoking stigmatising reactions, namely a) intangibility, b) chronicity, c) negative media portrayals of ADHD and, d) as a result of the ‘typical’ ADHD-like behaviour such as impulsivity, emotional dysregulation, leading them to be seen as ‘different’ or ‘abnormal’. The participants in this study reported experienced which align with Hinshaw’s (2005) theory. Namely, children’s behaviour was considered ‘naughty’ or ‘deliberate’ as opposed to a symptom of ADHD, as well as beliefs that children would outgrow ADHD, pointing to misunderstanding regarding the fact that ADHD is a life-long condition. Children may also be mistreated or treated differently by virtue of having been labelled with the diagnosis of ADHD and receiving treatment. This aligns with research which shows that parents and educators expected children with ADHD to perform poorly in relation to their peers, despite academic performance measures showing no evidence for this (Eisenberg & Schneider, 2007). In addition, parents report experiencing stigma related to their child’s behaviour, as well as being blamed for their children’s condition. Myths and misperceptions about ADHD exacerbate the stigma, leading to increased prejudicial and discriminatory behaviour. A visual representation was created to illustrate the complex interplay of factors which were evidenced in the findings of this study. This is presented in Figure 6.2.

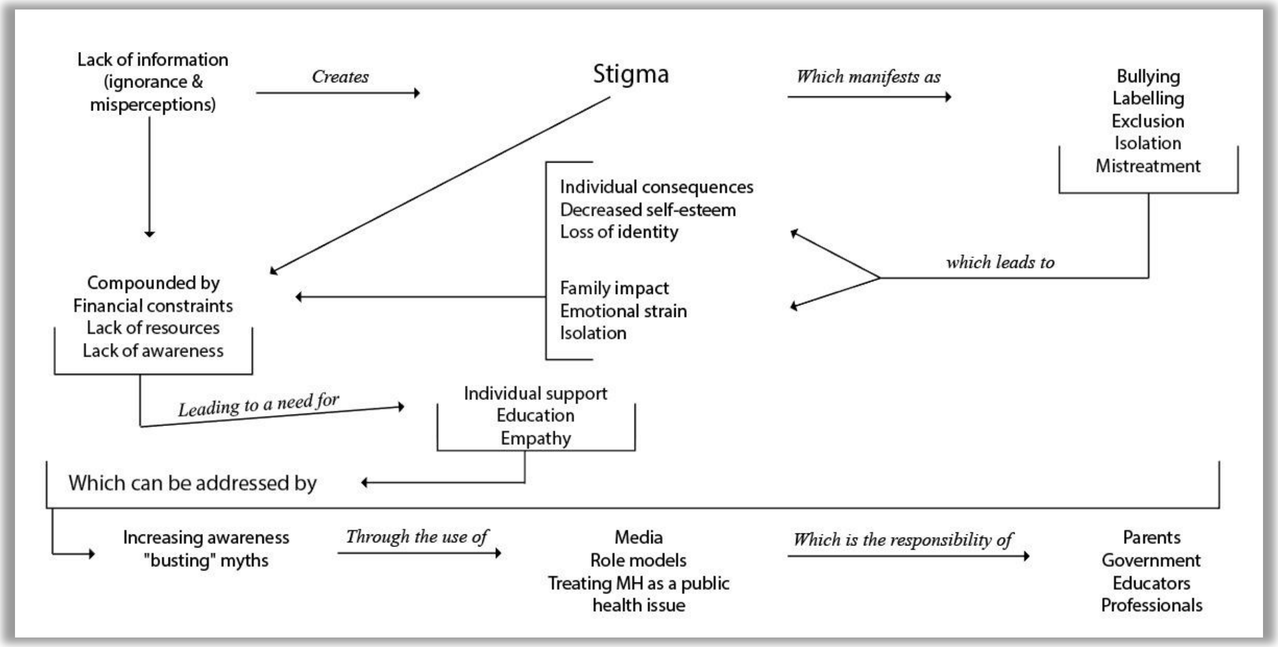


Figure 6.2: **Multiple Factors Influencing Access to Care**

6.8 SUMMARY

The findings from this study suggest that stigma does create a barrier to accessing treatment. However, the impact of stigma as a barrier reaches further than treatment. It negatively affects the quality of life of the child with ADHD and their family, leading to additional emotional distress and decreased social support.

Lack of information creates stigma which manifests as bullying, labelling, exclusion, isolation, and mistreatment. This affects children with ADHD and their families emotionally, leading to lowered self-esteem and increased isolation. This is further compounded by financial difficulties and lack of available help in the community, amongst other factors. The development and wellbeing of children with ADHD is influenced by multiple factors operating within their family, school and cultural environments.

Therefore, children with ADHD and their families carry a “triple burden” in as much as they need to: 1) manage the disorder, 2) deal with negative attitudes and prejudice from society and family, and 3) do so with limited resources and available help. This creates a need in the community for individual support and for psychoeducation regarding ADHD with the intention of increasing awareness and fostering more empathy in the community. These findings suggest that this could potentially be accomplished by normalising mental health through addressing it in the same way other stigmatised conditions (such as teenage pregnancy and HIV) have been successfully addressed leading to decreased stigma and discrimination. Participants in this study felt that challenging the stigma associated with ADHD was every person’s responsibility, including parents, educators, schools, government, and professionals in the mental health field.

CHAPTER 7

CONCLUSION AND RECOMMENDATIONS

The purpose of this study was to explore stigma as a barrier to accessing care for children with ADHD. The aims of the study included assessing parents' and educators' knowledge of ADHD, exploring their understandings and experiences of stigma, exploring factors which act as barriers to care and gaining a deeper understanding of how stigma impacts accessing treatment for children with ADHD. This section presents the conclusions from the study, the limitations and strengths of the research and posits some recommendations for future research.

7.1 CONCLUSIONS

ADHD is a pervasive and chronic disorder which negatively impacts an individual's academic, social, and emotional functioning. When untreated or mismanaged, ADHD has long-lasting negative fallout including scholastic failure, social impairment, a heightened risk of becoming involved in criminal activities and abusing substances, as well as higher levels of family discord. While mental health services do exist in the community, many children do not receive the necessary treatment and support that they require. The findings from this study indicate that stigma may play a role in the under-utilisation of treatment, although this does not account for all the reasons that children do not receive the necessary intervention. Additional important factors acting as barriers to mental health support that were highlighted are financial constraints, a lack of mental health services in the community, poor knowledge and awareness of ADHD, and lack of parental guidance and support.

Findings from this study indicate that stigma does not only influence the process of accessing mental health care. Rather, its impact can be felt throughout the life of a child with ADHD. These children experience bullying, exclusion, and a loss of individual identity. In addition, their individual needs are overlooked in the classroom leading to lack of educational opportunities, increased social isolation and decreased self-esteem. Furthermore, parents and families are subjected to courtesy and affiliate stigma which leads label avoidance, as well as increased emotional strain.

Based on these findings, there is an increased need for awareness of ADHD in the community. By increasing awareness, the condition may become more normalised, and in doing so, could result in less discrimination. Additionally, there is a need for parents, educators, and children to receive more support in the community, both emotionally and practically through upscaling of community mental health infrastructure.

7.2. STRENGTHS

Stigma is a global phenomenon which remains misunderstood and under-researched. This study provides insight into the knowledge gap which exists regarding ADHD and stigma in the South African context. Using a mixed method design contributed to the depth of the findings and enabled a critical examination of participants’ experience from different angles. The quantitative portion of the study highlighted important aspects of the participants’ knowledge of ADHD and the barriers which they face when accessing treatment. In addition, the qualitative portion facilitated a deep delve into stigma and the lived experience of children and families living with ADHD. Furthermore, conducting this research highlighted areas which require additional research and may guide future investigations which can steer stigma-reducing initiatives with the aim of enhancing the quality of life of children with ADHD living in South African communities. Finally, the participants were afforded the opportunity to tell their story and feel heard, in what I hope was a cathartic experience and to use their experiences to contribute meaningfully to the existing body of knowledge.

7.3 LIMITATIONS

The Covid-19 pandemic and resulting social distancing and lockdown regulation necessitated adjustments to the original research methods. A resulting weakness is that the sampling methods (i.e., relying on participants to have access to smartphones and data) were not optimal for the population. This potentially excluded willing participants and could have been one reason for the low response rate. The small sample size of this study limits the generalisability of the findings to the broader population. To address this, I used the qualitative interviews as an opportunity to gather rich data and immerse myself in the experience of the participants in order to portray a more accurate and authentic representation of their challenges.

A further limitation is that participants in the study were recruited through #gb4adhd who aim to bring mental health services to underprivileged communities. Thus, by virtue of their association with #gb4adhd, the parents and educators have received mental health support in some form – either through screening, or further assessment by a health care professional. This may have influenced their perceptions of mental health services in the community. Additionally, having previous interaction with me in the role of service provider, prior to my role as a researcher, may have impacted the way in which questions were answered. Being cognisant of this dual-role as both researcher and service-provider caused me to experience some anticipatory anxiety which at times led to increased internal distraction. To address this, I started each interview by reminding the participants about the purpose of the research, thus bringing both their focus and mine into the present moment. I also told participants that there would be an opportunity at the end of the interview for them to ask questions and discuss “non-research” related content and to debrief. This allowed the interview to be compartmentalised as “research”, separate from the day-to-day operations of #gb4adhd and the usual way in which I interact with parents and educators. I also actively engaged in critical self-reflection after each interview in order to process my own feelings and make necessary adjustments regarding my demeanour and interactions in subsequent interviews.

A limitation that needs to be considered in this study is that the KADDS, which was used to assess participants’ knowledge of ADHD, was published in 2005. Research regarding the aetiology, symptomology and treatment of ADHD is on-going and understandings of the condition have changed over time. Certain items of the KADDS do not reflect the current empirical evidence regarding ADHD. For example, Item 1 which states “Most estimates suggest that ADHD occurs in approximately 15% of school age children” is considered false according to the KADDS manual. However, current research indicates that between 2% and 16% of school age children meet the diagnostic criteria for ADHD (Schoeman & Liebenberg, 2017). It is therefore important to interpret the results of the KADDS from this study cautiously.

7.4 RECOMMENDATIONS FOR FUTURE RESEARCH

The study highlighted the need to address stigma at a community level in order to improve the lives of children with ADHD emotionally, socially, and academically. There is also a need for increased support for families and educators. Participants suggested different methods in which stigma could be reduced, with the common theme being increased awareness. Research regarding effective ways to promote community awareness in a culturally and contextually relevant manner would be beneficial in steering future stigma-reduction initiatives.

Multi-stakeholder collaborations create a platform for "integrating concerns, talents and resources in a meaningful way that promotes self-organising, builds critical mass for positive change and addresses messy situations" (Krawchuk, 2013, p. 11). The current state of mental health care and infrastructure in South Africa represents a "messy situation" which could benefit greatly from private public partnerships (PPPs) to increase awareness of mental health challenges, to conduct contextually relevant research to guide implementation of stigma decreasing initiatives and to enhance service provision in under-resourced communities.

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APPENDICES

Appendix A: DSM-5 Diagnostic criteria for ADHD (APA, 2013).

A. A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, as characterized by (1) and/or (2):

1. **Inattention**: Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:

Note: The symptoms are not solely a manifestation of oppositional behaviour, defiance, hostility, or failure to understand tasks or instructions. For older adolescents and adults (age 17 and older), at least five symptoms are required.

a. Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities (e.g., overlooks or misses details, work is inaccurate).

b. Often has difficulty sustaining attention in tasks or play activities (e.g., has difficulty remaining focused during lectures, conversations, or lengthy reading).

c. Often does not seem to listen when spoken to directly (e.g., mind seems elsewhere, even in the absence of any obvious distraction).

d. Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g., starts tasks but quickly loses focus and is easily sidetracked).

e. Often has difficulty organizing tasks and activities (e.g., difficulty managing sequential tasks; difficulty keeping materials and belongings in order; messy, disorganized work; has poor time management; fails to meet deadlines).

f. Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (e.g., schoolwork or homework; for older adolescents and adults, preparing reports, completing forms, reviewing lengthy papers).

g. Often loses things necessary for tasks or activities (e.g., school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones).

h. Is often easily distracted by extraneous stimuli (for older adolescents and adults, may include unrelated thoughts).

i. Is often forgetful in daily activities (e.g., doing chores, running errands; for older adolescents and adults, returning calls, paying bills, keeping appointments).

2. **Hyperactivity and impulsivity:** Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:

Note: The symptoms are not solely a manifestation of oppositional behaviour, defiance, hostility, or a failure to understand tasks or instructions. For older adolescents and adults (age 17 and older), at least five symptoms are required.

a. Often fidgets with or taps hands or feet or squirms in seat.

b. Often leaves seat in situations when remaining seated is expected (e.g., leaves his or her place in the classroom, in the office or other workplace, or in other situations that require remaining in place).

c. Often runs about or climbs in situations where it is inappropriate. (Note: In adolescents or adults, may be limited to feeling restless.)

d. Often unable to play or engage in leisure activities quietly.

e. Is often “on the go,” acting as if “driven by a motor” (e.g., is unable to be or uncomfortable being still for extended time, as in restaurants, meetings; may be experienced by others as being restless or difficult to keep up with).

f. Often talks excessively.

g. Often blurts out an answer before a question has been completed (e.g., completes people’s sentences; cannot wait for turn in conversation).

h. Often has difficulty waiting his or her turn (e.g., while waiting in line).

i. Often interrupts or intrudes on others (e.g., butts into conversations, games, or activities; may start using other people’s things without asking or receiving permission; for adolescents and adults, may intrude into or take over what others are doing).

B. Several inattentive or hyperactive-impulsive symptoms were present prior to age 12 years.

C. Several inattentive or hyperactive-impulsive symptoms are present in two or more settings (e.g., at home, school, or work; with friends or relatives; in other activities).

D. There is clear evidence that the symptoms interfere with, or reduce the quality of, social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of schizophrenia or another psychotic disorder and are not better explained by another mental disorder (e.g., mood disorder, anxiety disorder, dissociative disorder, personality disorder, substance intoxication or withdrawal).

Specify whether:

314.01 (F90.2) Combined presentation: If both Criterion A1 (inattention) and Criterion A2 (hyperactivity-impulsivity) are met for the past 6 months.

314.00 (F90.0) Predominantly inattentive presentation: If Criterion A1 (inattention) is met but Criterion A2 (hyperactivity-impulsivity) is not met for the past 6 months.

314.01 (F90.1) Predominantly hyperactive/impulsive presentation: If Criterion A2 (hyperactivity- impulsivity) is met and Criterion A1 (inattention) is not met for the past 6 months.

Specify if:

in partial remission: When full criteria were previously met, fewer than the full criteria have been met for the past 6 months, and the symptoms still result in impairment in social, academic, or occupational functioning.

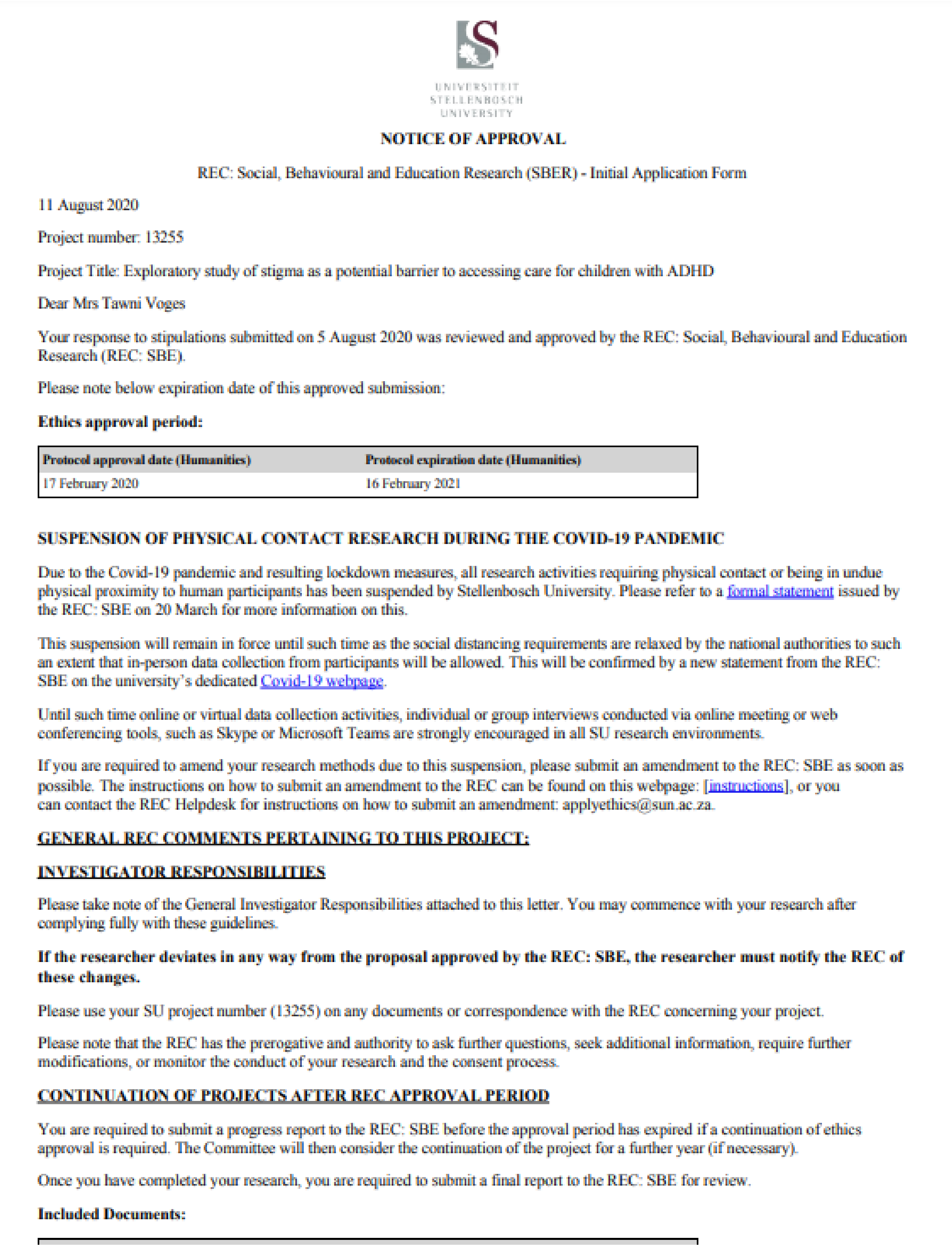
Specify current severity:

Mild: Few, if any, symptoms in excess of those required to make the diagnosis are present, and symptoms result in no more than minor impairments in social or occupational functioning.

Moderate: Symptoms or functional impairment between “mild” and “severe” are present.

Severe: Many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe, are present, or the symptoms result in marked impairment in social or occupational functioning.

Appendix B: Research ethics committee (REC) notice of approval to conduct research



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UNIVERSITY

NOTICE OF APPROVAL

REC: Social, Behavioural and Education Research (SBER) - Initial Application Form

11 August 2020

Project number: 13255

Project Title: Exploratory study of stigma as a potential barrier to accessing care for children with ADHD

Dear Mrs Tawni Voges

Your response to stipulations submitted on 5 August 2020 was reviewed and approved by the REC: Social, Behavioural and Education Research (REC: SBE).

Please note below expiration date of this approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
17 February 2020	16 February 2021

SUSPENSION OF PHYSICAL CONTACT RESEARCH DURING THE COVID-19 PANDEMIC

Due to the Covid-19 pandemic and resulting lockdown measures, all research activities requiring physical contact or being in undue physical proximity to human participants has been suspended by Stellenbosch University. Please refer to a formal statement issued by the REC: SBE on 20 March for more information on this.

This suspension will remain in force until such time as the social distancing requirements are relaxed by the national authorities to such an extent that in-person data collection from participants will be allowed. This will be confirmed by a new statement from the REC: SBE on the university's dedicated Covid-19 webpage.

Until such time online or virtual data collection activities, individual or group interviews conducted via online meeting or web conferencing tools, such as Skype or Microsoft Teams are strongly encouraged in all SU research environments.

If you are required to amend your research methods due to this suspension, please submit an amendment to the REC: SBE as soon as possible. The instructions on how to submit an amendment to the REC can be found on this webpage: [instructions], or you can contact the REC Helpdesk for instructions on how to submit an amendment: applyethics@sun.ac.za.

GENERAL REC COMMENTS PERTAINING TO THIS PROJECT:

INVESTIGATOR RESPONSIBILITIES

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: SBE, the researcher must notify the REC of these changes.

Please use your SU project number (13255) on any documents or correspondence with the REC concerning your project.

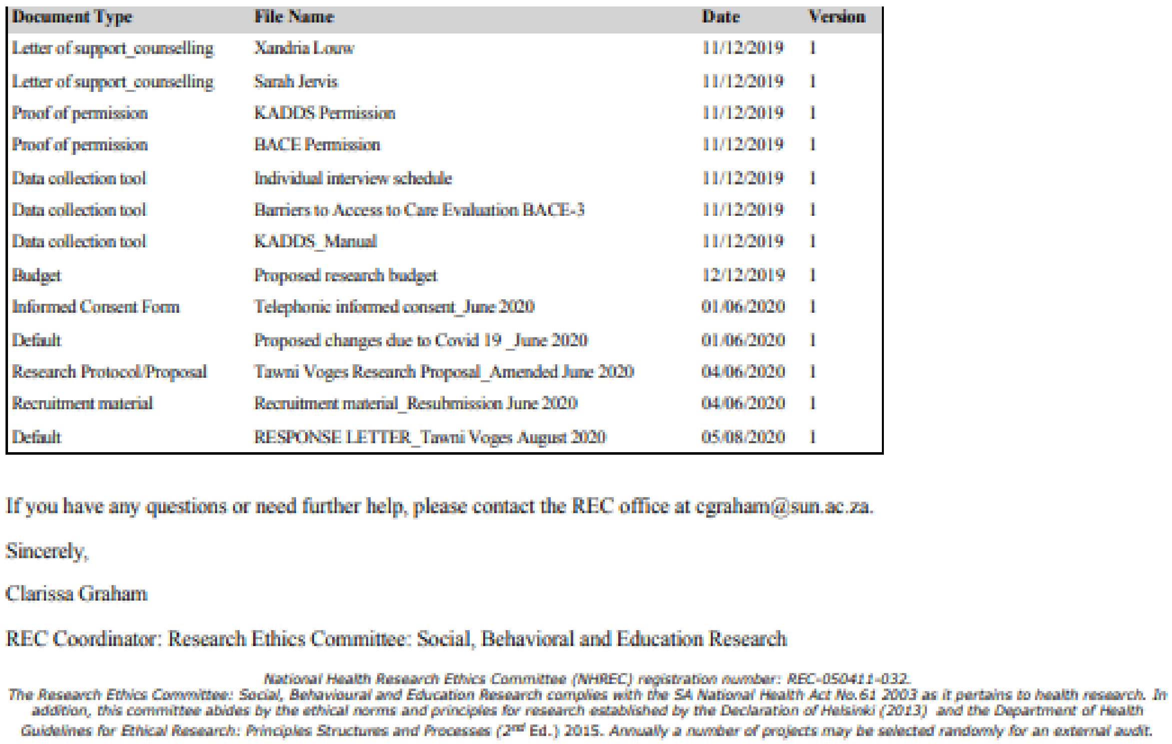
Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

You are required to submit a progress report to the REC: SBE before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary).

Once you have completed your research, you are required to submit a final report to the REC: SBE for review.

Included Documents:



Document Type	File Name	Date	Version
Letter of support_counselling	Xandria Louw	11/12/2019	1
Letter of support_counselling	Sarah Jervis	11/12/2019	1
Proof of permission	KADDS Permission	11/12/2019	1
Proof of permission	BACE Permission	11/12/2019	1
Data collection tool	Individual interview schedule	11/12/2019	1
Data collection tool	Barriers to Access to Care Evaluation BACE-3	11/12/2019	1
Data collection tool	KADDS_Manual	11/12/2019	1
Budget	Proposed research budget	12/12/2019	1
Informed Consent Form	Telephonic informed consent_June 2020	01/06/2020	1
Default	Proposed changes due to Covid 19 _June 2020	01/06/2020	1
Research Protocol/Proposal	Tawni Voges Research Proposal_Amended June 2020	04/06/2020	1
Recruitment material	Recruitment material_Resubmission June 2020	04/06/2020	1
Default	RESPONSE LETTER_Tawni Voges August 2020	05/08/2020	1

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Social, Behavioral and Education Research

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Social, Behavioural and Education Research complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

Appendix C: Western Cape Education Department (WCED) permission to conduct research

Western Cape Government
Education

@westerncape.gov.za
tel: +27 021 000 0000
Fax: 0865902282
Private Bag x9114, Cape Town, 8000
wced.wcape.gov.za

REFERENCE: 20200220-4736
ENQUIRIES: Dr XXXXXX

Mrs Tawni Voges

Dear Mrs Tawni Voges

RESEARCH PROPOSAL: EXPLORATORY STUDY OF STIGMA AS A POTENTIAL BARRIER TO ACCESSING CARE FOR CHILDREN WITH ADHD

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

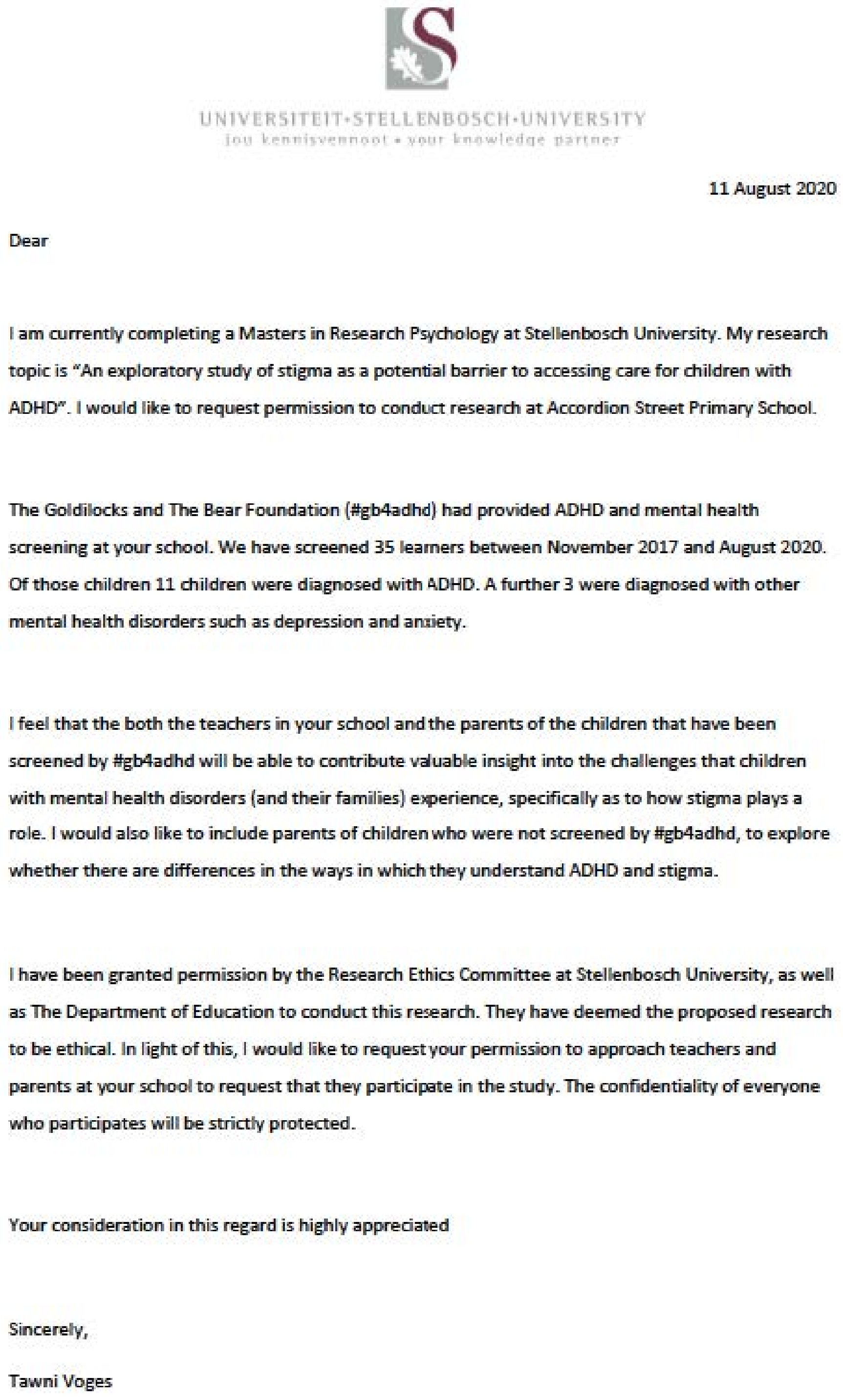
1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **24 February 2020 till 19 March 2021**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr XXXXX at the contact numbers above quoting the reference number?
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

The Director: Research Services
Western Cape Education Department
Private Bag X9114
CAPE TOWN
8000

We wish you success in your research.

Kind regards.
Signed: Dr
Directorate: Research
DATE: 04 September 2020

Appendix D: Example of request to the school principal to conduct research



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jou kennisvennoot • your knowledge partner

11 August 2020

Dear

I am currently completing a Masters in Research Psychology at Stellenbosch University. My research topic is "An exploratory study of stigma as a potential barrier to accessing care for children with ADHD". I would like to request permission to conduct research at Accordion Street Primary School.

The Goldilocks and The Bear Foundation (#gb4adhd) had provided ADHD and mental health screening at your school. We have screened 35 learners between November 2017 and August 2020. Of those children 11 children were diagnosed with ADHD. A further 3 were diagnosed with other mental health disorders such as depression and anxiety.

I feel that the both the teachers in your school and the parents of the children that have been screened by #gb4adhd will be able to contribute valuable insight into the challenges that children with mental health disorders (and their families) experience, specifically as to how stigma plays a role. I would also like to include parents of children who were not screened by #gb4adhd, to explore whether there are differences in the ways in which they understand ADHD and stigma.

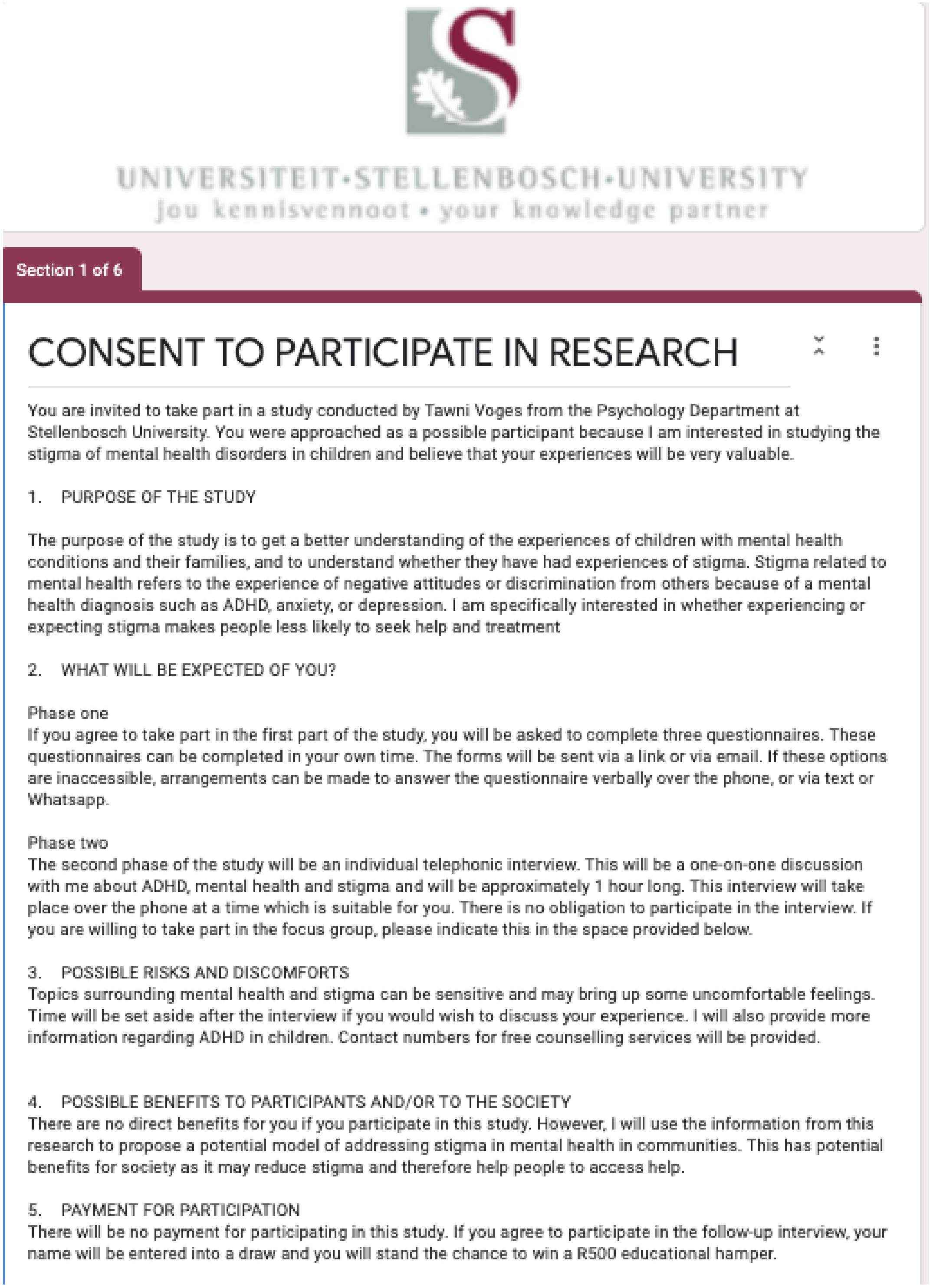
I have been granted permission by the Research Ethics Committee at Stellenbosch University, as well as The Department of Education to conduct this research. They have deemed the proposed research to be ethical. In light of this, I would like to request your permission to approach teachers and parents at your school to request that they participate in the study. The confidentiality of everyone who participates will be strictly protected.

Your consideration in this regard is highly appreciated

Sincerely,

Tawni Voges

Appendix E: Information sheet and consent form



CONSENT TO PARTICIPATE IN RESEARCH

You are invited to take part in a study conducted by Tawni Voges from the Psychology Department at Stellenbosch University. You were approached as a possible participant because I am interested in studying the stigma of mental health disorders in children and believe that your experiences will be very valuable.

1. PURPOSE OF THE STUDY

The purpose of the study is to get a better understanding of the experiences of children with mental health conditions and their families, and to understand whether they have had experiences of stigma. Stigma related to mental health refers to the experience of negative attitudes or discrimination from others because of a mental health diagnosis such as ADHD, anxiety, or depression. I am specifically interested in whether experiencing or expecting stigma makes people less likely to seek help and treatment

2. WHAT WILL BE EXPECTED OF YOU?

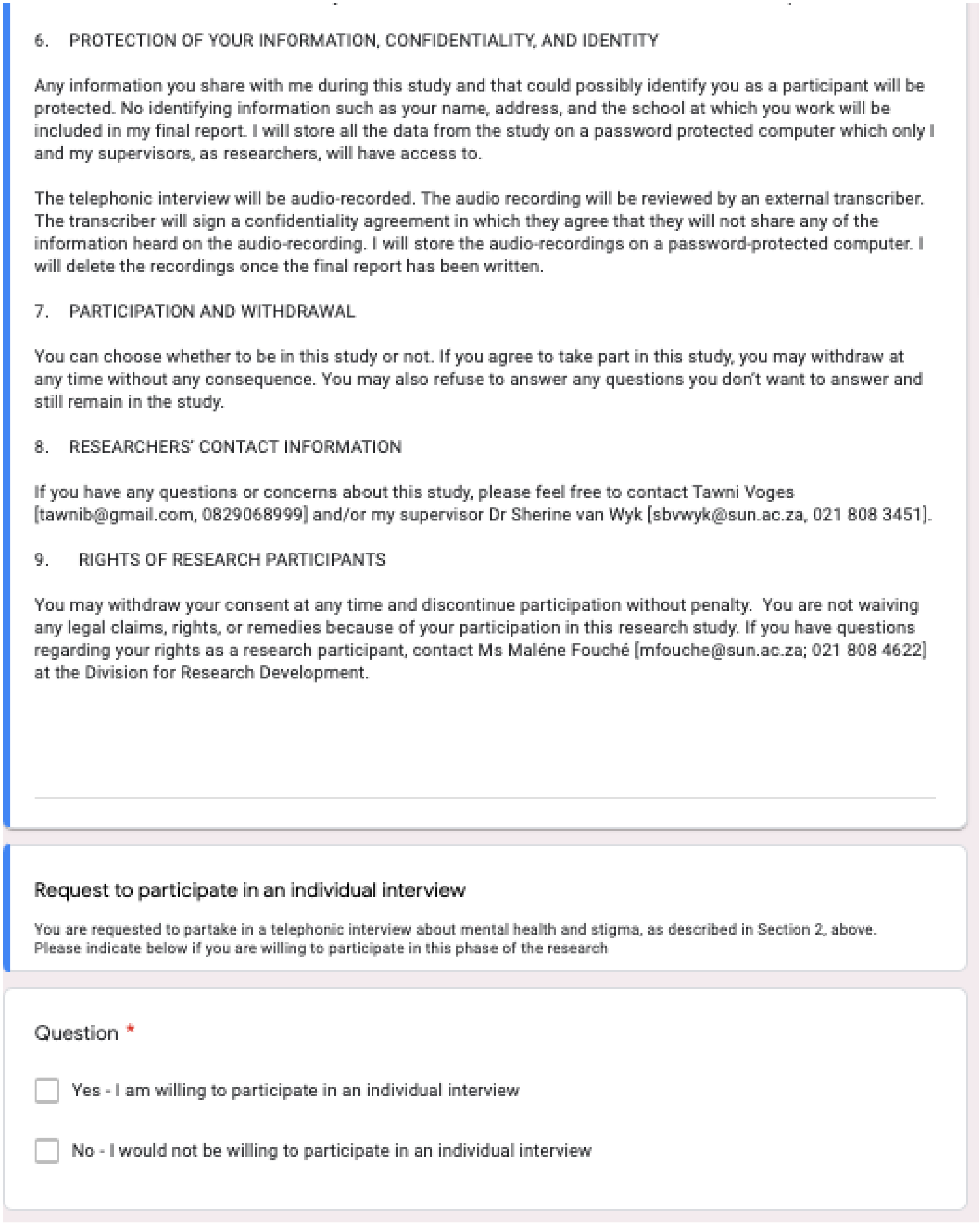
Phase one
If you agree to take part in the first part of the study, you will be asked to complete three questionnaires. These questionnaires can be completed in your own time. The forms will be sent via a link or via email. If these options are inaccessible, arrangements can be made to answer the questionnaire verbally over the phone, or via text or Whatsapp.

Phase two
The second phase of the study will be an individual telephonic interview. This will be a one-on-one discussion with me about ADHD, mental health and stigma and will be approximately 1 hour long. This interview will take place over the phone at a time which is suitable for you. There is no obligation to participate in the interview. If you are willing to take part in the focus group, please indicate this in the space provided below.

3. POSSIBLE RISKS AND DISCOMFORTS
Topics surrounding mental health and stigma can be sensitive and may bring up some uncomfortable feelings. Time will be set aside after the interview if you would wish to discuss your experience. I will also provide more information regarding ADHD in children. Contact numbers for free counselling services will be provided.

4. POSSIBLE BENEFITS TO PARTICIPANTS AND/OR TO THE SOCIETY
There are no direct benefits for you if you participate in this study. However, I will use the information from this research to propose a potential model of addressing stigma in mental health in communities. This has potential benefits for society as it may reduce stigma and therefore help people to access help.

5. PAYMENT FOR PARTICIPATION
There will be no payment for participating in this study. If you agree to participate in the follow-up interview, your name will be entered into a draw and you will stand the chance to win a R500 educational hamper.



6. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY, AND IDENTITY

Any information you share with me during this study and that could possibly identify you as a participant will be protected. No identifying information such as your name, address, and the school at which you work will be included in my final report. I will store all the data from the study on a password protected computer which only I and my supervisors, as researchers, will have access to.

The telephonic interview will be audio-recorded. The audio recording will be reviewed by an external transcriber. The transcriber will sign a confidentiality agreement in which they agree that they will not share any of the information heard on the audio-recording. I will store the audio-recordings on a password-protected computer. I will delete the recordings once the final report has been written.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you don't want to answer and still remain in the study.

8. RESEARCHERS' CONTACT INFORMATION

If you have any questions or concerns about this study, please feel free to contact Tawni Voges [tawnib@gmail.com, 0829068999] and/or my supervisor Dr Sherine van Wyk [sbvwyk@sun.ac.za, 021 808 3451].

9. RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights, or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

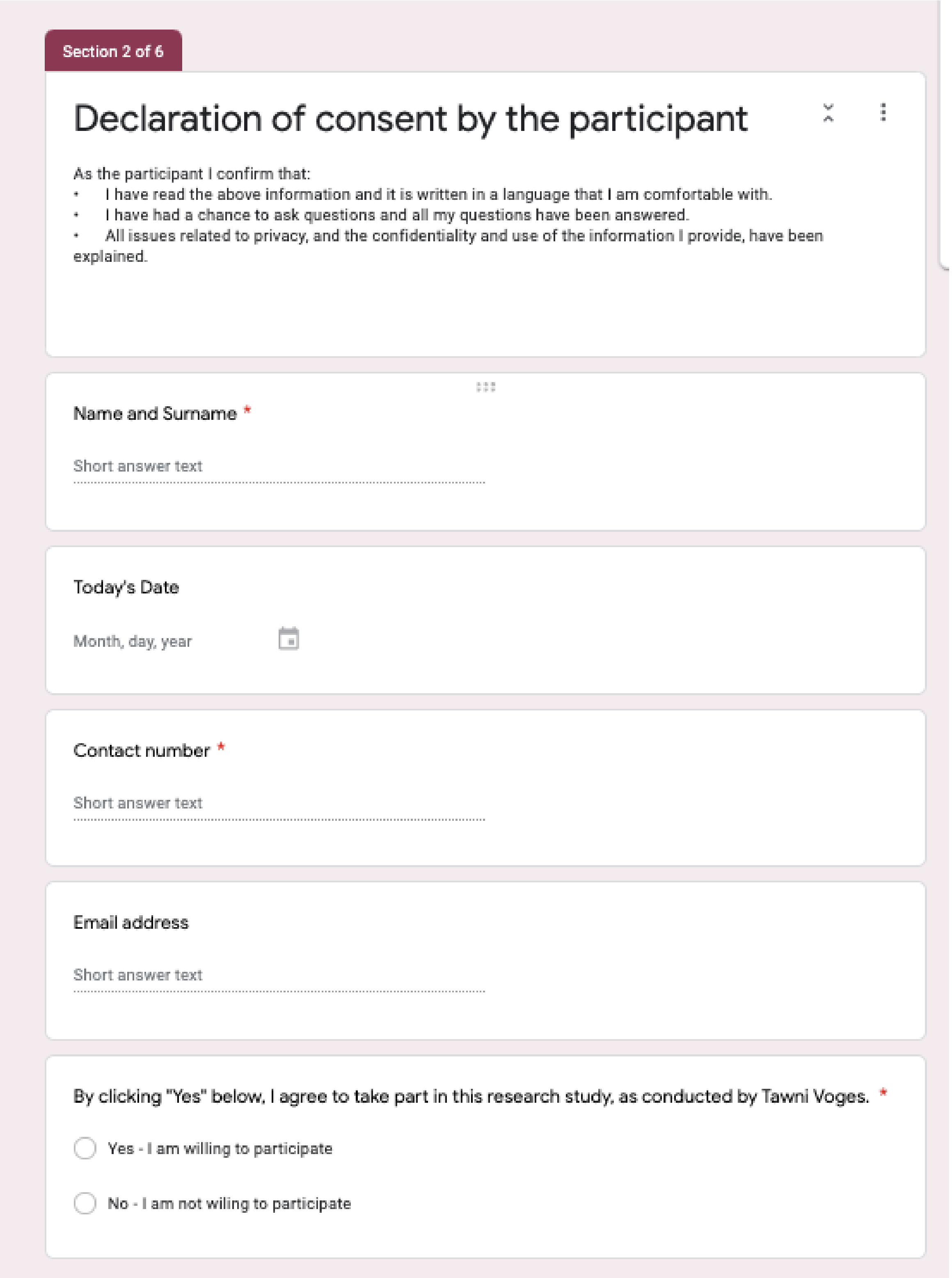
Request to participate in an individual interview

You are requested to partake in a telephonic interview about mental health and stigma, as described in Section 2, above. Please indicate below if you are willing to participate in this phase of the research

Question *

☐ Yes - I am willing to participate in an individual interview

☐ No - I would not be willing to participate in an individual interview



Section 2 of 6

Declaration of consent by the participant

As the participant I confirm that:
- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

Name and Surname *

Short answer text

Today's Date

Month, day, year

Contact number *

Short answer text

Email address

Short answer text

By clicking "Yes" below, I agree to take part in this research study, as conducted by Tawni Voges. *

○ Yes - I am willing to participate

○ No - I am not wiling to participate

Appendix F: Demographic Questionnaire

Name:

Age:

How would you identify yourself?

☐ White
☐ Black
☐ Coloured
☐ Indian
☐ Asian
☐ Other ________________(Please specify)

Highest level of education

☐ No formal education
☐ Primary school only
☐ Secondary school only
☐ Secondary school with matric
☐ Post matric
☐ Other ___________________(Please specify)

Employment status

☐ Unemployed
☐ Employed in a temporary position
☐ Employed

If you are employed, please specific what work you do: __________________

Income

☐ No income
☐ Up to R2500 per month
☐ R2500 to R5000 per month
☐ R5000 to R10 000 per month
☐ More than R10 000 per month

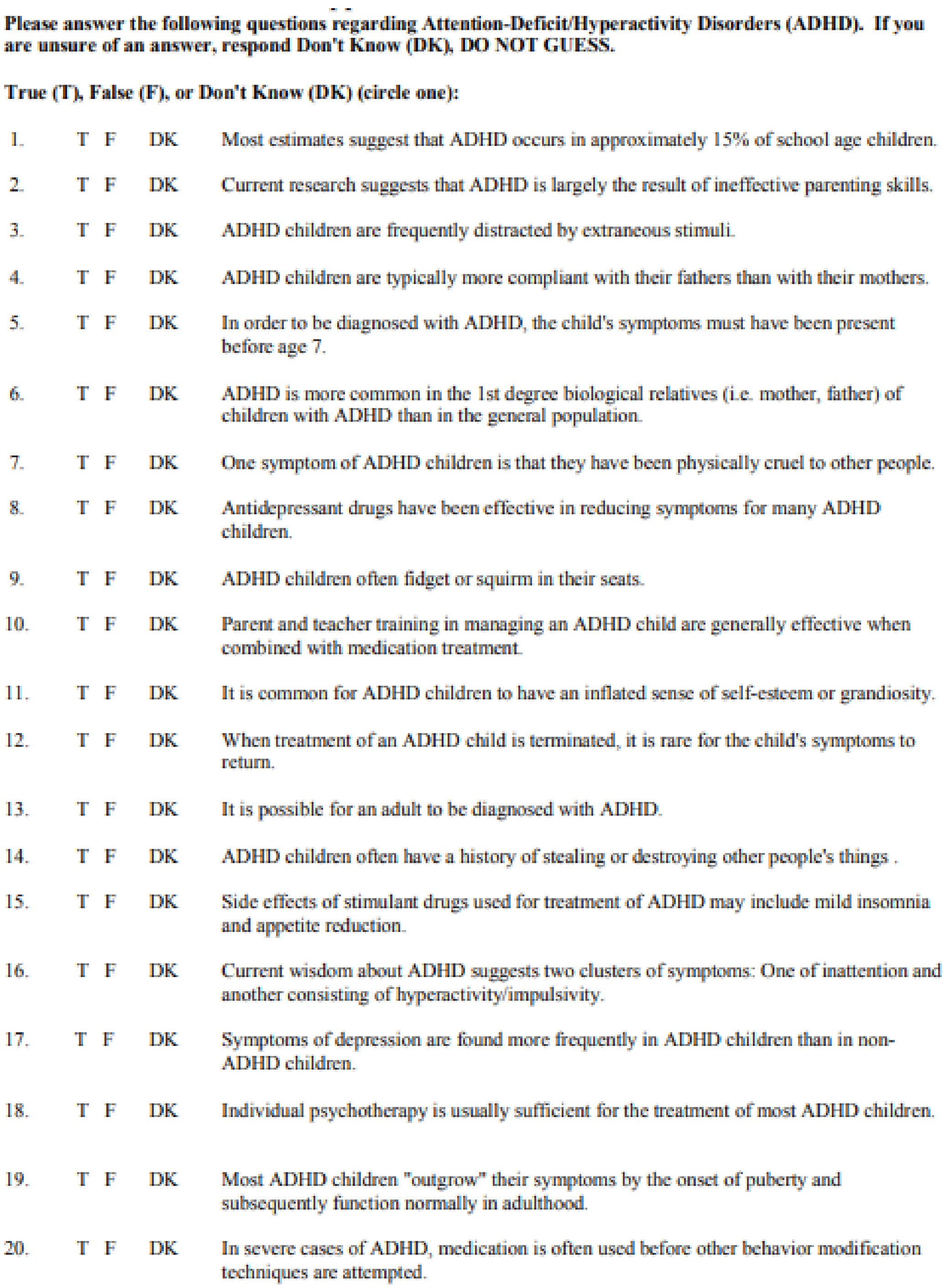
Please tick which of the following apply

☐ I have been diagnosed with mental health condition (e.g. anxiety, depression, ADHD)
Please specify your diagnosis: ________________________________

☐ I have a child who has been diagnosed with a mental health condition (e.g. anxiety, depression, ADHD)
Please specify your child's diagnosis: __________________________

☐ I do not have a child who has been diagnosed with a mental health condition (e.g. anxiety, depression, ADHD)

Appendix G: Knowledge of Attention Deficit Disorder Scales (KADDS) Items



Please answer the following questions regarding Attention-Deficit/Hyperactivity Disorders (ADHD). If you are unsure of an answer, respond Don't Know (DK), DO NOT GUESS.

True (T), False (F), or Don't Know (DK) (circle one):

1. T F DK Most estimates suggest that ADHD occurs in approximately 15% of school age children.

2. T F DK Current research suggests that ADHD is largely the result of ineffective parenting skills.

3. T F DK ADHD children are frequently distracted by extraneous stimuli.

4. T F DK ADHD children are typically more compliant with their fathers than with their mothers.

5. T F DK In order to be diagnosed with ADHD, the child's symptoms must have been present before age 7.

6. T F DK ADHD is more common in the 1st degree biological relatives (i.e. mother, father) of children with ADHD than in the general population.

7. T F DK One symptom of ADHD children is that they have been physically cruel to other people.

8. T F DK Antidepressant drugs have been effective in reducing symptoms for many ADHD children.

9. T F DK ADHD children often fidget or squirm in their seats.

10. T F DK Parent and teacher training in managing an ADHD child are generally effective when combined with medication treatment.

11. T F DK It is common for ADHD children to have an inflated sense of self-esteem or grandiosity.

12. T F DK When treatment of an ADHD child is terminated, it is rare for the child's symptoms to return.

13. T F DK It is possible for an adult to be diagnosed with ADHD.

14. T F DK ADHD children often have a history of stealing or destroying other people's things .

15. T F DK Side effects of stimulant drugs used for treatment of ADHD may include mild insomnia and appetite reduction.

16. T F DK Current wisdom about ADHD suggests two clusters of symptoms: One of inattention and another consisting of hyperactivity/impulsivity.

17. T F DK Symptoms of depression are found more frequently in ADHD children than in non-ADHD children.

18. T F DK Individual psychotherapy is usually sufficient for the treatment of most ADHD children.

19. T F DK Most ADHD children "outgrow" their symptoms by the onset of puberty and subsequently function normally in adulthood.

20. T F DK In severe cases of ADHD, medication is often used before other behavior modification techniques are attempted.

22. T F DK If an ADHD child is able to demonstrate sustained attention to video games or TV for over an hour, that child is also able to sustain attention for at least an hour of class or homework.

23. T F DK Reducing dietary intake of sugar or food additives is generally effective in reducing the symptoms of ADHD.

24. T F DK A diagnosis of ADHD by itself makes a child eligible for placement in special education.

25. T F DK Stimulant drugs are the most common type of drug used to treat children with ADHD

26. T F DK ADHD children often have difficulties organizing tasks and activities.

27. T F DK ADHD children generally experience more problems in novel situations than in familiar situations.

28. T F DK There are specific physical features which can be identified by medical doctors (e.g. pediatrician) in making a definitive diagnosis of ADHD.

29. T F DK In school age children, the prevalence of ADHD in males and females is equivalent.

30. T F DK In very young children (less than 4 years old), the problem behaviors of ADHD children (e.g. hyperactivity, inattention) are distinctly different from age-appropriate behaviors of non-ADHD children.

31. T F DK Children with ADHD are more distinguishable from normal children in a classroom setting than in a free play situation.

32. T F DK The majority of ADHD children evidence some degree of poor school performance in the elementary school years.

33. T F DK Symptoms of ADHD are often seen in non-ADHD children who come from inadequate and chaotic home environments.

34. T F DK Behavioral/Psychological interventions for children with ADHD focus primarily on the child's problems with inattention.

35. T F DK Electroconvulsive Therapy (i.e. shock treatment) has been found to be an effective treatment for severe cases of ADHD.

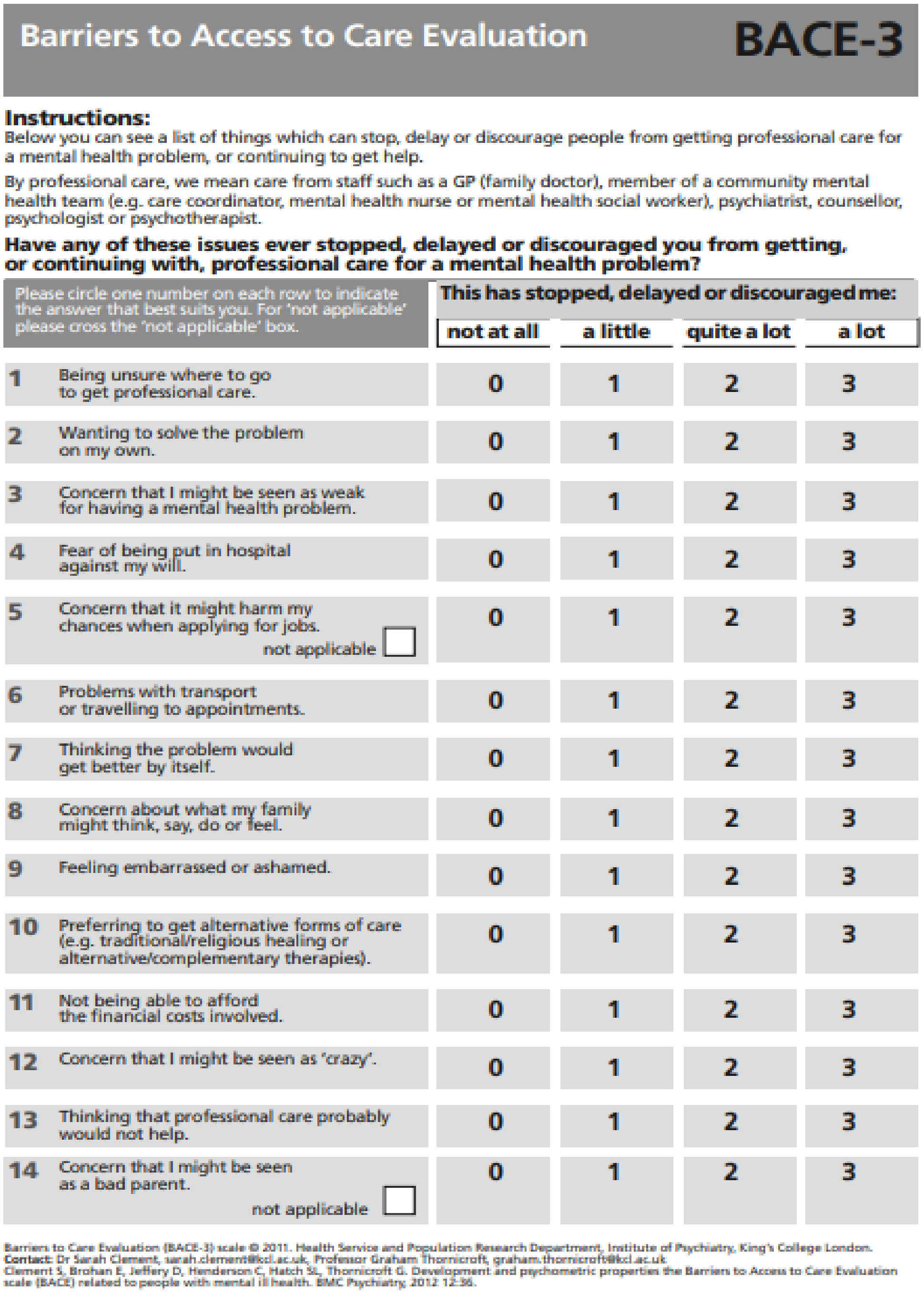
36. T F DK Treatments for ADHD which focus primarily on punishment have been found to be the most effective in reducing the symptoms of ADHD.

37. T F DK Research has shown that prolonged use of stimulant medications leads to increased addiction (i.e., drug, alcohol) in adulthood.

38. T F DK If a child responds to stimulant medications (e.g., Ritalin), then they probably have ADHD.

39. T F DK Children with ADHD generally display an inflexible adherence to specific routines or rituals.

Appendix H: Barriers to Access to Care Evaluation (BACE-3) Items



Barriers to Access to Care Evaluation BACE-3

Instructions:

Below you can see a list of things which can stop, delay or discourage people from getting professional care for a mental health problem, or continuing to get help.

By professional care, we mean care from staff such as a GP (family doctor), member of a community mental health team (e.g. care coordinator, mental health nurse or mental health social worker), psychiatrist, counsellor, psychologist or psychotherapist.

Have any of these issues ever stopped, delayed or discouraged you from getting, or continuing with, professional care for a mental health problem?

Please circle one number on each row to indicate the answer that best suits you. For 'not applicable' please cross the 'not applicable' box.

		This has stopped, delayed or discouraged me:			
		not at all	**a little**	**quite a lot**	**a lot**
1	Being unsure where to go to get professional care.	0	1	2	3
2	Wanting to solve the problem on my own.	0	1	2	3
3	Concern that I might be seen as weak for having a mental health problem.	0	1	2	3
4	Fear of being put in hospital against my will.	0	1	2	3
5	Concern that it might harm my chances when applying for jobs. not applicable ☐	0	1	2	3
6	Problems with transport or travelling to appointments.	0	1	2	3
7	Thinking the problem would get better by itself.	0	1	2	3
8	Concern about what my family might think, say, do or feel.	0	1	2	3
9	Feeling embarrassed or ashamed.	0	1	2	3
10	Preferring to get alternative forms of care (e.g. traditional/religious healing or alternative/complementary therapies).	0	1	2	3
11	Not being able to afford the financial costs involved.	0	1	2	3
12	Concern that I might be seen as 'crazy'.	0	1	2	3
13	Thinking that professional care probably would not help.	0	1	2	3
14	Concern that I might be seen as a bad parent. not applicable ☐	0	1	2	3

Contact: Dr Sarah Clement, sarah.clement@kcl.ac.uk, Professor Graham Thornicroft, graham.thornicroft@kcl.ac.uk
Clement S, Brohan E, Jeffery D, Henderson C, Hatch SL, Thornicroft G. Development and psychometric properties the Barriers to Access to Care Evaluation scale (BACE) related to people with mental ill health. BMC Psychiatry, 2012 12:36.

Barriers to Access to Care Evaluation

BACE-3 page 2

Please circle one number on each row to indicate the answer that best suits you. For 'not applicable' please cross the 'not applicable' box.	This has stopped, delayed or discouraged me:			
	not at all	a little	quite a lot	a lot
15 Professionals from my own ethnic or cultural group not being available.	0	1	2	3
16 Being too unwell to ask for help.	0	1	2	3
17 Concern that people I know might find out.	0	1	2	3
18 Dislike of talking about my feelings, emotions or thoughts.	0	1	2	3
19 Concern that people might not take me seriously if they found out I was having professional care.	0	1	2	3
20 Concerns about the treatments available (e.g. medication side effects).	0	1	2	3
21 Not wanting a mental health problem to be on my medical records.	0	1	2	3
22 Having had previous bad experiences with professional care for mental health.	0	1	2	3
23 Preferring to get help from family or friends.	0	1	2	3
24 Concern that my children may be taken into care or that I may lose access or custody without my agreement. not applicable ☐	0	1	2	3
25 Thinking I did not have a problem.	0	1	2	3
26 Concern about what my friends might think, say or do.	0	1	2	3
27 Difficulty taking time off work.	0	1	2	3
28 Concern about what people at work might think, say or do. not applicable ☐	0	1	2	3
29 Having problems with childcare while I receive professional care. not applicable ☐	0	1	2	3
30 Having no one who could help me get professional care.	0	1	2	3

Barriers to Care Evaluation (BACE-3) scale © 2011. Health Service and Population Research Department, Institute of Psychiatry, King's College London.
Contact: Dr Sarah Clement, sarah.clement@kcl.ac.uk, Professor Graham Thornicroft, graham.thornicroft@kcl.ac.uk
Clement S, Brohan E, Jeffery D, Henderson C, Hatch SL, Thornicroft G. Development and psychometric properties the Barriers to Access to Care Evaluation scale (BACE) related to people with mental ill health. BMC Psychiatry, 2012 12:36.

Appendix I: Transcribed interview example

R: Hello. It's Tawni speaking. How are you?

P3: I'm fine. I thought this is gonna be a video, but okay.

R: Oh, we can do a video call if you'd prefer or voice call whatever works best for you?

P3: No no, a voice call is fine then.

R: Okay. All right. How are you today?

P3: Ah, very well thank you, and yourself?

R: Yeah ,I'm doing good, thank you. I just wanted to double check, it did say in the consent form that the interviews are audio recorded just so that I can use it for my research later Are you comfortable with me doing that?

P3: Yes

R: Okay, wonderful ...

P3: ... [inaudible]... Hello? You're breaking up....

R: Sorry, can you hear me now?

P3: Yes.

R: Okay. All right.

P3: Hello? ... [inaudible]... and you are doctor?

R: So, I'm not a doctor. My name is Tawni and I work for the Goldilocks and the Bear Foundation, and I work there as the operations manager, and then in my private capacity I'm doing a Master's in Research psychology. And what I'm looking at is about ADHD and what the barriers are that centre around getting treatment for ADHD. So, thank you very much for agreeing to help me. I have some questions about those types topics and we can just chat about them. And if there's anything you're not comfortable in answering, you can tell me and we can skip over that. And then afterwards we can have a bit of a chat about Skye and you can tell me what your concerns were, what your experience was and how we can assist you? [*In reference to a text message the participant had sent me earlier in the day with specific questions about her daughter]*.

P3: Okay, thank you.

R: Okay wonderful. All right. So the first question that I have is, have you or someone that you know being diagnosed with any mental health condition?

P3: No.

R: No? Okay. All right. And anybody that you know with ADHD?

P3: My friend's son.

R: Your friend's son has ADHD?

P3: Yes.

R: Okay. And then, okay so and then I saw on the form that you sent me that you had mentioned that - I don't know if it was Skye specifically, or another child of yours - that has a diagnosis of ADHD is that correct.

P3: It's the person that I just said now

R: Okay. All right. Wonderful. Okay, so thank you very much for that. And can you tell me a little bit more about that in terms of your experience of ADHD and what you understand about it?

P3: Well, what I'm experiencing with Skye, it's like she's in her own world. And she does stuff her own way, her own person. But Skye is like you, you talk to her, but she don't listen, she won't hear you, until you like touch her and say "Skye I'm talking to you", you know? She blocks out like everybody in the room. She will watch TV, I will tell her Skye go sit in your room... she will sit there up until I tell her can come out, you know? Stuff like that. And she will say... 5 days ago, she will say 10 days ago, you know? So, I mean she 10 years old and she just, she ... [inaudible]... does act like a 10 year old.

R: Yeah, so she's, she's maybe just a little bit behind her peers. Is that what you experienced.

P3: Ja... Yes.

R: Okay. And so Skye has, so she's a little bit in her in her little dream world, it sounds like. And she has hasn't been diagnosed with ADHD is that correct?

P3: Yes.

R: Okay. All right. Do you, do you feel like...

P3: *[interrupting]* Yes, yes, the doctor did.

R: Oh yes, okay, so she has been diagnosed with ADHD? Yes I remember you, you mentioned so in the test that you sent me.

P3: Yes

R: Okay. And she, she's not currently taking medication for that hey?

P3: I only bought her Release, and the Omega 3.

R: Okay. All right, so she's on that in the moment.

P3: Yes.

R: Okay, and then I wanted to know what do you what do you think are the biggest challenges in your community for children with ADHD or other mental health conditions like depression or anxiety?

P3: Umm, the children will mock them because she would think that 2/10, like seriously 2/10 is the best that she could have done. She feels, she will say "mommy, I got 2/10" You know? Excited about it. And I'm like yoh, really now? For her that is something great, you know? And umm, her glasses is like very thick, so children will mock about that. They usually break her glasses. She don't talk... like the teacher, this morning, the teacher sent me "please send the letter that I gave yesterday" and she sent that at ten to seven this morning. Umm, the letter must be completed. I was like what letter? So I went to Skye, the letter is in her bag, neatly in her bag, she's very neat on herself but, you know? She just forget. And it was yesterday that the teacher told her. Do you understand? So this morning I had to rush to fill in the form, to complete the form .You know? And then she put like a small uniform on (laughing) this morning, sometimes it's a bit (...poor audio quality)... because she, she does such things, you know?

R: She gets a little bit confused sometimes?

P3: Yes, like for instance, I will send he, go get a blue cup in the cupboard. She will come back and say, you asked for a glass, and I said no I wanted a cup. She will bring you warm water to drink (laughing). You understand? She will hear you that you want water, she will go to the tap. She won't check if it's warm water or... She will just, because you asked for water, she will just bring you whatever comes out of the tap.

R: Yeah. Yeah, so she's quite literal in her interpretations?

P3: Too yes. Too literal, yes.

R: And you mentioned to me that the children will tease her and mock her, and I was wondering when that happens, what it feels like for you?

P3: It's not nice at all because I actually had to go to school, because she was bullied last year. And even the mother of the child that bullies Skye, or did bully her, didn't actually recognize that the fact that her child was actually doing that to other children. And that for me was like, so your child is going to do that to somebody else's child also.

R : Mmmm

P3: You know? She would like take Skye's whole pencil bag and then the mother would say nothing. And then Skye can't do her homework, because her pencil bag is not in her bag. You understand? But now ... [inaudible] ... me, now the teacher asked me why Skye's schoolwork is not done. You understand? ... [inaudible]... She won't come tell me the child did this or that, I have to find out by her cousin. We asked school because my sister 's child is also 10 years old, she must be in Skye's class. So that she can look after her, so that she can say, "listen here, the teacher says so.." because Skye can't. Skye don't listen....[inaudible]... the teachers just don't interest her. So last year the teacher said, while they must write the exam, she will play with a pencil whatever else, whatever is on the table.

R: Yeah

P3: She will play. She won't start. Do you understand? So I asked the school, how can you accommodate my child? Because then she failed last year, because of this. And then I applied by Jan Kriel. I had a meeting with the Department of Education, and they figured that the doctor who diagnosed her and scored her right? I can, I'm going to send you a picture of the score, but the file is at home. I'm going to send it to you later. Then.... *[sighing]*... the doctor scored her too much.

R: In terms of her intellectual functioning?

P3: Yes.

R: Okay.

P3: Now she's is clever, she's a very clever girl but it's just the fact that if the teacher shouts at, say Liam, then Skye won't talk to the teacher because she feels that the teacher is going to shout at her as well. Now she has a fear for the teacher.

R: Mmm, okay, that makes sense that makes sense. She's also struggling to speak up in class in terms of what she needs, and to communicate with you, which makes very difficult for you as a mom.

P3: Yes. Now the thing was, we didn't have a meeting last year up until June, right? And then I saw Skye's table was right at the back. So I said miss, my child has umm, already a learning disorder you know? She is taking very long, and she needs like, to be in front. In order to, you know? So that nobody can distract her there at the back you know? Because anything distracts her, or so, sometimes. And ja... and her eyes is very, very weak. She has that thick, thick, thick lens. So I told her ... [inaudible]... So for me, it's like this morning... [inaudible]... I felt I really need help. Because it frustrates me...most of... How can I say it? Because ... [inaudible]....she will frustrate me with the stuff that she does, the stuff that she do. She can't, she is 10 years old, but I must still say, "Skye, take out this, take that out", you know? She's almost like a 3-year-old.

R: Yeah. Yeah

P3: Do you understand what I'm saying?

R: Yes, I do. And that can be very challenging as a parent as well.

P3: Too. Yes. Very.

R: And is medication something that you guys have tried, if she has the diagnosis of ADHD?

P3: I would really love to try. Really. With immediate effect. If anything helps her, I will try it. Seriously.

R: And, do you, do you get your... Would you get medication through the clinic or would you get medications, through a private GP?

P3: I will ask the GP if he can maybe prescribe the stuff, I can go get it at Clicks? Can you get it at Clicks?

R: The Ritalin?

P3: Ja...

R: The Ritalin will need to be prescribed by a GP or psychiatrist. But when you generally, when you generally go to the doctor as a family, do you guys go to a private GP or do you go to the clinic.

P3: I can go to the clinic as well hey, it's going to be much cheaper, a lot cheaper. Free. It's free there by the clinic.

R: Yeah, so what we can do if you like so, once I've, you know, we'll conclude the research interview then I can talk to you about the logistics that potentially, through the foundation, we can meet with Skye again and have a have a chat and whatever and then see what we think would be the best way moving forward. And depending on the family income, we may have to charge a small amount but I can pop it all in an email to you and then you can discuss it and then we can see if there's some way that we can assist

P3: Thank you very very much

R: Wonderful. Yes, so, there's just a few more questions with regards to my research if you're happy to continue?

P3: Yes, absolutely. It's fine.

R: Okay. All right. So another thing that we're looking at in my research is the idea of stigma. So I was just wondering what the word stigma or the concept of stigma means to you?

P3: It's like people label you. They will, they will call her a nerd. How she's nerdy, she can't... if she participates in stuff, they would laugh her because she almost fell now recently, when was it? They had a show at school, and she was.. oh ja, the Jerusalema dance, and she would go...

[inaudible]... in the class, and that was devastating. She came home and then my sister's child told me, "Ooh, I just want to tell you that Skye almost fell and Skye go so....[inaudible].... And I was like, you know? And that's the other thing. She, she gets so mad, and she forget ... [inaudible]... and she will go for that child. And she won't.... [inaudible].... she won't fight, put don't push Skye. She is very...last year she choked iemand, uhh, somebody ... [inaudible]...at school.

R: Mmm, so it sounds maybe as if she's struggling to control her emotions a little bit or her impulses a little bit when she does get pushed.

P3: Yes, yes. Definitely.

R: Yeah. And that can be very hard.

P3: Definitely. Because of the bullying...because of the constant bullying and the name calling and you know? All that. It's very difficult for her.

R: Yeah, I can imagine it must be very hard.

P3: You know. And I don't' ....[inaudible]... I don't ... [inaudible]... slap.... [inaudible]... just on her hands or something because then it will look like you gave her a big hiding. So, that is...[inaudible]... also traumatic for her man. You see?

R: Yeah. Yeah, it's horrible that she's going through that. Very difficult.

P3: Yes, it is.

R: Very hard.

P3: And me and her father's is not together and that is also difficult for her because she hardly sees him.

R: Okay. Okay, so she struggles with that, not being with him.

P3: He must come pick her up every second weekend.

R: Okay.

P3: He don't, you know? He will, I said, if you can't pick her up, rather phone. She don't talk a lot. It's "hello daddy", "how are doing?", "how's my sister doing?". How is.... she will ask ever how's the wife doing, you know? Stuff like that. And "when are you picking me up?", "Oh, when you taking me to McDonald's daddy?". "I love McDonald's daddy". You know? Stuff like that. ...[inaudible].... go by .... [inaudible]... She won't listen to him actually. She won't let him finish her questions, answer her questions but it's also... [inaudible]... all the questions she wanted to ask him. You understand what I'm saying? That is how she is.

R: So it makes it a bit tricky as well with communication maybe.

P3: Ja

R: And do you think people like for example Skye or someone else that has ADHD or a different mental health condition like depression or anxiety, do you think those children are discriminated against or treated differently?

P3: Definitely

R: And in what ways do you imagine that happens?

P3: Umm, what I experienced with my child, she didn't get attention at school.

R: Okay

P3: Honestly speaking, her teacher literally didn't give attention. Whatever she told me, she didn't do with Skye. Whatever she promised me, I mean I took results of the doctor.... I mean, I must be open with her in order for her to help me child.

R: Yes, absolutely.

P3: You know? And do you know what happened? She actually put the bully next to Skye last year. How can you do that as a teacher?

R: That's not fair.

P3: That for me was very, seriously ... [inaudible]...I actually, I was, I was devastated. Because if I don't have a nice commander, this guy gives me...I'm a 43 years old lady and I come to work and I have a knot in my tummy because my Captain is not nice towards... [inaudible]... I'm an adult When I was a child. Sure. How can she find some absolute thing. Yeah, that's just what I asked the other day that I'm attacking. I'm a police officer. Police. We have a social insurance. Stop. Stop. Now, then when I spoke to the mother. The mother is actually I'm an adult, how must my child feel to sit there? How must she feel? How can she concentrate? That is what I ask the teacher, and then the teacher felt I'm attacking her. I said, "I'm not", I'm a police office, I know... We work for this. We go to schools, we talk to bullies, we take bullies, you know? We deal with these situations. So now, my child is being bullied and now you still put this bully next to her. She's not going to... the bully is not going to stop.... [inaudible]... then when I spoke to the mother, the mother is actually bullying her at home. Because her mother grabs her hair...[inaudible]... shuts her up or... [inaudible]. So I said, okay, the bullying is starting at home. So I told her, whatever ever you do... I mean, if I can't do... You can't treat Skye the same way as you are treating somebody else, you know? Skye is... you can't go put Skye on the mat and expect Skye is gonna read for you amongst all the other children. Skye is reading, this child, the first child read and then Skye hears how this child is reading fluently. But we practiced it last night... So this morning she will not talk because she knows she have a lisp. So when she talk, there is a.... You know? So there's a few words that she won't pronounce properly. But every time, now this morning when the teacher sent me her progress, she said that Skye must read a lot. I bought Skye, I bought her that doll in order for her to hear the words also, because most of the time then I don't have time to read for her. Then I gave her the books, I bought her that thing umm, that you press with the doll giving instructions, you follow instructions, and she did well. Just doing really great with that. I'm impressed.

R: Oh, that's wonderful.

P3: She's doing...but that is when she's alone at home.

R Ja, ja....

P3: You understand the difference now? When she comes to school, and the difference at home. The spelling... we give her spelling tests, she will get a good mark, maybe 7 or 6. When she comes to school, because of the time, remember... I think you do know what the do... [inaudible]... (phone ringing in the background).... They give them their zone, their own zone, and then after when they're finished, then Skye maybe started.

R: Ja, ja...

P3: You understand?

R: Ja, ja.

P3: She's going to get a 2 out of 10.

R: So it seems, it seems, it seems to me that the classroom environment is also very distracting for her. That when she's at home and she has that individual attention that she's able to perform, but at school she really struggles.

P3: Yes. Now that is what the doctor didn't understand, what I'm trying to say. He assessed is Skye that high score. So I told him, it's because she likes you. And whatever you're going to tell her, she will do. But now it comes to the teacher and now she don't like what the teacher did putting her bully next to her. So what is she going to do? She's not gonna listen to you, because you... you're harming her. You understand what I'm saying? And now she blocks the teacher out completely. Now she got a new teacher. And this teacher gave her stickers for every good thing she's doing. And she speaks very well of the teacher, she is excited because... you know? Because the teacher acknowledged, "Skye, well done". You know? "Great job, Skye" the whole week. I mean... [inaudible]... "mommy mommy, I did this"... I'm excited coming from school, you know? So ja....

R: That positive reinforcement really helped her.

P3: Yes. Definitely.

R: Yeah. And then, and then I wanted to, I wanted to ask.... so you mentioned that you think children are definitely treated differently and there is a stigma around it. So, how do you imagine that that stigma can be addressed in your community?

P3: Umm... sjoe.... I think it starts at school. They are mostly at school, during the day. It starts there. Umm, I don't know what the teacher can do about it... I can't, I can't....Maybe talk to the children, that children glasses, umm children with umm lisps or with disabilities are still children, can still be their friends, you know? Because she don't have friends.

R: Ja, that's very difficult.

P3: She don't have friends that can say, listen I want to go to a party you know? Or that invites her or .... no she don't have. Do you understand?

R: Mmm....So it feels as if, if someone were to talk about it at school and teach the other children about, about the differences and you know that that would that would help in terms of the bullying and being treated differently and all those types of things.

P3: Hopefully.

R: And then what do you what do you wish people knew about ADHD or mental health challenges? What do you wish, other people knew?

P3: Umm... that that people is very very sensitive people. Skye is very sensitive. My friend's child is so sensitive. You need to know how to treat them, really. Skye will stand in front of me, and speak to me with her hands behind her back. I'm her mother... do you understand what I'm saying? She will like almost stand at attention when she talks to me. I mean, that for me, it's not nice. I would like "come sit on mommy's lap", you know? "Come, you're still my baby" you know? Baby in the sense of, I can still cuddle you, I can still you know, bath you. I don't, I don't pamper her but you know what I'm trying to say.

R: Yes, ja...

P3: Don't block out me as well, because, you know?

R: Yeah, yeah,

P3: The way she blocks out everybody

R: Yeah, yeah I exactly what you're saying, I can understand what you're saying. And do you imagine that the fact that she blocks out people is because of experiences that she's had?

P3: Yes. Definitely.

R: With regards to the bullying for example, or from teachers or other adults or how do you.... what do you make....

P3: Every.... EVERYTHING! EVERYWHERE. Even children. And that's one of the reasons she don't have friends. Umm, she would say... one.... a few years back, they invited her for a party, and she said "you can bring my cake. And I want to go"

R: Aww, shame.

P3: And, do you understand? And I mean that was a few years back, I think, she was 5, 6, 7. you know?

R: Little...

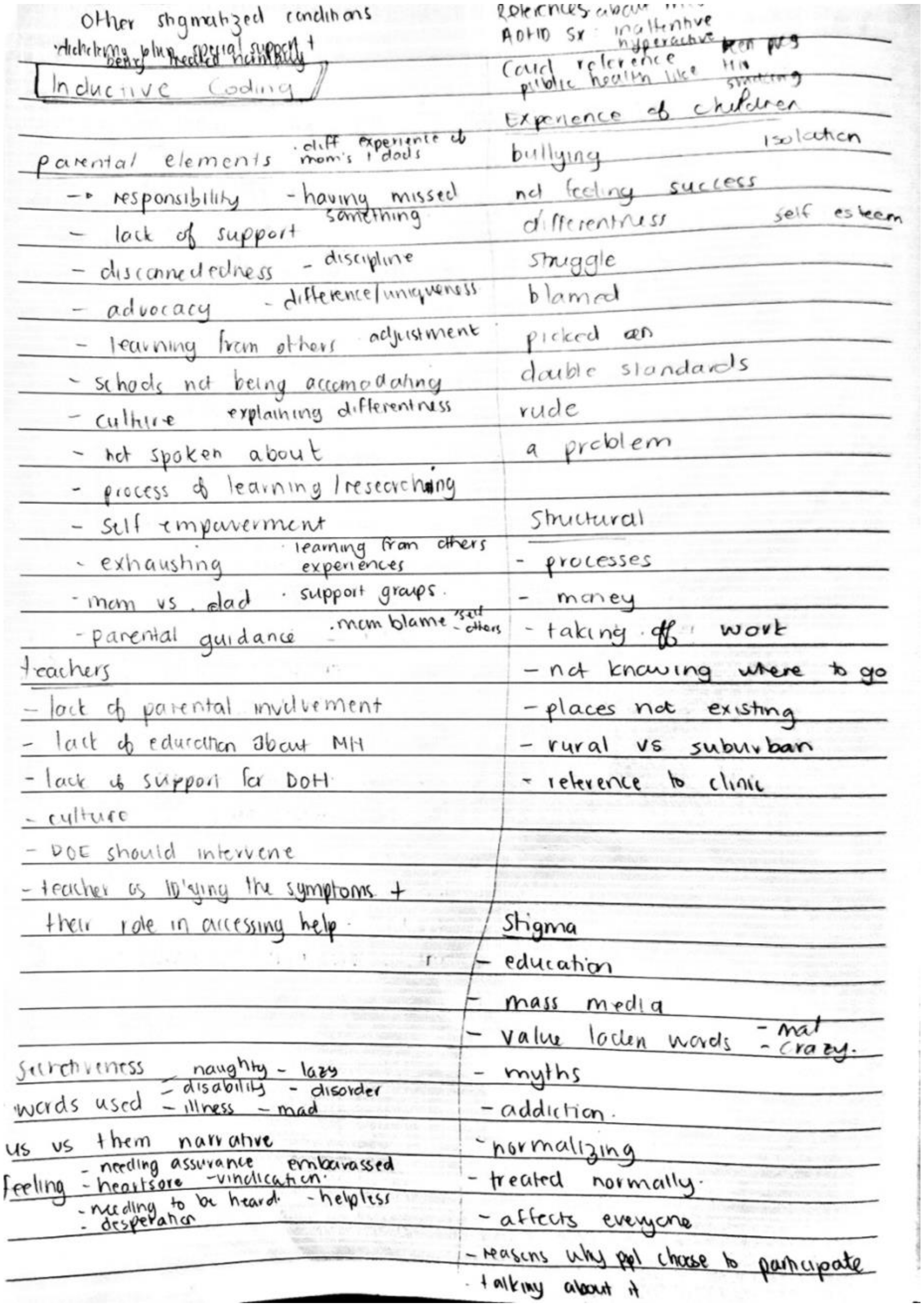
P3: And she already had that. But, ummm when she was five they realize that she can't see properly, and then we've got her glasses. And she said "oh, mommy. This is so beautiful". I was so shocked because she didn't talk, so we couldn't really say she don't, she can't see. You know what I'm trying to say? So, she won't read, she won't... Ss I was like, okay maybe she don't like books. But the other children like the books, you know? And I was, ah it's fine.... [inaudible]... all children ... [inaudible].... but then when the teacher, when I was in grade R. The teacher said, "No, but I don't think Skye can see because she's writing upside down". I'm like "oops". And then we went for the glasses and everything started.

R: Okay and have things improved a little bit with the glasses?

P3: Umm, no.... *[laughing]*. She has she glasses. She must go every second year ...[inaudible].... And I would like you to help me get to one of those special needs school. I don't mind if I must pay R10000 or something, a year or, I don't know...you know? But Skye is seriously not coping in that school.

[The discussion continued regarding Skye, specifically in relation to her interaction with #gb4adhd and the ways in which the Foundation can assist moving forward].

Appendix J: Thematic analysis



Other stigmatized conditions
·dichotomy plus special support + being treated normally

Inductive Coding

parental elements ·diff experience of mom's + dads
- responsibility - having missed something
- lack of support
- disconnectedness - discipline
- advocacy - difference/uniqueness
- learning from others ·adjustment
- schools not being accomodating
- culture ·explaining differentness
- not spoken about
- process of learning/researching
- self empowerment
- exhausting ·learning from others experiences
- mom vs. dad ·support groups.
- parental guidance ·mom blame - self - others

teachers
- lack of parental involvement
- lack of education about MH
- lack of support for DOH
- culture
- DOE should intervene
- teacher as ID'ing the symptoms + their role in accessing help.

secretiveness naughty - lazy
words used - disability - disorder - illness - mad
us vs them narrative
feeling - needing assurance embarrassed - heartsore - vindication - needing to be heard - helpless - desperation

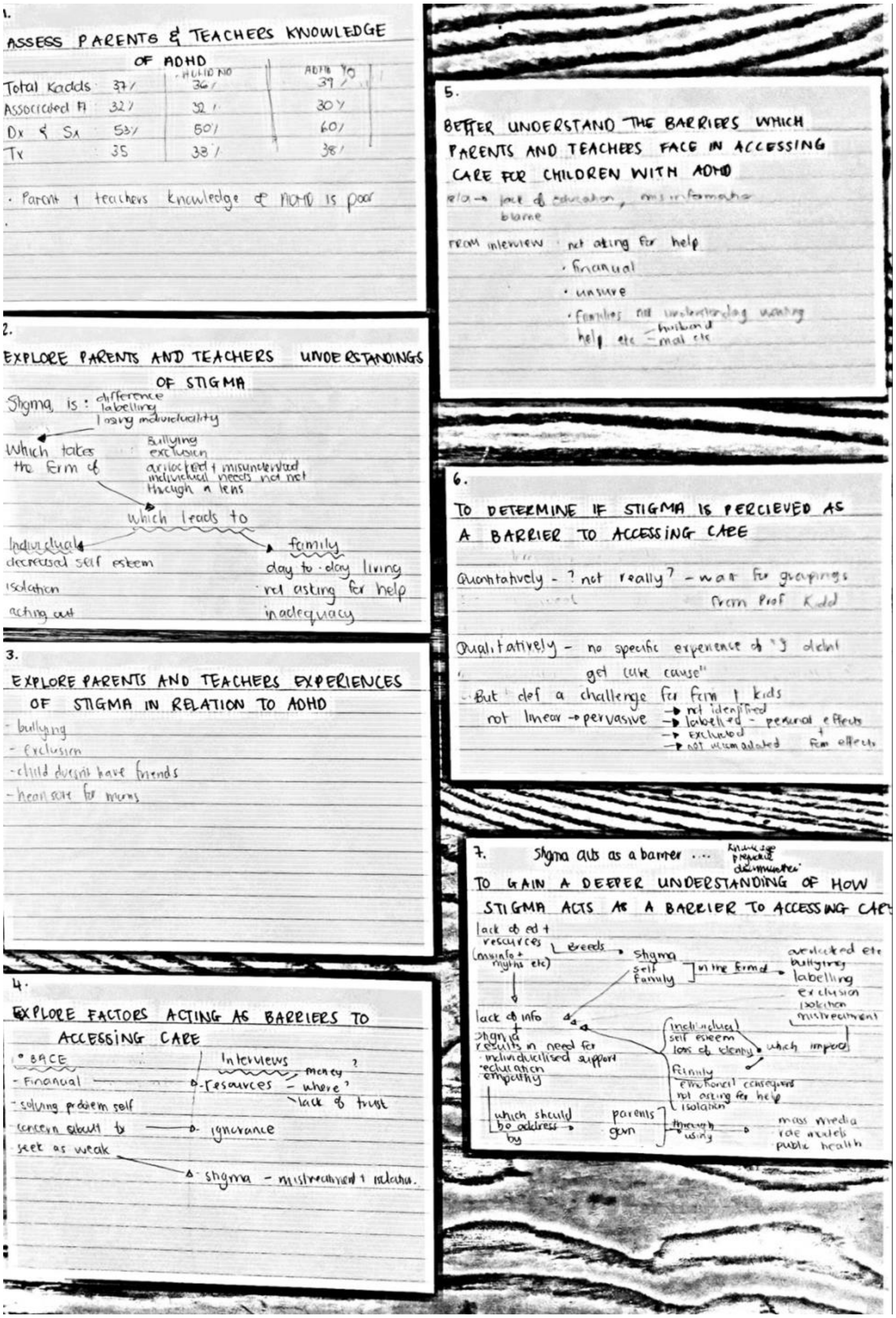
References about [illegible]
ADHD Sx: inattentive hyperactive
Could reference public health like teen preg HIV smoking

Experience of children
bullying isolation
not feeling success
differentness self esteem
struggle
blamed
picked on
double standards
rude
a problem

Structural
- processes
- money
- taking off work
- not knowing where to go
- places not existing
- rural vs suburban
- reference to clinic

Stigma
- education
- mass media
- value laden words - nat - crazy.
- myths
- addiction.
- normalizing
- treated normally.
- affects everyone
- reasons why ppl chose to participate
·talking about it

Figure J1: **Initial Pen-and-Paper Analysis**



1.

ASSESS PARENTS & TEACHERS KNOWLEDGE OF ADHD

		ADHD NO	ADHD YO
Total Kadds	37%	36%	39%
Associated F	32%	32%	30%
Dx & Sx	53%	50%	60%
Tx	35	33%	38%

· Parent + teachers knowledge of ADHD is poor

·

2.

EXPLORE PARENTS AND TEACHERS UNDERSTANDINGS OF STIGMA

Stigma is : difference
labelling
losing individuality

which takes the form of : Bullying
exclusion
overlooked + misunderstood
individual needs not met
through a lens

which leads to

Individual
decreased self esteem
isolation
acting out

family
day to day living
not asking for help
inadequacy

3.

EXPLORE PARENTS AND TEACHERS EXPERIENCES OF STIGMA IN RELATION TO ADHD

- bullying
- exclusion
- child doesn't have friends
- heart sore for moms

4.

EXPLORE FACTORS ACTING AS BARRIERS TO ACCESSING CARE

° BACE
- Financual
- solving problem self
- concern about tx
- seek as weak

Interviews
- resources – money ?
– where ?
– lack of trust
- ignorance
- stigma – mistreatment + isolation.

5.

BETTER UNDERSTAND THE BARRIERS WHICH PARENTS AND TEACHERS FACE IN ACCESSING CARE FOR CHILDREN WITH ADHD

e/a → lack of education, misinformation
blame

FROM interview · not asking for help
· financial
· unsure
· families not understanding wanting help etc – husband
– mal etc

6.

TO DETERMINE IF STIGMA IS PERCIEVED AS A BARRIER TO ACCESSING CARE

Quantitatively – ? not really ? – wait for groupings from Prof Kidd

Qualitatively – no specific experience of "I didn't get care cause"

· But def a challenge for fam + kids
not linear → pervasive → not identified
→ labelled – personal effects
→ excluded +
→ not accommodated fam effects

7. Stigma acts as a barrier … knowledge
prejudice
discrimination

TO GAIN A DEEPER UNDERSTANDING OF HOW STIGMA ACTS AS A BARRIER TO ACCESSING CA

lack of ed + resources (misinfo + myths etc) breeds → stigma
self
family] in the form of → overlooked etc
bullying
labelling
exclusion
isolation
mistreatment

which impacts

individual
self esteem
loss of identity

family
emotional consequences
not asking for help
isolation

lack of info + stigma results in need for
· individualised support
· education
· empathy

which should be address by → parents
govn] through using → mass media
role models
public health

Figure J2: Themes Related to Research Questions

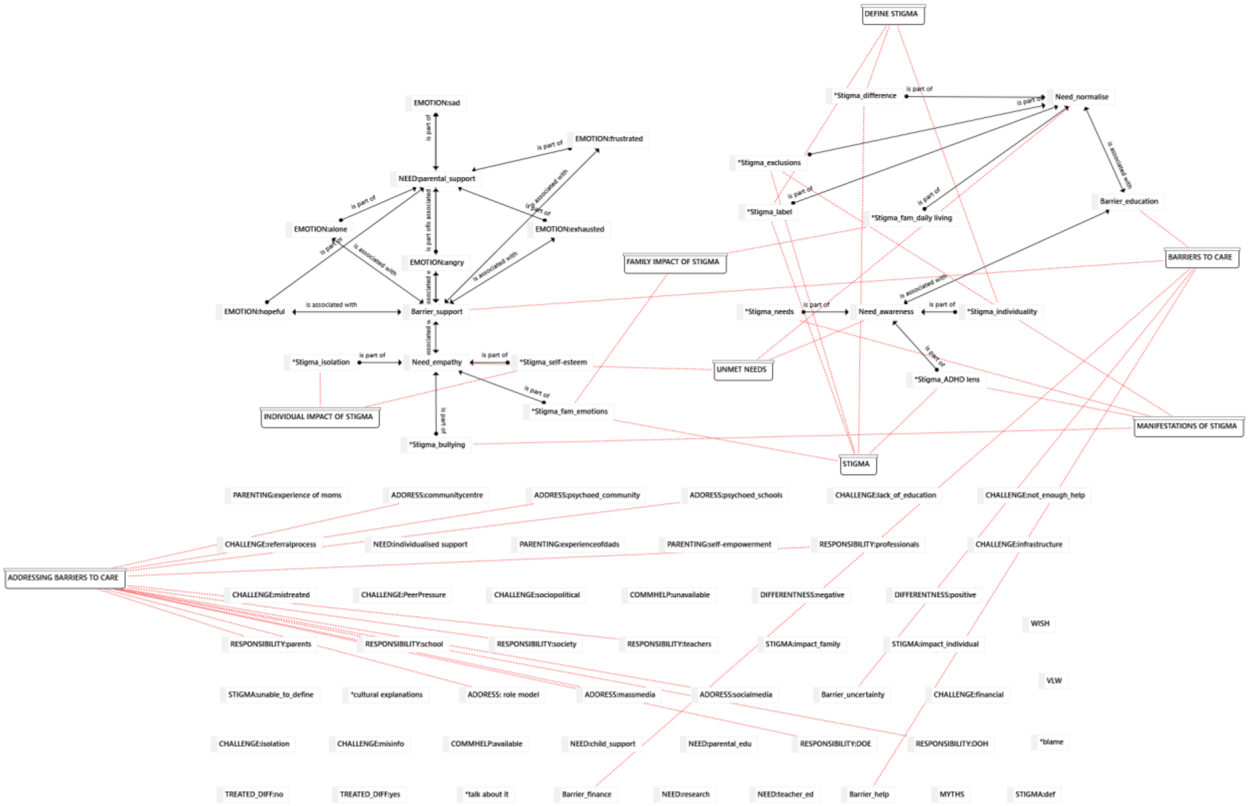


Figure J3: Network View of Initial coding

Note. The solid blank lines indicate links between codes. The dotted red lines indicate groups which the codes belong to.

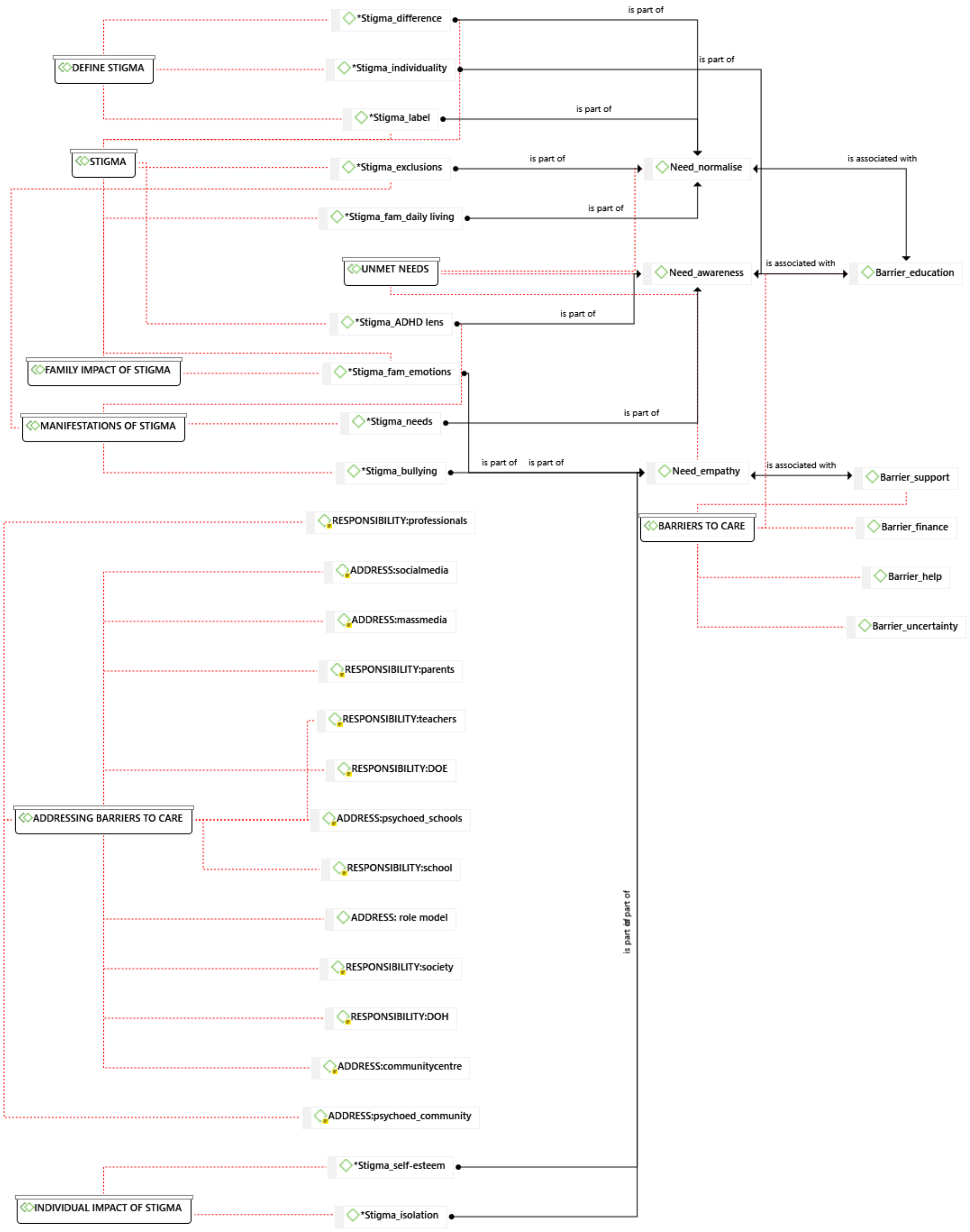


Figure J4: Searching for Themes Using Atlas.ti Networks

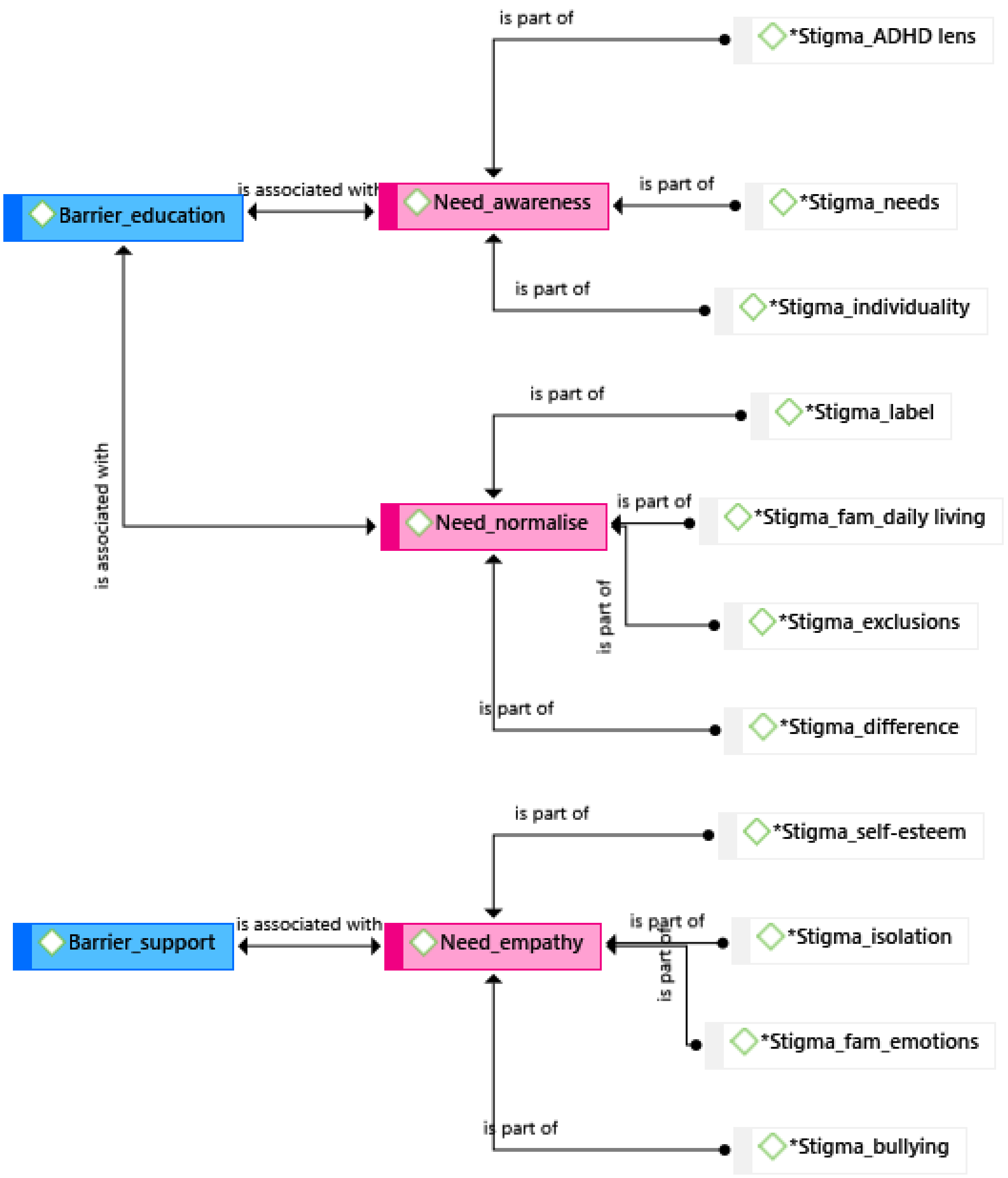


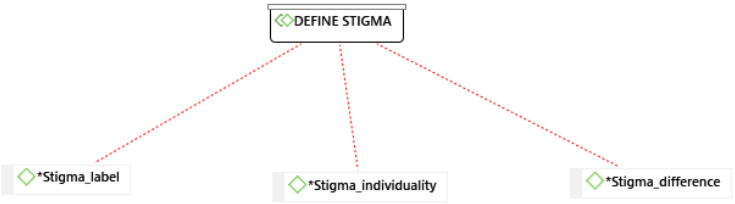
***Figure J5*: Unmet Needs in the Community with Related Elements of Stigma and Barriers**

Appendix K: Code book

Code name (frequency of appearance across interviews): description

UNDERSTANDING STIGMA

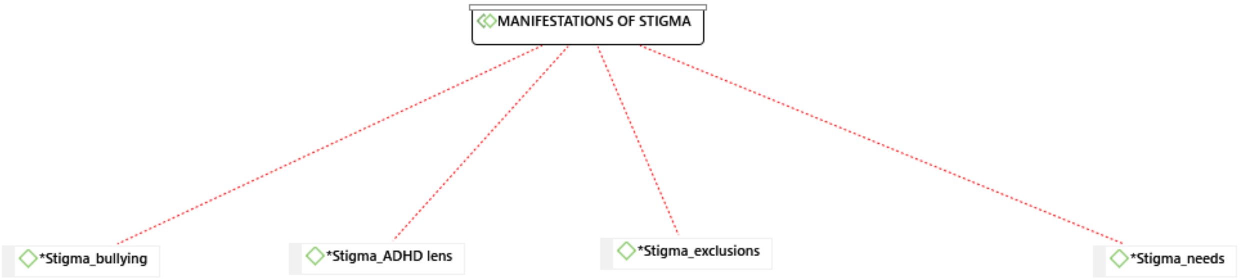
This category describes the ways in which participants define stigma, the ways in which the experience stigma, and the impact of stigma on the stigmatised individual and their family



Stigma_label (14): References to labelling

Stigma_individuality (6): References to children being seen as part of an ADHD "group" / loss of individuality

Stigma_difference (8): References to children with ADHD being seen as different

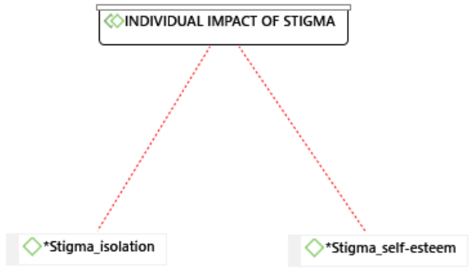


Stigma_bullying (7): References to children being bullied due to ADHD

Stigma_ADHD lens (7): References to children's behaviour being interpreted differently due to ADHD

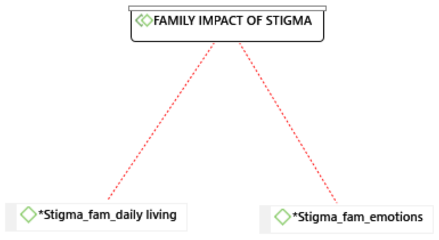
Stigma_needs (23): References to the needs of children with ADHD being neglected

Stigma_exclusions (8): References to children being excluded due to ADHD



Stigma_isolation (10): References to being socially isolated due to ADHD

Stigma_self-esteem (5) References to poor self-esteem due to stigma related to ADHD

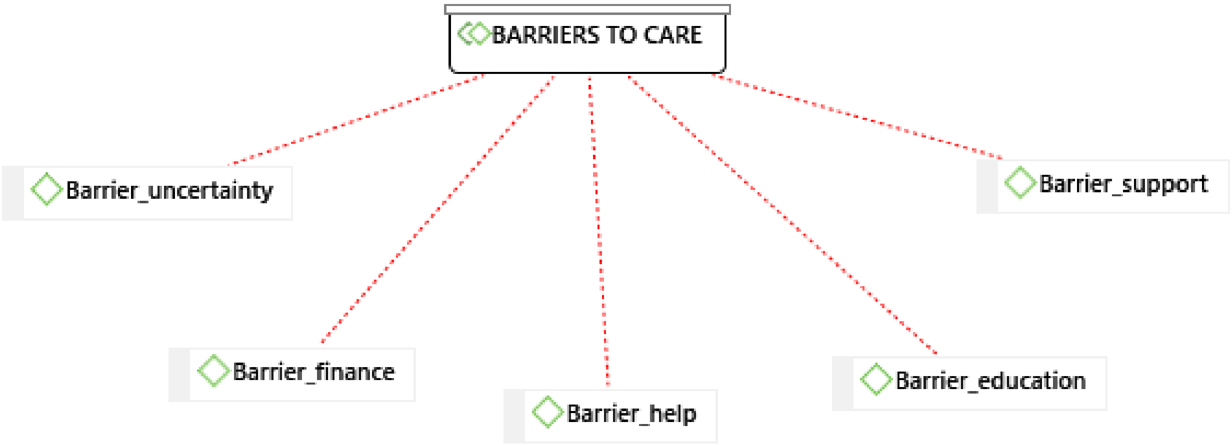


Stigma_fam_living (3): References to the effect of ADHD on family life

Stigma_fam_emotions (14): References to the emotional impact of ADHD on the family

FACTORS INFLUENCING ACCESS TO CARE

This category describes the barriers which participants expressed as barriers to accessing care



Barrier_uncertainty (10): References to uncertainty about where to access treatment as a barrier to care

Barrier_finance (4): References to lack of financial resources as a barrier to care

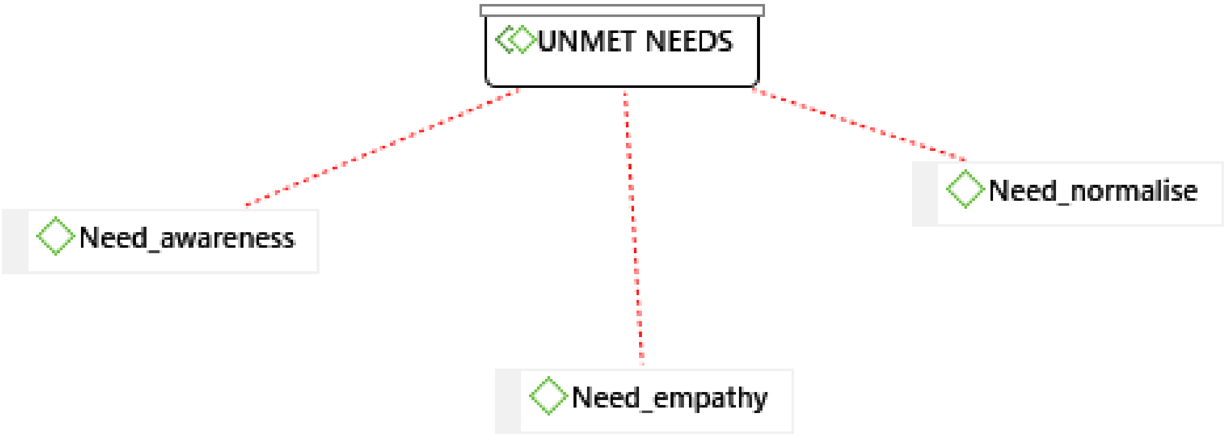
Barrier_help (11): References to lack of available help as a barrier to care

Barrier_education (18): References to lack of education as a barrier to care

Barrier_support (10): References to lack of support as a barrier to care

UNMET NEEDS IN THE COMMUNITY

This category refers to the needs that currently exist in the community which need to be addressed in order to facilitate adequate access to care.



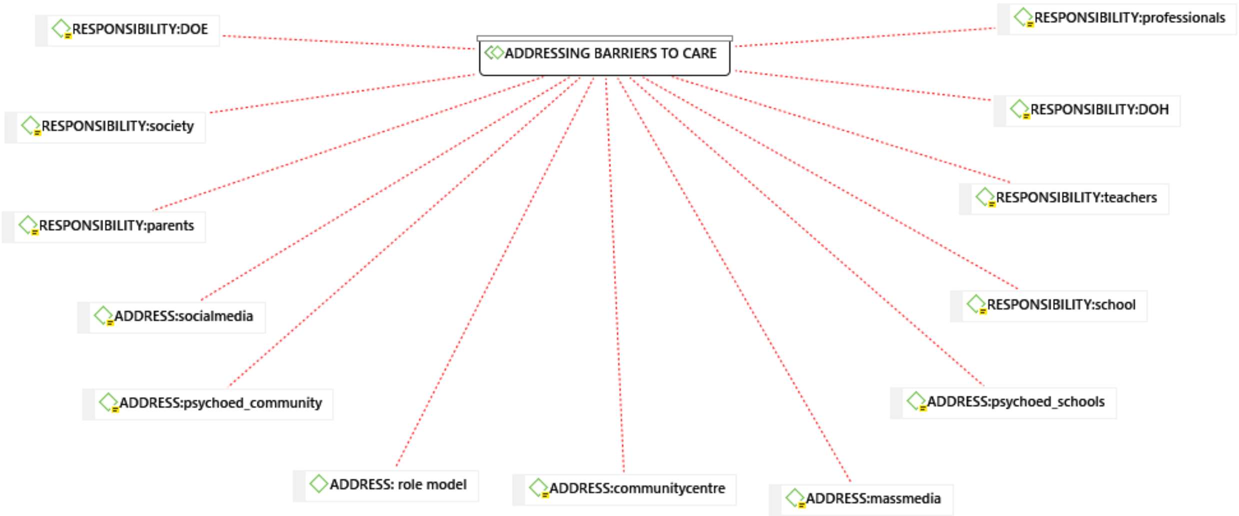
Need_awareness (19): Reference to the need for more awareness about ADHD and/or mental health in the community

Need_empathy (9): Reference to the need for increased empathy towards children with ADHD

Need normalise (8): References to the need for ADHD to be seen as normal/the same as other health conditions

ADDRESSING BARRIERS TO CARE

This category describes the way in which participants feel stigma can be addressed in the community, as well as whose responsibility it is to do so.



Address_role model (1): References to role models being used to address stigma

Address_community centre (2): References to community centres being used in addressing stigma

Address_MassMedia (1): References to the use of mass media to address stigma

Address_psychoed_community (10): References to community education as a means to address stigma

Address_psychoed_schools (6): References to schools as a means to address stigma

Address_SocialMedia (3): References to the use of social media to address stigma

Responsibility_DOE (2): References to the Department of Education holding the responsibility to educate people about ADHD and mental health

Responsibility_DOH (4): References to the Department of Health holding the responsibility to educate people about ADHD and mental health

Responsibility_parents (7): References to parents holding the responsibility to educate people about ADHD and mental health

Responsibility_professionals (2): References to medical professionals holding the responsibility to educate people about ADHD and mental health

Responsibility_school (3): References to schools holding the responsibility to educate people about ADHD and mental health

Responsibility_society (4): References to schools holding the responsibility to educate people about ADHD and mental health

Responsibility_teachers (1): References to teachers holding the responsibility to educate people about ADHD and mental health