UNIVERSITY OF CAPE TOWN

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University of Cape Town

FACULTY OF HUMANITIES

DEPARTMENT OF PSYCHOLOGY

Exploring the first-hand experiences of adult males diagnosed with high functioning autism during their adulthood.

A minor dissertation to be submitted to the Department of Psychology, the University of Cape Town in partial fulfilment of the requirements for the award of the Degree of:

Masters in Clinical Psychology

By

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March 2019

COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people, has been attributed and has been cited and referenced.

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DEDICATION

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I draw my strength from my loving mother. I look up to her in so many ways. Even though she didn’t have the same opportunities I do, I am because she is, and I owe everything to her. In light of all this, this dissertation is dedicated to my mother Thembeka Lupindo. I have committed and will continue to commit myself to my studies because I see myself as honouring my mother and living up to the standards she sees in me.

ACKNOWLEDGEMENTS

The first thing the Bible reveals about God's nature is that He is a creator (Genesis 1:1 "In the beginning God created the heavens and the earth") and Genesis 1:26 says that "Then God said, 'Let us make mankind in our image, in our likeness…". This means that the ability to create is engraved in our very nature. For this reason, I would like to first and foremost thank and acknowledge God for giving me the ability to create. If it weren't for Him imparting His nature, knowledge and wisdom within me, I would not have been able to create this piece of work. 'Thank you' is not enough to convey my humble gratefulness for my blessings and experiences of strength during this challenging journey. When I felt fear and anxiety, I was replenished with faith and hope, and for that, thanks can only go to God.

I also wish to acknowledge the following people:

- To the men and their families who participated in this study. This project would not have been a reality without you.
- To the Neurodiversity Centre and their entire team, thank you for the patience, assistance and provision that you have given me throughout this project. I cannot thank you enough for taking time off your busy schedules to organize not only participants for my study but also the office space to conduct my interviews.
- To Ben Truter. I don't even have the words to thank you enough for everything you have done to make this project a success. Thank you for your knowledge and wisdom that you so freely shared with us. Thank you for the words of encouragement and constantly reminding us what our strengths are and how to use them to succeed not only for this project but throughout our careers. You have gone above and beyond what I would have expected from even my own supervisors, yet all this was done from the kindness of your heart.
- I would also like to thank my supervisors, Dr Nokuthula Shabalala and Dr Anastasia Maw, for being good supervisors, mentors and positive influences. Most importantly, I thank you for believing in me when I started doubting myself and for responding to my countless emails, text messages and requests for consultation during my many states of confusion and episodes of panic.
- I would like to thank all my friends and colleagues for their love, words of encouragement and support, and a special thank you to those who had a direct

impact be it through assisting with transportation, offering me information (input, sharing of articles), and proofreading, namely, Yonela Sopotela, Chipo Makombe, Kwanele Shishane, Sanele Nkosi and Catharine Michelson.

- To my mother and my sisters – your unconditional love and uplifting words have been my source of inspiration and determination. You have been, and continue to be, my guardian angels and my pillars of strength.

TABLE OF CONTENTS

ABSTRACT 1
CHAPTER ONE: INTRODUCTION 2
1. 1. Background of the study 2
1.2. Context 6
1.3. Statement of the research problem 7
1.4. The Aim of the Study and Objectives 8
1.5. Research questions 9
1.6. The significance of the study 9
1.7. Outline of the thesis 9
CHAPTER TWO: LITERATURE REVIEW 11
2.1 The Nature of Autism Spectrum Disorders (ASD) and the Initial Presenting Symptoms 11
2.1.1 Autism Spectrum Disorders 11
2.1.2. Development and Course 17
2.2. Gender-related Diagnostic Issues 18
2.3. Factors Related to Delayed Diagnosis 20
2.3.1 Factors related to delayed diagnosis 20
2.3.2. Factors Contributing to Late-Diagnosis of Autism in Males 22
2.4 Challenges and Impact of Receiving an Adulthood Diagnosis of Autism 23
2.5. Conclusion 26
CHAPTER THREE: RESEARCH METHOD 28
3.1. Study Design 28
3.2. Description of Data Collection Site 28
3.3. Description of Participants 29
APPENDIX G: DEMOGRAPHIC INFORMATION RELATED TO PARTICIPANTS 30
Table 1.1. Table Representing the Demographical Information of the Participants 30
3.4. Sampling 33
3.5. Data collection 33
3.6. Procedure 35
3.7. Data analysis 35
3.8. Ethical Considerations 37
3.9. Reflexivity 37
CHAPTER FOUR: RESULTS 39
4.1. Process Issues 39
4.2 Diagnostic trajectory 40

4.4. Self-perception 51
4.5. Being an Adult with Late Diagnosed ASD 56
4.6. Chapter summary 63
CHAPTER FIVE: DISCUSSION AND CONCLUSION 64
Conclusion 69
Limitations 71
Recommendations 71
REFERENCES 73
APPENDIX A: ACCEPTANCE OF MASTERS PROPOSAL LETTER 84
APPENDIX B: LETTER REQUESTING TO CONDUCT MY STUDY AT THE 84
Neurodiversity Centre 85
APPENDIX C: LETTER REQUESTING PARTICIPATION IN RESEARCH STUDY 85
APPENDIX D: INFORMED CONSENT 87
APPENDIX E: INTERVIEW SCHEDULE 90
APPENDIX F: HANDWRITTEN NOTE FROM PARTICIPANT (Luke) 92
APPENDIX G: DEMOGRAPHIC INFORMATION RELATED TO PARTICIPANTS 88
Table 1.1. Table Representing the Demographical Information of the Participants 88

ABSTRACT

This study aimed to explore the first-hand experiences of adult males diagnosed with high-functioning autism during their adulthood. Particularly, it aimed to explore the nature of their initial presenting symptoms, gender-related factors that contribute to adulthood diagnosis of autism in males, the challenges they experienced prior to and succeeding their diagnosis, and lastly, the impact that receiving a late diagnosis had on their overall early development. This study applied the exploratory qualitative research design as a method of inquiry. Participants recruited were current (during the time the study was conducted) clients at the Neurodiversity Centre and ten participants were selected using the purposive sampling technique. An interview schedule with open-ended questions was used as a guide to collect data on participants' life histories. To analyze the findings, the thematic analysis technique was used in conjunction with the NVivo 12 qualitative analysis software; which was used to assist in organizing the data and identifying the themes.

The findings of this study highlighted four key features of the experiences of males diagnosed with high functioning autism during adulthood. It was evident that initial presenting symptoms were noticeable during early childhood, however, various factors resulted in these challenges being misinterpreted or overlooked. This lack of a formal diagnosis is perceived to have impacted the participants' early life in various ways forcing them to navigate through life without an understanding of their difficulties. Without these challenges being adequately addressed and understood, participants felt forced to adapt and find coping strategies (some of which were maladaptive) to navigate through life and maintain some sort of "normalcy". It was evident that succeeding their diagnosis, the lack of support services and guidance for adults with autism left the participants feeling that the future does not look any brighter than the past. To the researcher's knowledge, this study was the first (within the African context) to explore the experiences of adults with Autism Spectrum Disorder (ASD). With this being said, these findings highlight the importance of creating more knowledge and understanding, for professionals and the general public, around the experiences of adults with autism, as these individuals encounter major life challenges (especially without a formal diagnosis) and urgently need support, both professionally and personally, in managing their difficulties.

CHAPTER ONE: INTRODUCTION

In the past years; the global prevalence rate of Autism Spectrum Disorders (ASD) has increased significantly. The initial estimates were as low as 5 in 10 000 children (Lotter, 1966) and more recent studies indicate that 1 in 160 children globally have autism (World Health Organization, 2017). In response to this increase, an extensive body of knowledge has been developed exploring the experiences of individuals with autism (Chamak & Bonniau, 2016; Cordier, Brown, Chen, Wilkes-Gillans, & Torbjorn, 2016; DePape & Lindsay, 2016). However, these studies have focused on individuals who receive a diagnosis of autism during their early childhood. This has resulted in a gap in knowledge regarding the experiences of individuals, particularly males, who are diagnosed during their adulthood, as there is little to no literature exploring this area.

This chapter will present the background and contextual understanding of the current study, provide the rationale and significance, and state the research questions and research objectives. The chapter will end with an outline of the thesis.

1. 1. Background of the study

For decades, little was known about autism and its presenting symptoms. As a result, many people who would now be diagnosed as presenting with an early-onset neurodevelopmental condition on the autism spectrum, previously received or were classified as presenting with another diagnosis, such as intellectual disability (Hurlbutt & Chalmers, 2002), schizophrenia (NICE, 2012) and attention deficit and hyperactive disorder (Hendrickx, 2015). In this way, other developmental, learning and psychiatric diagnoses were made; or other factors (such as parenting style) were identified as paramount to autism (Bettelheim, 1967). Currently, theorists agree that conditions on the autism spectrum can co-present with any psychiatric, psychological (Hurlbutt & Chalmers, 2002; Leyfer et al., 2006; NICE, 2012) and socio-cultural diagnoses or factors (Bakare et al., 2009; Zeleke, Hughes, & Chitiyo, 2017).

Although the term ‘autism’ was coined in 1912 by psychiatrist Eugen Bleuler, while referring to a subset of patients suffering from schizophrenia who were self-absorbed and withdrawn (Blake, Hoyme, & Crotwell, 2013), autism as a condition was first described by Leo Kanner in 1943 (Kanner, 1943). Kanner identified eleven children who, while intelligent, lacked a social instinct that orientated them towards others; displaying a strong desire for solitude and tenaciously insistent on monotony (Kanner, 1943). They experienced difficulties

with transitions and changes to their routine, while others showed regression in already established skills. Around the same time, in National Socialist Austria, Hans Asperger independently reported a milder form of autism (Attwood, 2000; as cited in NICE, 2012). Dr Asperger, a physician working at the University of Vienna in Austria, reported a group of children who were socially aloof, withdrawn, and struggled with all dimensions of shared social interaction. Although presenting with behavioural problems commonly seen in children with autism, these children did not experience any language or speech deficits and did not display any deficits in terms of their adaptive functioning. He referred to their symptoms as "autistic psychopathy" (Attwood, 2000, p. 14; Ducharme & Gullato, 2013, p. 15) and in 1981, Lorna Wing coined the term Asperger's Syndrome (Wing, 1981).

At that time, little was known about autism and treatment options were limited. Children who presented with symptoms of autism were institutionalized and placed in residential areas that were far from the general public (Bettelheim, 1967; Eyal, Hart, Onculer, Oren, & Rossi, 2010). With limited knowledge about the disorder, professionals believed that the symptoms that these children were presenting with were a result of what was referred to as 'refrigerator mothers' (Mash & Wolfe, 2005, p. 284). The deficits in functioning that were observed in children with autism were attributed to mothers being "cold" towards their children (Mash & Wolfe, 2005), stating that they were indicative of poor attachments and/ or absent parenting (Bettelheim, 1967). Bettelheim (1967) adds that this evoked strong feelings of shame for having children with ASD as these parents blamed themselves for their child's disorder.

Although there is no definitive cause that has been identified, the consensus is that autism is the result of multiple factors (Barlow & Durand, 2009; Mash & Wolfe, 2005), the most significant being genetic factors (Geschwind, 2008; Mash & Wolfe, 2005). Twin studies estimate that genetic factors account for forty to ninety percent of the aetiology of autism (American Psychiatric Association, 2013; Hallmayer *et al.*, 2011). Environmental factors that were previously believed to contribute to the disorder included what was referred to as 'refrigerator parents' as well as measles, mumps and rubella vaccinations, however, this misconception has been disproved (Dodd, 2005; Taylor *et al.*, 1999).

On the contrary, factors contributing to the cause of the disorder that are considered as being more credible include those described by Auyeung *et al.* (2009) and Lovaas & Smith (1988). According to Auyeung *et al.* (2009) and Lovaas & Smith (1988), some of the environmental factors that may be contributing to the development of autism include, foetal

sex steroid hormones and social experience, respectively. Furthermore, research has found that "prenatal stress, infectious disease, and exposure to mercury, exemplifying some of the specific health concerns prevalent in Sub-Saharan Africa", are risk factors to the development of ASD (Franz, Chambers, von Isenburg, & de Vries, 2017, p. 15). In addition, "a variety of nonspecific risk factors, such as advanced parental age, low birth weight, or foetal exposure to valproate, may contribute to the risk of autism spectrum disorder" (American Psychiatric Association, 2013, p. 56). While no definitive environmental factors have been identified, it is clear that autism is caused by a gene-environment interaction.

In 1994, when Asperger's disorder was introduced to the DSM-IV-TR, there were controversies as to whether it was a distinct condition or a form of high functioning[1] autism (Hazen, McDougle, & Volkmar, 2013). To date, numerous studies have failed to provide evidence for a distinction between Autism and Aspergers (Macintosh & Dissanyake, 2004; Witwer & Lecavalier, 2008). This suggests that these two 'sets of conditions' are likely to be a variation of the same underlying disorder or cause. Furthermore, the genetic distinctiveness of these two disorders was questionable due to their high concurrent rate in single families (Bishop et al., 2004; Ghaziuddin, 2005). Therefore, the DSM-V collated these disorders into one condition defined on the basis of severity than type. This was also an attempt to identify and describe the core qualitative features of the 'autisms'.

[1] High functioning autism is not an official diagnosis found in the DSM nor is it an official medical term. It is used to describe the level of ability of an individual with an autism spectrum disorder (Borgman, 2015), typically describing individuals who to a large extent 'blend in' with neurotypicals. There has been a lot of controversy around the term 'high functioning' with arguments centred around the fact that the term 'functioning' is vaguely defined and leads to misunderstanding (Borgman, 2015). It is unclear whether functioning refers to social, physical or mental functioning and the question of what standards are used to measure whether individuals are high or low functioning and who decides on the standards remains unanswered. Furthermore, it has been argued that labelling people based on their 'functionality' is dehumanizing and insulting. Robison (2014, p. 2) states that being referred to as high functioning feels like being told "you talk pretty good for a retard". For the purpose of this study, the term high functioning will be used to refer to individuals who were diagnosed with Asperger's and/ or individuals who were diagnosed with ASD and are classified as presenting with 'milder symptoms' (that is, aren't severely impacted in their social communication abilities) of autism and are able to verbally express themselves and their experiences. Although this term is problematic, it is useful for the purpose of this study as it is both well known and distinguishes between individuals who are severely impacted by autism in terms of their functioning and those whose functioning isn't severely impacted.

Previously, the Diagnostic and Statistical Manual for Mental Disorders Fourth Edition text revision (DSM-IV-TR) grouped autism as part of the Pervasive Developmental Disorders (PDD) category. This category consisted of Autism Disorder, Asperger's Disorder, Rett's Disorder, Pervasive Developmental Disorders Not Otherwise Specified and Childhood Disintegrative Disorder (American Psychiatric Association, 2000). PDD was an umbrella for disorders characterised by impairments in social reciprocity, communication, and restricted, repetitive behaviour and interests. However, it was argued that the subtypes of PDD cannot reliably be differentiated from one another (Tsai & Ghaziuddin, 2014) and therefore, their validity was questionable (Hazen et al., 2013). Similarly, Happé (2011) found that when the DSM-IV-TR was applied, the predictor of diagnosis for individuals was the clinic in which they were diagnosed than any of their characteristics, thus further questioning the validity of the sub-categories. The more recent edition of the DSM, the DSM-V, has made changes to the diagnostic categories, replacing the autistic disorder, Asperger's Syndrome and PDD-NOS sub-categories with Autism Spectrum Disorder, thereby conceptualizing the disorder as a single diagnostic continuum defined by two domains, namely social communication/ interaction, and restricted, repetitive behaviours (American Psychiatric Association, 2013; Hyman & Faap, 2013; Kent et al., 2013).

The changes made from the DSM-IV-TR to the DSM-V have significant implications. Studies that compared the two versions suggest that, due to the new and more stringent criteria, many individuals who were previously diagnosed with conditions within the PDD category and Asperger's syndrome will no longer meet the criteria for a diagnosis with conditions within the autism spectrum (Gibbs et al., 2012; Mandy, Charman, & Skuse, 2012; Mayes et al., 2014). Furthermore, Mandy et al. (2012) concluded that, although the DSM-V provides greater validity compared to the DSM-IV-TR, the social communication domain fails to capture high functioning forms of autism. Similarly, Gibbs et al. (2012) as well as Worley and Matson (2012) found that, despite presenting with significant symptoms of ASD compared to neurotypicals and having similar symptom severity to those diagnosed using the DSM-V, children who were previously diagnosed with conditions within PDD did not meet the DSM-V criteria. In relation to these arguments, these changes made in the diagnostic criteria may worsen the late diagnosis of high functioning males. In addition, Matson, Kozlowski, Hattier, Horovitz, & Sipes (2012) state that this exclusion from receiving a diagnosis could have a

devastating effect on families of individuals who were previously diagnosed as they would no longer be eligible for support services available for people who receive a formal diagnosis.

1.2. Context

The World Health Organization (2013) states that autism is a growing public health concern and may represent the greatest disease burden among children and adolescents. Epidemiological studies, in areas such as Singapore; describing autism as contributing to the highest disability among children under the age of fifteen (Epidemiology & Disease Control Division Ministry of Health Singapore, 2014). Although the majority of children and adolescents live in low to middle-income countries, limited research has been conducted within these regions (Kieling et al., 2011). In Sub-Saharan Africa (SSA), the bulk of research conducted has focused on communicable diseases, with little to no research being done on neurodevelopmental disorders such as autism (Bakare, Munir, & Bello-Mojeed, 2014).

It is estimated that the current prevalence rate of autism, for global north and global south countries, is one per cent of the entire population, with equal representation among adults and children (American Psychiatric Association, 2013). Although South Africa has no data on prevalence, which in part is due to lack of access to gold standard diagnostic instruments (Abubakar, Ssewanyana, de Vries, & Newton, 2016), there is no reason to believe that it is any lower than in global north countries, as the disorder has no boundaries in ethnicity and socioeconomic status, There are also a sufficient number of reported cases to suggest that it is a not cultural bound syndrome. According to Bateman (2013) at least ten children are diagnosed with autism weekly in the Western Cape hospitals such as the Red Cross Children's Hospital, Lentegeur and Tygerberg Hospitals. However, care should be taken in considering the reported figures, given that no epidemiological studies pertaining to autism have been undertaken in South Africa - or indeed anywhere in Sub-Saharan Africa (Franz et al., 2017).

With this increase in the recognition of neurodevelopmental disorders on the autism spectrum, the crucial need to conduct more research in this area within the African context is evident. In a comprehensive scoping review by Franz et al. (2017, p. 22), they found "only 53 peer-reviewed articles about ASD that reported data on participants who lived in SSA". This is a small number considering that Africa is the second largest and second most populated continent (World Population Review, 2019). The focus of the studies that were found were centred around eight themes, namely the phenotype of autism in Africa; genetic factors that contribute to its aetiology; risk factors that predispose children in Africa to the condition;

screening and diagnosing the disorder, professional knowledge around the disorder; interventions that are currently used as a treatment approach, family perspectives around the disorder and lastly; factors relating to social-cognitive neuroscience pertaining to the disorder. Notably, no early intervention, school-based or adult studies were found (Franz et al., 2017). In light of the lack of studies, this study is warranted.

The high costs related to the diagnosis and treatment of conditions on the autism spectrum may further amplify the prevalence of late diagnosis and the impact the disorder has on individuals within various contexts. In Australia, it is estimated that the median family cost of autism is $34 900 (AUD) per annum (Horlin, Falkmer, Parsons, Albercht, & Falkmer, 2014). A further estimate of $1 400 (AUD) for the family per annum was reported as an increase in the cost of ASD for each additional symptom that individuals presented with. Within the South African context, characterised by limited access to resources, the costs may further limit access to diagnostic and treatment services. In addition, considering that the majority of the South African local population relies on public health services (Statistics South Africa, 2017) access to diagnostic and treatment interventions may be further challenging as these services may not be available at public health care facilities. Given the significant costs, early detection is made less probably, with significant implications for children who go undiagnosed. Such implications further highlight the needs for studies that will create an understanding of context-specific factors, such as resource scarcity and low socio-economic status characteristic of African countries, as they relate to adulthood diagnosis of autism and the impact adulthood it has on individuals.

1.3. Statement of the research problem

Autism Spectrum Disorder has a profound impact on many aspects of life for individuals diagnosed with the disorder and their families. According to Howlin and Moss (2012), individuals with conditions on the autism spectrum are at risk of experiencing difficulties in social, behavioural, emotional, occupational and economic areas. Furthermore, their families are profoundly impacted by the disorder in economic and emotional areas (Loukisas & Papoudi, 2016). As a result, there has been a growing body of knowledge exploring the experiences of diagnosed individuals and the impact the disorder has on their families (Chamak & Bonniau, 2016; Cordier et al., 2016; DePape & Lindsay, 2016).

However, most of the above-mentioned research has focused on the experiences of individuals who received a diagnosis during early childhood. In addition, most of these studies

have relied on second-hand accounts of these experiences from parents. Therefore, due to the limited research in this area, there is a gap in knowledge regarding the first-hand experiences of individuals, particularly males, diagnosed with autism during adulthood. This results from research on adulthood diagnosis of autism being predominantly focused on the experiences of females and understanding the female phenotype of autism (Bargiela, Steward & Mandy, 2016; Lehnhardt et al., 2016) as they generally receive a diagnosis during their adulthood. Amongst males diagnosed during adulthood, little is known regarding the nature of their earliest presentation (which will be referred to as initial presenting symptoms), the challenges they experienced prior to and succeeding their diagnosis, and lastly, the impact that receiving a late diagnosis has on their overall development, particularly their identity. Furthermore, it is important to recognise that there is likely to be a difference in the life trajectories of males and females diagnosed late because of social mores and expectations, therefore, this draws attention to the need for more research that focuses on the experiences of late diagnosed males with ASD.

1.4. The Aim of the Study and Objectives

This study aims to explore the experiences of males diagnosed with high functioning autism during their adulthood.[2]

The specific study objectives are:

1. To explore the nature of the initial presenting symptoms of males diagnosed with autism during their adulthood.
2. To explore gender-related diagnostic issues that contribute to males being diagnosed with autism during adulthood.
3. To explore factors related to delayed/adulthood diagnosis of ASD in males?
4. To explore the challenges experienced, prior and post-diagnosis, by males diagnosed with autism during adulthood and how these challenges impacted their development.

[2] For the purpose of this study, the terms delayed, and/or late diagnosis will be used interchangeably to refer to an adulthood diagnosis of autism that occurs after the South African legal age of 18 (Legal Aid South Africa, 2015).

1.5. Research questions

The research questions that the study attempted to answer include:

1. What is the nature of the initial presenting symptoms of males diagnosed with autism during their adulthood?
2. What are the gender-related diagnostic issues that contribute to males being diagnosed with autism during adulthood?
3. What factors contribute to delayed/adulthood diagnosis of ASD in males?
4. What are the challenges experienced, prior and post-diagnosis, by males diagnosed with autism during adulthood and how do these challenges impacted their development?

1.6. The significance of the study

This study aims to explore the first-hand experiences of males who receive a late diagnosis of autism. It will explore the diagnostic and treatment trajectories of these individuals and their implications for the participants of this study. It is hoped that the findings will provide insights regarding factors that contribute to males being diagnosed in adulthood and the impact that this has on them. These findings may further provide information that is necessary for early diagnosis and treatment interventions that are essential for better managing the risk factors that these individuals are exposed to and improve their quality of life. In addition, it is hoped that the research will draw attention to the importance of health care professionals being trained to identify the broader presentations of conditions on the autism spectrum to reduce the number of individuals who receive a late diagnosis. Lastly, being the first of its kind, it is hoped that the study will contribute to the limited body of knowledge about adults with spectrum conditions within the African context.

1.7. Outline of the thesis

Chapter One introduced and contextualized the study. It also presented the rationale and significance of the study and stated the research questions and research objectives. Chapter Two of the thesis consists of an overview of the literature that is available related to the late diagnosis of autism. The gaps in knowledge will also be highlighted and explored. Chapter Three will describe the research design and method used to collect and analyse data, including key features of qualitative research, the description of the setting in which the study took place and the procedures that were undertaken to access participants. The chapter will end by

presenting the ethical considerations that were undertaken during the study. Chapter Four will present the findings of the study, which will be described with reference to existing literature. The final chapter, Chapter Five, will begin with a brief summary of the research project, followed by a discussion of the findings and the implications thereof. The conclusion section will summarize the key findings of the study, discuss the strengths and limitations of the study, make recommendations for future research and lastly, make final remarks pertaining to the study.

CHAPTER TWO: LITERATURE REVIEW

The aim of this chapter is to review the literature on issues related to the late diagnosis of autism. This is a complex task, not just because of the paucity of valid research into the late diagnosis of adult males, but also because of the lack of any such literature in the South African context. The section will focus on the impact that receiving a diagnosis in adulthood has, as opposed to the critical developmental period of childhood when available supports and interventions may affect life outcomes for diagnosed individuals (Hurlbutt & Chalmers, 2002; Khan et al., 2012).

This chapter will present a discussion of what are referred to as Autism Spectrum Disorders (ASD), including an orientation of the broad "spectrum" of ways in which the condition presents itself. The section will also present a general discussion of the characteristics of ASD and the development and course of the disorder. This will be followed by the factors that are linked to diagnostic issues and gender differences will be described. The next section will focus on the factors related to delayed diagnosis of autism, all the while drawing attention to the limited research conducted on those who receive a diagnosis in their adulthood. In addition, challenges experienced by these individuals and the impact they have will also be explored. This chapter will end with a summary of the limitations and gaps found in current literature pertaining to the topic of interest and present concluding remarks with regards to how this study intended to address these gaps.

2.1 The Nature of Autism Spectrum Disorders (ASD) and the Initial Presenting Symptoms

2.1.1 Autism Spectrum Disorders

According to the American Psychiatric Association (2013), Autism Spectrum Disorders (ASD) are pervasive neurodevelopmental disorders that are associated with atypical functioning and qualitative impairments in individuals across three major areas. These areas are often referred to as the triad of impairments, namely; social interaction, social communication and restricted, repetitive behaviour (in areas of social imagination or make-believe play, concrete thinking, poor abstract reasoning and a strong need for consistency and repetitiveness) (American Psychiatric Association, 2013; Dodd, 2005; Wall, 2004). Although the disorder is present during early childhood, presenting symptoms may only manifest during later stages, when demands on the individual increase and exceed their capabilities (American

Psychiatric Association, 2013; Hyman & Faap, 2013). Importantly, the presentation of the disorder is unique to each person diagnosed with ASD and may evolve over time (Wall, 2004). Therefore, 'blanket' statements as to the 'autisms' should be avoided.

Of late, many theorists have begun to focus on the underlying social impairments in interaction, communication and imagination, as well as the pattern of repetitive preoccupations, the need for 'sameness' and difficulties tolerating change (Attwood, 2007; Mash & Wolfe, 2005; Welton, 2004). Although these dimensions are discussed separately in this paper, they have continuous interaction and should not be perceived as separate entities. A suggested visual representation of the triad of impairments is illustrated below:

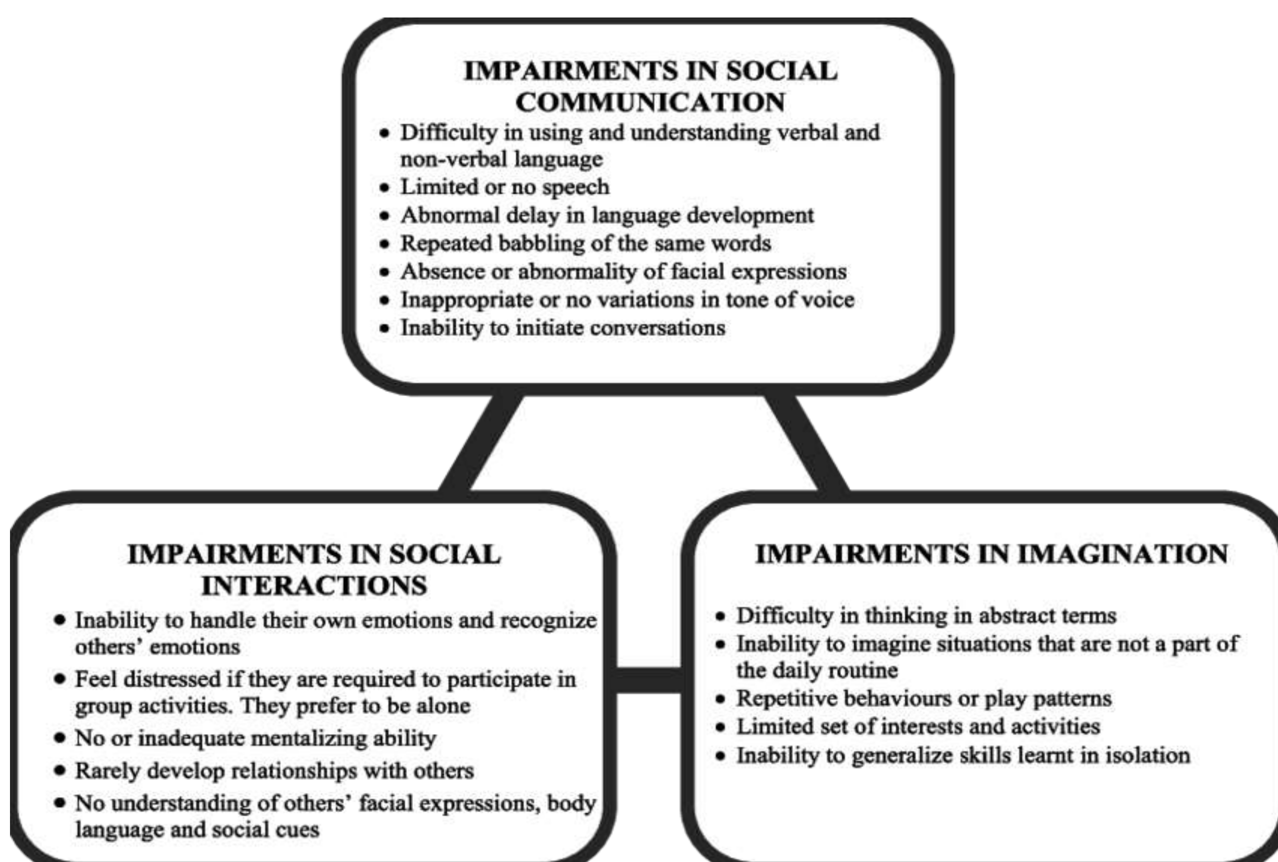

Figure 1: Triad of Impairments
Source: https://www.researchgate.net/figure/The-triad-of-impairments-in-Autism-Spectrum-Disorder-ASD_fig1_299565400

One of the core characteristics of autism is a qualitative impairment in social interactions. It is suggested that, because individuals with autism process social information in atypical ways, children on the spectrum have difficulty in developing social relations that are age-appropriate (Mash & Wolfe, 2005). This results from an impaired ability to engage appropriately in both verbal and non-verbal communication. They experience difficulties in

understanding and using non-verbal behaviour to regulate social interactions, such as maintaining eye contact, reading facial expressions and understanding body gestures (American Psychiatric Association, 2013). This inability to understand non-verbal communication influences their poor capacity to understand other people's states of mind, such as understanding others' feelings and emotions (Attwood, 2007). In addition, due to their limited ability to understand social rules and expectations for social situations, such as turn-taking in games and conversations, as well as contextualising social actions, intent and communication of others, these individuals tend to become socially withdrawn (Welton, 2004). Although they have a high desire for social relationships due to being constantly isolated, it is suggested that these individuals develop rigid patterns of interactions (Van Hees, Moyson, & Roeyers, 2015; Wall, 2004) that result in them being described as aloof, stilted and indifferent of others (Koudstaal, 2011; Van Hees et al., 2015) which further isolates them.

In light of the above, it could be expected that males who are diagnosed during their adulthood experience various challenges in relation to social interactions and forging relationships during adolescence. However, little is known about how others perceived their impairments in social interactions when they were children and why a diagnosis of autism was not considered during the earlier stages of their development. Several theorists and writers who themselves are adults with ASD have referred to the role of 'masking', pretending, and 'mimicking (others)' as strategies that are employed by adults who, whilst experiencing themselves as socially 'different', made attempts to 'fit in' (Hendrickx, 2015; Holliday-Willey, 2015). It is also prudent to note that several researchers suggest that these skills can be developed, especially through intervening at a young age, which may reduce the gap in social skills that these individuals experience compared to those regarded as neuro-typical (Ozonoff et al., 2010; Rogers et al., 2014).

Kanner (1943) was amongst the first to highlight the benefits of early diagnosis and education for children with autism. Similarly, more recent studies have attested to the benefits of early diagnosis as it allows for determining interventions appropriate for the individuals' needs (Hendrickx, 2015; Khan et al., 2012; Koegel, Koegel, Ashbaugh, & Bradshaw, 2014; Rogers et al., 2014; Wong et al., 2015). Due to limited knowledge about the disorder and the absence of support systems in place, late-diagnosed individuals miss the opportunity to receive early interventions that reduce symptomology and optimize developmental outcomes from childhood to adulthood (Berg, Acharya, Shui, & Msall, 2017). Research conducted by Aldred,

Green and Adams (2008) consistently attested to the crucial importance of both early interventions in socially-oriented skills and developmental behaviour of children. The implications from these research findings indicate a need to explore adulthood diagnosis of autism among males and the impact it had on the social aspects of their lives. In the absence of an 'earlier' diagnosis, it is possible that these individuals have been disadvantaged through not receiving support and directed interventions during childhood and adolescence, when interventions may have had a positive impact in their ability to not just establish relationships, but to utilise some of the skills to develop and sustain these relationships.

Language and communication difficulties are also a defining characteristic of autism. Individuals with ASD experience challenges in understanding different forms of communication, and in expressing themselves. For many, in the context of their semantic-pragmatic challenges, there are direct and underlying challenges in representing thoughts, feelings and experiences in conventional language (Mandy et al., 2012) They are also described as experiencing difficulties in the ability and willingness to initiate and sustain conversations (American Psychiatric Association, 2013; Van Hees et al., 2015) as they are often unaware of the rules and expectations of conversations – for example, that conversations are between two or more people and are oscillating in their nature (Wall, 2004). It is also at times suggested that their underlying lack of awareness of the fact that conversations require talking about topics outside of their specific areas of interest, results in them being socially awkward, uncomfortable, stressed and often exhausted and withdrawn, while others perceive them as being boring or frustrating (Wall, 2004).

In addition, Mash and Wolfe (2005) state that individuals with autism tend to take a literal sense of what is communicated to them. This concrete ideation is, in qualitative terms, unsettling and has confounding impacts on the individual's attempts to engage appropriately. For example, the idiom "it's raining cats and dogs" could be interpreted by an autistic person as a direct expression of cats and dogs falling from the sky. Their inability to distinguish between jokes and teasing makes them vulnerable to being bullied, and it also compromises their relational experiences (Welton, 2004). This causes distress, misunderstanding, and even anger and social suspicion (Hendrickx, 2015).

Considering that the social aspects of communication are one of the fundamental ways of interacting with others, indicators of qualitative impairments in social communication are likely to be present from early childhood and, with correct assessment, may be distinguishable

from simple speech and language difficulties. Many individuals with a condition on the autism spectrum may have little to no problems with expressive language but have confounding challenges in the social aspect of communication (American Psychiatric Association, 2013). It is perhaps possible that males who received a late diagnosis presented with what was then understood (by parents, educators or other significant adults) as difficulties in social communication during their childhood. These difficulties may also have contributed to additional vulnerabilities (symptoms) which may have been misunderstood or overlooked. An understanding of other additional vulnerabilities they were predisposed to as a result of the qualitative impairments in social interaction and communication should be explored.

A further aspect of the autism 'triad' of impairments are difficulties in social imagination. Attwood (2007) asserts these challenges are often visible in the way in which individuals with autism struggle to adapt what they say or do, or how they react, as a result of the needs, states and feelings of others. Adapting how one behaves or communicates because of the ability to 'imagine' the experiences, feelings and needs of others (Attwood, 2007) is a core facet of social reciprocity. Amongst other difficulties, individuals with ASD have challenges imagining alternative situational outcomes or intuiting and 'reading' the impact of their actions in social situations. This could result in individuals on the autism spectrum appearing to rely on routines as a strategy of avoiding ambiguity and uncertainty in situations that are anxiety provoking (Mash & Wolfe, 2005). Changes in routine may be perceived as disorienting and frightening for individuals who lack an ability to imagine an alternate sequence of events. According to Wall (2004), the state of monotony achieved through routine and repetitive behaviour provides a sense of comfort and security for individuals with autism who find the world confusing and anxiety provoking. Repetitive behaviour is one of the core diagnostic features of autism in the DSM-V (American Psychiatric Association, 2013). Therefore, understanding whether males diagnosed during their adulthood also employ repetitive behaviour as a means of reducing anxiety or whether they engage in strategies that disguise these autistic traits is important. Furthermore, it is also important to explore whether other conditions, such as Obsessive-Compulsive Disorder (OCD), were misdiagnosed amongst late diagnosed males to account for the repetitive behaviour evident in individuals with autism.

In relation to the triad of impairments, individuals on the autism spectrum have been described as lacking a strong theory of mind, with authors such as Hill and Frith (2003), describing it as mind-blindness. According to Attwood (2007, p. 112), the psychological term

> Theory of Mind (ToM) means an ability to recognize and understand thoughts, beliefs, desires and intentions of other people in order to make sense of their behaviour and predict what they are going to do next.

Their limited ability to understand that others think differently from themselves, inability to read other's behaviour by observing external cues, and unawareness of others' feelings, contributes to an impaired ability to be empathetic and may add to their difficulties related to social interaction and communication (Attwood, 2007). Attwood (2007, p. 112) describes this as an inability of "putting oneself in another person's shoes".

However, it is necessary to note that this inability to appropriately show empathy when social situations necessitate, does not mean the absence thereof. According to Attwood (2007, p. 114),

> to imply an absence of empathy [implies] that the person does not recognize or care about the feelings of others. The person does care, very deeply, but may not be able to recognize the more subtle signals of emotional states or 'read' complex mental states".

Furthermore, Jamieson (2008, p.80) makes the important link between Theory of Mind and attachment amongst individuals on the autism spectrum by stating that:

> Despite attachment security, these children seem to have mentalising difficulties and although they seem to have emotional empathy they have poor cognitive empathy… children on the spectrum have a 'cognitive empathy deficit disorder'… children with AS have and share other's emotions due to secure attachments but that they lack the skills and understanding of how to express their sense of empathy due to neurological deficits in mentalisation.

Having said that, authors such as Attwood (2007) state that there are various strategies that can improve the Theory of Mind, such as Theory of Mind computer programs, social stories and comic strip conversations. It was also found that interventions aimed at improving the Theory of Mind that were administered to children were effective and had socially viable outcomes (Eason, 2014). This further highlights the importance of early intervention in improving their overall functionality and life outcomes. Furthermore, in instances where these challenges were prevalent, there is a need to understand why these

impairments were not considered as being diagnostic. On the other hand, if the impairments were diagnosed as something else, a further understanding of the underlying reason for the misdiagnosis is needed in situations where autism was only identified in adulthood.

Conditions on the autism spectrum are currently referred to as neuro-developmental disorders as the impairments stem from atypical neuro-development in the infant's neurobiology. The development of the child with autism appears to deviate markedly from that of a neuro-typical or non-ASD child (American Psychiatric Association, 2013). Importantly, while these conditions are neurobiological, they can be behaviourally defined (American Psychiatric Association, 2013; Mandy et al., 2012). Each and every presentation of a condition on the spectrum is unique from one person to another, and over the last forty years, there have been a multitude of suggested casual factors, many of which have been found to be incorrect (Bettelheim, 1967; Dodd, 2005; Taylor *et al.*, 1999). What is known is that there is a broad heterogeneity in the clinical presentation, which is linked to genetic diversity that is seen in each individual's symptomology (Eapen & Clarke, 2014). This will naturally make the presenting clinical 'pictures' of autism difficult to describe, classify, understand and treat as both a single 'category' or single disorder. In this way, it can be assumed that the experience of having autism are diverse and will vary extensively from individual to individual.

2.1.2. Development and Course

Initial indicators of autism tend to appear during the early months of children's development. According to the American Psychiatric Association (2013), symptoms can be identified as early as birth. In cases where the developmental delays are severe, symptoms are noticeable earlier than twelve months, whereas, when symptoms are subtle, autism may only be recognized later than twenty-four months (American Psychiatric Association, 2013; Christensen et al., 2016). In most cases, ASD deficits become increasingly noticeable during the second year of life (American Psychiatric Association, 2013) or before the age of five years (United States Centers for Disease Control and Prevention, 2009). Generally, children with conditions on the spectrum do not experience a period of normal development. Descriptions of initial presenting symptoms include developmental delays or losses in language and social skills (Bryson et al., 2007; Ozonoff et al., 2010). In rare instances, children may experience a relatively normal pattern of development before the age of two years, however, development seems to stagnate before the age of three (American Psychiatric Association, 2013; Goldberg

et al., 2003; Moolman-Smook, Vermoter, Buckle, & Lindenberg, 2008; Ozonoff et al., 2010). This tendency of normally developing children to regress in their development was previously referred to as childhood disintegrative disorder but specific criteria had to be met, such as disintegrating occurring by the age of 6 months (American Psychiatric Association, 2013).

Several studies (De Giacomo & Fombonne, 1998; Ozonoff et al., 2010; Young, Brewer, & Pattison, 2003; Zeleke et al., 2017) have highlighted early indicators of autism identified by parents that cause concerns and lead them to seek professional help during early stages of development. These early indicators include abnormalities in social responses such as sharing affect (Ozonoff et al., 2010), poor eye contact, not responding to their name or parent's voice, delays in language and speech development, extremes of temperament ranging from pronounced irritability to excessive passivity, and difficulties regulating behaviour (De Giacomo & Fombonne, 1998; Ozonoff et al., 2010; Young et al., 2003; Zeleke et al., 2017). However, some of the abnormalities reported may not be specific to autism and can be the result of common medical conditions, infectious diseases, auditory deficits and intellectual disabilities (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; De Giacomo & Fombonne, 1998). Goldberg et al. (2003), Moolman-Smook et al. (2008) and Ozonoff et al., (2010) state that in some cases, parents have also reported that their apparently normally developing children regress in their development and lose already developed skills, such as language, between the ages of two and four years.

2.2. Gender-related Diagnostic Issues

Autism has been described as a gender biased disorder, with authors such as BaronCohen, Knickmeyer and Belmonte (2005) describing it as a phenotype representation of the exaggerated form of the male brain. This may be due to the fact that autistic people employ a mechanistic approach to understanding the world that is an exaggerated version of what may be socially accepted as the norm for boys in some contexts. Within clinical samples, females with autism tend to have intellectual disability, therefore, in cases where language delays and intellectual impairments are not recognized, these females are overlooked for diagnosis as the manifestation of social and communication impairments may be more subtle (American Psychiatric Association, 2013). As such, the likelihood of males being diagnosed with ASD is greater than that of females. The commonly reported estimate of the overall sex ratio of males to females is four to one (Fombonne, 2009; Shane, 2009). However, although the disorder has been described as being biased towards males, there is a significant portion of males who only

receive a diagnosis in their adolescence and adulthood years (Christensen et al., 2016; Lewis, 2016).

Various factors have been linked to differences in ASD diagnosis amongst individuals of different sex. These factors include differences in clinical symptoms, biological components like genetic differences between males and females, the diagnostic process, and behavioural and communicative factors (Shane, 2009). For example, gender differences that children begin to be socialized into during infancy, such as girls using empathy to understand the world while boys understand and respond using mechanistic approaches to understand rules that govern systems within the world (the extreme version of this is also a core feature in autism), increase the prospect of boys receiving an ASD diagnosis in instances where the behaviour is exaggerated to the extent that it becomes pathological (Baron-Cohen et al., 2005). In addition, the tendency for girls with ASD to have an intense interest in people, as opposed to objects, which is characteristic amongst males with autism, further contributes to females being overlooked for a diagnosis of the disorder (Hendrickx, 2015).

In addition, girls have been found to have less impairment in communication and social skills (McLennan, Lord, & Schopler, 1993; Sedgewick, Hill, Yates, Pickering, & Pellicano, 2015). This has been attributed to the fact that, to compensate for their difficulties with understanding other's thoughts and challenges with social interactions, women with autism may apply learned strategies to help them navigate social situations (Hiller, Young, & Weber, 2015). According to Bargiela et al. (2016) and Mandy et al. (2011), women on the autism spectrum learn various strategies, from social media and others, on how to engage in social interactions in order to appear typical. This tendency to engage in masking and imitation is a strategy to camouflage their impairments. As a result, this increases the probability of girls being misdiagnosed with conditions such as Pervasive Developmental Disorder (Bargiela et al., 2016; Gould & Ashton-Smith, 2011). However, it has been noted that these studies (BaronCohen et al., 2005; Gould & Ashton-Smith, 2011) have compared boys and girls with different cognitive functioning, which may confound their findings.

Although useful for camouflaging their autistic impairments and their lack of a strong theory of mind, this approach of creating scripts for social interactions comes at a cost. According to the American Psychiatric Association (2013) and Bargiela et al. (2016) individuals who engage in masking experience difficulties in novel situations and tend to become unusually anxious. In addition, Hull et al. (2017) state that these individuals experience

challenges in their self-perception as they develop negative attitudes and emotions towards themselves, feeling that their relationships are based on deception as they are forged through portraying a false self-presentation. Without adequate social skills training, individuals who receive a late diagnosis are left with limited tools, such as masking, to help them navigate through the social world with their difficulties. This draws attention to how a late diagnosis can further negatively impact individuals' identity and self-perception, therefore, it is imperative that more knowledge is gained about the factors that lead to late diagnosis and how it impacts individuals.

2.3. Factors Related to Delayed Diagnosis

2.3.1 Factors related to delayed diagnosis

Clinical symptoms of autism tend to vary in terms of their presentation and intensity from one individual to another, resulting in difficulties in diagnosing the disorder. According to Baghdadli et al. (2003) and Mandell, Novak and Zubritsky (2005), children severely impaired by autism tend to be diagnosed earlier than children with milder forms of the disorder, such as Asperger's Syndrome or high functioning autism. Furthermore, individuals with conditions on the autism spectrum also tend to have other comorbid conditions such as anxiety, attention deficit and hyperactive disorder (ADHD) (American Psychiatric Association, 2013; Hendrickx, 2015; Leyfer et al., 2006), and specific phobias, like fear of needles (Leyfer et al., 2006). Due to these co-occurring conditions, these individuals tend to be misdiagnosed with the comorbid condition, such as ADHD, as a primary diagnosis (Davidocitch, Levit-Binnun, Golan, & Manning-Courtney, 2015; Hendrickx, 2015) and in some cases, receive a misdiagnosis of intellectual disability (Hurlbutt & Chalmers, 2002).

The period between identification of early indicators of ASD and the subsequent diagnosis may also be a contributing factor for late diagnosis. According to Zeleke et al. (2017), the average age for initial symptoms for autism becoming evident is three years old. However, the average age for diagnosis ranges between five to six years for those on the severe end of the spectrum (Chamak & Bonniau, 2016; Frith, 1989) and nine to fourteen years for those described as presenting with milder symptoms, such as high functioning autism (Attwood, 1997; Chamak & Bonniau, 2016). During the period between identifying the initial symptoms and receiving a formal diagnosis, parents describe experiencing difficulties, upon initial referral, with primary health care providers not being able to identify the children's symptoms as being reflective of autism (Kishore & Basu, 2011; Young et al., 2003). Furthermore, there

were difficulties in accessing psychiatric and paediatric facilities (Kishore & Basu, 2011; Zeleke et al., 2017). In instances where these services were accessed, some psychiatrists would refuse to give a formal diagnosis of autism due to the stigma surrounding the disorder (Kishore & Basu, 2011) such as nurses believing that it is caused by lineage curses or cursed ancestral spirits (Bakare et al., 2009).

Cultural beliefs were also found to be involved in the decision-making process regarding seeking professional advice for ASD symptoms, which may also be a contributing factor to delayed diagnosis (Kishore & Basu, 2011; Mthombeni & Nwoye, 2018; Zeleke et al., 2017). For example, Zeleke et al. (2017) found that parents attributed ASD to spiritual causes, therefore, professional advice was not sought. Similarly, in their study exploring Black South African caregivers' understanding and responses to children with ASD, Mthombeni and Nwoye (2018, p.9) found that ASD symptoms were understood and attributed to supernatural explanations known as "ukufa-kwaBantu". According to this study, this animistic theory of ASD as resulting from a displeasure from the ancestors, for factors such as having had the child outside of wedlock and/or not appeasing ancestors through performing certain cleansing ceremonies, resulted in caregivers seeking traditional healing methods to ameliorate symptoms. These culturally specific factors may further contribute to late diagnosis, highlighting the need to explore context-related factors that result in autism being diagnosed during adulthood.

Other studies describe low socio-economic status (Mandell et al., 2009; Rosenberg, Landa, Law, Stuart, & Law, 2011; Zeleke et al., 2017) difficulties in accessibility of health care services (Kishore & Basu, 2011; Zeleke et al., 2017), and ethnic factors that influence the perceptions and understanding of atypical development (Kishore & Basu, 2011; Mandell et al., 2009; Zeleke et al., 2017), as further contributing factors to delayed diagnosis of ASD. This was also observed in a study by Mthombeni and Nwoye (2018) as they found that when caregivers of children with ASD felt financially burdened by treatment processes, they often opted for indigenous treatment methods over mental health professionals. Notably, there was inconclusive evidence as to whether this was motivated by cultural beliefs, financial implications or both. It is also imperative that one is cognisant of the fact that, in the aforementioned studies, delayed diagnosis referred to a diagnosis made after the age of six years. Limited information was found regarding factors that result in individuals not receiving a diagnosis until adulthood.

Bastiaansen et al. (2011) state that the reasons for delayed diagnosis among adults who are diagnosed with autism during adulthood is unknown. It has been speculated that some of the contributing factors include the use of compensatory strategies to camouflage deficits (Bargiela et al., 2016; Bastiaansen et al., 2011); or parents managing, minimising and/ or avoiding the problem until these individuals are in situations that require them to use these deficient skills. For example, Duquette, Orders, Fullarton, & Robertson-Grewal (2011) report that in some instances parents view their children's autistic traits as not being problematic but rather perceive their child as being gifted. Furthermore, the perceived intelligence of these individuals is believed to manifest as a result of their tendency to have narrow interests and devotion to certain topics, resulting in parents not perceiving these autistic traits as necessitating help from mental health professionals (Duquette et al., 2011). Horlin et al. (2014) add that while a delay in diagnosis has no immediate financial implications, it was associated with an increase in the number of ASD symptoms, thus indirectly impacting the overall financial burden among these individuals and their families. Although these assumptions give us insights into possible contributing factors to adulthood diagnosis of autism, all the studies that provide insight into the issue were conducted in high-income countries. Therefore, it is imperative to explore whether similar factors are associated with a delayed diagnosis within global south countries such as South African.

2.3.2. Factors Contributing to Late-Diagnosis of Autism in Males

Interestingly, although there are a significant number of individuals, the majority of whom are males, who are only diagnosed with autism during their school years (Christensen et al., 2016) and adulthood (Lewis, 2016), little to no research has been conducted to understand the underlying reasons for their late-diagnosis and the impact it has had. This can partly be attributed to autism being described as representing the extreme of the male brain (BaronCohen et al., 2005), leading research on late diagnosis to be focused on studying the experiences of females (Bargiela et al., 2016; Lehnhardt et al., 2016) as they receive a diagnosis during their adulthood. Only one study was found (Lewis, 2016) that examined the experiences of male individuals. Although there is no set phenotype for males and females with autism, the focus on females who receive a diagnosis during adulthood has resulted in a gap in the literature that explores the same issue in males and how this may differ from individuals who are diagnosed during earlier stages of development.

Although in the past thirty years, there has been an improvement in the identification and refinement of the diagnostic process, for example, by using "multidisciplinary assessment clinics, identification and validation of various screening tools and diagnostic instruments" (NICE, 2012, p. 81) for children with autism, no equivalent clinics, assessment instruments and diagnostic tools have been developed for adults who present with conditions on the autism spectrum. Furthermore, according to Abubakar et al. (2016), Franz et al. (2017) and NICE (2012), the shortage of clinicians who are trained in identifying and diagnosing autism has further increased the number of individuals who are misdiagnosed with other conditions. In global south countries such as South Africa, these issues are further exacerbated and made more complex by the lack of resources (Abubakar et al., 2016; Franz et al., 2017). This further indicates the importance of exploring the experiences of males who were diagnosed with autism during their adulthood to uncover the extent to which these context-specific factors contribute to the late diagnosis.

In addition, the use of the DSM as a diagnostic tool has also been found to contribute to the late diagnosis of autism. According to Baron-Cohen et al. (2009), fifty to sixty percent of individuals with Asperger's disorder were likely to remain undiagnosed when the DSM-IV-TR diagnostic criteria were used. Mayes et al. (2014) further state that the amended criteria for ASD diagnosis in the DSM-V are likely to lead to the under-diagnosis of individuals previously diagnosed with Asperger's and Pervasive Developmental Disorder which may further contribute to the increase of undiagnosed adults. This has been attributed to the DSM-V having increased specificity for diagnosing conditions on the autism spectrum, and poor sensitivity to symptoms of those individuals who are considered as falling towards the mild end of the spectrum (Hazen et al., 2013; Kent et al., 2013). Although this partially explains why individuals with high functioning autism may receive a late diagnosis, there is still not enough literature that explores this from the perspective of males.

2.4 Challenges and Impact of Receiving an Adulthood Diagnosis of Autism

Despite the reported positive outcomes of early interventions that have previously been discussed, Chamak and Bonniau (2016) caution that, although they improve functionality, severely impaired individuals do not experience much improvement. Furthermore, these authors state that the heterogeneity in life outcomes is linked to the characteristics of the disorder. Individuals with milder symptoms, such as those diagnosed with Asperger's disorder

or high functioning autism, have good overall life outcomes. In addition, Howlin, Mawhood and Rutter (2000) state that cognitive ability and language skills are the common predictors of positive life outcomes. Although early interventions may have improved the abilities of individuals diagnosed in their adulthood, other factors that contribute to their overall life outcomes may have acted as a protective factor which may potentially result in them having positive life outcomes.

It is also important to consider that life outcomes go beyond symptomology and diagnostic status, and include other factors such as employment, independence, level of social contact and residential factors. According to DePape and Lindsay (2016) adults with autism experience difficulties in social outcomes, obtaining and maintaining employment, and continue to be dependent on their family, relying on them for support. Within the workplace, they experience difficulties with information processing and multi-tasking, inability to tolerate injustice, inflexibility in the approach of executing tasks and difficulties adapting to the work environment, to mention a few (Hendrickx, 2009, 2015). It is estimated that the impact of under-recognition and inadequate treatment of autism results in eighty-eight percent unemployment rate (Barnard, Harvey, Potter, & Prior, 2001). This inability to obtain and sustain employment may further hamper their ability to achieve independence, even among those considered as more high functioning. According to Leyfer et al. (2006), individuals who are diagnosed late have been found to be at high risk of depression, anxiety and suicide. Without understanding the underlying reasons for their challenges, it is likely that their failure at meeting normative outcomes further negatively impacts their mental health.

In addition to the above-mentioned challenges, individuals who receive a late diagnosis have been found to experience various other challenges. Lewis (2016) reported that these adults struggle to find interventions and support services that are for adults with high functioning autism. Similarly, Eaton (2012) states that, once adults receive their diagnosis, no further expert knowledge is provided for them or their families regarding the way forward. This may have a devastating effect, especially for those who struggle to live independently. Furthermore, in contexts such as Sub-Saharan Africa, characterised by resource scarcity, there is little to no knowledge regarding transitional arrangements from school-age to adulthood, including those who were diagnosed with autism in early childhood (Franz et al., 2017).

Equally important, late-diagnosed adults with autism have also been reported to experience issues with conflicting identity before, during and after their formal diagnosis

(Lewis, 2016). These conflicting identities are described as 1) pre-identity alignment, whereby, individuals have difficulties understanding why they are different; 2) transitional identity alignment, which involves individuals self-identifying as autistic and beginning to accept their diagnosis; and 3) post-identity alignment, which refers to when these adults learn how to master their new identity and view themselves from a positive stance (Lewis, 2016). DePape and Lindsay (2016) describe varied experiences relating to identity, with other individuals experiencing conflicting identities following their diagnosis, while others felt indifferent. It is evident that realizing a diagnosis in adulthood not only affects individuals in terms of accessibility to interventions but may also affect their self-perception and identity.

It has also been found that receiving an adult diagnosis of autism has positive connotations. According to Hendrickx (2015), individuals who receive a late-diagnosis have the advantage of being taken more seriously by service providers and have access to practical support. Receiving a diagnosis in adulthood also improves their self-esteem and confidence as they gain more knowledge about themselves and their condition. Furthermore, uncovering that the challenges they experienced during their earlier stages of development and their feelings of being different are a result of their condition reportedly brings about a sense of relief (Hendrickx, 2015; Lewis, 2016). This suggests that although receiving a diagnosis during adulthood has negative implications with regards to maximising gains made from early intervention, there are benefits to gaining a formal diagnosis regardless of when it occurs.

Once a diagnosis of autism has been confirmed, individuals decide who they want to disclose their condition too. The way in which the diagnosis is experienced was found to be influenced by the level of acceptance of the diagnosis by significant others (Hendrickx, 2015; Hurlbutt & Chalmers, 2002; Wylie, 2014). According to Hurlbutt and Chalmers (2002), latediagnosed adults encountered difficulties with their families struggling to accept their diagnosis. With females, the disclosure of their condition brought about feelings of disbelief, as others claimed that they could not have autism because they were 'too capable' (Hendrickx, 2015; Wylie, 2014). This results in difficulties in accepting their own diagnosis as they are not receiving support from their families. This may potentially have harmful effects of their mental wellbeing, as it has been found that acceptance of a diagnosis of autism by external sources such as family, friends and society, reduces the symptoms of stress and depression (Cage, DiMonaco, & Newell, 2017).

On the other hand, a number of individuals who choose to share their diagnosis become advocates for the disorder. Hendrickx (2015) states that this allows them to share knowledge and increase understanding of their condition and allows them to celebrate their uniqueness. However, in some instances, they become reluctant to disclosing to others about their condition. According to Van Hees et al. (2015), some of the underlying reasons for individuals' resistance to disclosing about their diagnosis include a lack of knowledge about the disorder, ignorance and generalizations surrounding it, and concerns about privacy. This may be the fundamental motivation for those who become advocates, as they may view it as a strategy to address the lack of knowledge surrounding the disorder, for both themselves and those around them which may increase the likelihood that they will be accepted for who they are.

2.5. Conclusion

This chapter provided a review of relevant literature, showing how recently, the prevalence rate of autism has experienced a remarkable increase. The way in which the disorder presents itself in individuals is varied. Wall (2004, p. 8) states that "No two children with autism will present the same characteristics to the same degree, as no two children are the same". This draws attention to the fact that each individual with autism has a combination of unique characteristics and their lived experiences will differ from one person to another. Furthermore, the level at which these characteristics may be distressing varies from one person to another, with some individuals learning strategies to deal with their impairments.

Although there are studies investigating the experiences of these individuals, the reports have focused on individuals who received a diagnosis in their early stages of development. Therefore, it is evident that there is a need to study and account for the experiences of those who receive a diagnosis during their adulthood, as the current literature is not all-encompassing. This late diagnosis may reflect the hidden nature of the condition, thus, there is a need to investigate the nature of the initial presenting symptoms of individuals, particularly males, who receive a diagnosis during their adulthood. This may be the starting point in minimizing late-diagnosis of conditions on the autism spectrum and providing appropriate support for these individuals. Furthermore, due to context-specific factors influencing the time of diagnosis, it is important to understand the disorder within the South African context to improve the current diagnosis process and ensure that autism is diagnosed during early stages of development. Lastly, it is also important that studies be conducted that explore how to

recognise ASD in adult males as well as investigating the support services that are needed following the diagnosis.

CHAPTER THREE: RESEARCH METHOD

This chapter describes the research method that was applied to the study and elucidates the way in which the study was conducted. This includes the research design, the context in which the study was conducted, the participants and sampling method, how the data was collected and the method of analysis that was used to synthesise and analyse the data. The chapter will end with a description of the ethical considerations undertaken and a section addressing reflexivity will be provided.

3.1. Study Design

This study applied the exploratory qualitative research design as a method of inquiry. Levitt et al. (2018) describe qualitative research as an approach that provides a detailed analysis of expressed experiences. It aims to understand how people socially construct meanings and perspectives. Maxwell (2013) adds that qualitative research explores the reciprocal relationship between individuals' immediate environment and the construction of individual meanings and perspectives which aligns with the research questions. This research design was suitable for this study because it allowed the researcher to explore a phenomenon that has not been extensively studied in the South African context. Furthermore, this approach has enabled for an in-depth description and understanding of the participants' experiences.

3.2. Description of Data Collection Site

The study was conducted at the Neurodiversity Centre. The centre is located between Paarl, Stellenbosch and Franschhoek, in the Western Cape, South Africa. It was established in December 2016 and caters for children and adults with neurodevelopmental challenges, by providing multi-disciplinary and advocacy services (Neurodiversity Centre, n.d.). The centre currently has over one hundred clients, sixty percent of whom are white, thirty percent selfclassify as coloured and ten percent are black African. [3]

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[3] The total of the South African population is made up of 79.4 % Black Africans, 9.2% White, 8.8% Coloured and 2.6% Indian or Asian (World Population Review, 2019). This is important to take note of as the clients at the Neurodiversity centre are predominantly White (who are the minority of the total South African population), while black Africans (being the majority of the South African Population) are the minority in the client base of the centre. This draws attention to how the majority of the South African population cannot access private health care facilities such as the Neurodiversity centre, with economic constraints being one of the main contributing factors (Statistics South Africa, 2017).

The Neurodiversity Centre was selected as the site for this study as it specializes in providing services for social communication challenges and autism spectrum disorders. Thus, participants recruited for the study who met the inclusion criteria were easily accessible. Although the centre caters for predominantly white middle-class clients, the study hoped to include individuals from all demographic backgrounds. However, due to challenges in recruiting participants, the sample of the study was not representative of the demographics of South Africans.

3.3. Description of Participants

The study aimed to recruit ten participants who were clients at the Neurodiversity Centre. It has been suggested that in a qualitative study among a homogenous group, data saturation is reached when there are between eight to ten participants (Coenen, Stamm, Stucki, & Cieza, 2012; Namey, Guest, McKenna, & Chen, 2016). Similarly, this study hoped that hoped that 10 participants would be enough to reach data saturation. To be considered for participation, the participants had to have received a formal diagnosis of ASD and self-identify as autistic males. They had to be between the ages of twenty-five and sixty-five years. In addition, participant selection was limited to those males who received their diagnosis within twelve months prior to this study being conducted. This was to ensure that participants had enough life experience following diagnosis and, thus were able to provide rich data that was pertinent to the study, about their experiences before and after diagnosis. The study aimed to have an exclusion criterion that excluded individuals who had received their diagnosis less than twelve months prior to being interviewed from the sample. However, it is important to mention that two participants had been diagnosed six months prior to being interviewed for the study, while two others had been diagnosed less than three months prior to being interviewed for the study, and due to limited available prospective participants, they were included.

APPENDIX G: DEMOGRAPHIC INFORMATION RELATED TO PARTICIPANTS

Table 1.1. Table Representing the Demographical Information of the Participants

Participant's Pseudonym	Age at time of interview	Age at time of diagnosis	Year of diagnosis	Marital/ partnership status	Number and age of children	Living arrangements	Highest level of education	Qualifications	Employment status
Albert	35	32	2015	Single	None	I live in my parent's flat. They assist me with minor housework and transport.	Bachelor's Degree	Bachelor of Science: Computing	Unemployed, student
Anthony	28	26	2016	Single	None	I live with my parents. I am dependent on my parents as I am unemployed and also on my friends for things like transport	Information not available	Information not available	Unemployed

Boris	47	47	April 2018	Married	Children: 1; Ages: 9	I live with my wife and child, no assistance	Information not available	Information not available	Self-employed
Francois	41	40	Feb 2018	Married	Children: 3; Ages: 2, 7 and 9	I live with my wife and kids in our own home, no assistance	National Diploma	National Diploma: Information Technology	Employed
Hennie	35	33	2016	Married	No children	I live with my wife, I do receive advice from psychologist and wife in dealing with people	Project Management NQF8. MBA Essentials NQF8.	I do not have a degree but have a lot of certificates. I am planning to do my BCOM – Financial Management.	Employed
Hugo	44		2017	Married	Children: 2; Aged: 16 and 19	I live with my wife and children, no assistance	Technicon qualification	Technicon qualification	Employed
Luke	39	35	2014	Single	None	I live alone, I receive financial assistance from my mother	National Diploma	National Diploma: Information Technology	Employed

Nicholas	56	56	2018	Married	Children: 3; Ages: 23, 14 and 8	I live with my wife and children, no assistance	Honours degree	Undergraduate degree: Marketing Management Honours degree: Business	Self-employed
Mendel	48	44	2014	Married	Children: 4;	I live with my wife and children, I get assistance from my wife	Grade 12	High School certificate	Self-employed
Philip	64	64	February 2018	Married	Children: 1; Age/s: 18	I live with wife and son. Don't receive or need assistance yet	Post Graduate Diploma, Post Graduate Certificate and MSc	Degree in Engineering, Media, Film & Television, Marketing and Humanities equivalent.	Unemployed

3.4. Sampling

The participants were sampled using the purposive sampling technique. According to Neuman (2014), purposive sampling is a non-random sampling technique that involves selecting participants who possess unique traits that will be useful for the study. Notably, this is based on the subjective judgment of an expert. With this in mind, the aims of the study were discussed with the clinicians at the Neurodiversity Centre. It was then agreed that prospective participants who were identified as being suitable for the study, would be approached by the clinicians as they have already established relationships with the clients as well as for confidentiality reasons. This was also important, given that autism is characterized by a qualitative impairment in social interaction and social communication skills (American Psychiatric Association, 2013) and being approached by a stranger may exacerbate the anxiety experienced by prospective participants. In addition, the clinicians were aware of which clients would be suitable for the study. Therefore, the purposive sampling technique was used in this study, as it allowed the clinicians to select participants who would provide in-depth descriptions of their experiences and information that was pertinent to the study.

Once prospective participants had been identified by the clinicians, they were individually contacted by the training coordinator at the centre informing them about the study. Those who showed interest were then directly contacted by the researcher inviting them to participate. Although the researcher contacted twenty prospective participants, not all of them agreed to partake. This was a result of various reasons such as poor response rate to interview invitations, difficulties in arranging interview times and venues that suited participants, and sometimes, participants agreed to be interviewed and then withdrew at the last minute. As a result, the initial target of twelve participants proved to be difficult to reach and the researcher opted to include four participants, who had been diagnosed less than twelve months prior to the data collection process, to make a total of ten participants.

3.5. Data collection

For the researcher to adequately explore the experiences of males diagnosed in adulthood with conditions on the autism spectrum, life history interviews were conducted with the participants. Jupp (2006) states that life history interviews are a qualitative research method to gather data that requires participants to provide an in-depth personal account of their life experiences. This method was appropriate for this study as it created a platform whereby

participants could reflect on their life experiences using their own words and timelines. The interview schedule was used as a guide to conduct the interviews, which were semi-structured in nature and involved the researcher asking each participant predetermined questions. Any themes or information given in response to the open-ended questions served as a guideline for further probing by the researcher, at their own discretion as suggested by Neuman (2014). A voice-recording device was used to record the interviews.

The interview schedule contained a set of open-ended questions that were asked during the interviews (see Appendix E). The interview schedule used by Bargiela et al. (2016) was used as a guide to developing a semi-structured questionnaire informed by the objectives of the study. This particular study was used as a guide for developing the interview schedule as Bargiela et al. (2016) conducted a similar study to the current research, albeit they investigated the female phenotype of women diagnosed with ASD in adulthood. Therefore, it was deemed necessary to use an already established interview schedule as a guide to the type of questions that would capture the data needed for this study. The questions were developed with the assistance of the supervisors and the manager of the Neurodiversity Centre, both of whom are clinical psychologists and experts in the field of autism. A roleplay of an interview was conducted by the researcher and a clinician from the Neurodiversity Centre. This tested whether the questions in the schedule were appropriate for the study and allowed the researcher to prepare on how to engage with participants during the interview.

Considering the nature of autism, extra measures were taken to ensure that the data collection process produced the least amount of stress for the participants and that enough data was collected to achieve the objectives of the study. The interview schedule was sent to each of the participants beforehand to allow them to familiarize themselves with the questions. This reduced the uncertainty of the interview and allowed the participants to prepare their responses to ensure that they were satisfied with the responses they provided. In cases where participants were highly anxious, the researcher rescheduled the interviews and used the session to get to know the participant and make him feel at ease. In some instances, interviews were conducted in the presence of a family member or spouse, as requested by the participant. This increased the level of comfort during the interview, as the presence of a familiar other with whom they had a close relationship, made the experience less anxiety provoking.

3.6. Procedure

The study commenced immediately after receiving ethical clearance from the University of Cape Town (UCT) Human Research Ethics Committee. A formal letter requesting participation and outlining the aim of the study, along with the informed consent stating participants' rights during the study, was sent to those identified as prospective participants by their clinicians. The letter was sent out through the training coordinator at the centre. The first ten participants who responded and showed an interest in participating were selected for the study.

Once participants had been recruited, data collection commenced. A schedule indicating the dates and times on which interviews may be conducted was distributed to the participants, allowing them to select their preferred interview appointment. Two interview venues were made available to accommodate participants who lived in Cape Town and those who lived in Stellenbosch. Therefore, the interviews were conducted either at the Neurodiversity Centre or at the UCT Child Guidance Clinic. To ensure that the participant was comfortable and to ease their anxiety about meeting the researcher for the first time, the first ten minutes of the interview was spent having general conversations with the participant. Once participants were settled, the researcher explained the study to them, went through the informed consent, and addressed any questions that emerged. After the interviews, the researcher spent a few minutes answering any further questions the participant had.

3.7. Data analysis

Interviews from all participants were audio recorded and transcribed verbatim. The thematic analysis technique outlined by Braun and Clarke (2006) was used to analyze the data. Braun and Clarke (2006) describe thematic analysis as a systematic method for identifying, analysing and organizing data into discrete categories that are comparable and replicable. Thematic analysis was appropriate for this study as it revealed the shared experiences of the participants through the recurring themes found in the data. In addition, the NVivo 12 qualitative analysis software was used to assist in organizing the data and identifying the themes. The data analysis was conducted in the following steps:

1. The first step to thematic analysis is to become familiar with the data. This begins by being immersed in the data through reading, understanding and becoming familiar with

the data. Each of the participants' transcripts was read and re-read in an interpretative manner to gain a better understanding of their mental and social world.

2. After being more familiar with the transcript, coding of the data began by identifying key segments of the data that provide details that address the research questions. Open coding was used, meaning that no predetermined codes were available, but each code was established based on what was deemed as meaningful information that addressed the aim of the study and the research questions.
3. After being more familiar with the transcript and the data was used to generate codes that were relevant to the study, the search for themes began. This involved identifying key concepts and patterns that emerge within each transcript and assigning comments to each of the meaning units identified. These themes were arranged in the order that they emerged during the analysis.
4. After identifying the themes, each theme was reviewed. This aimed at determining whether themes made sense, did not overlap, were supported by the data and addressed the research questions.
5. The themes were then defined. At this stage, each theme was refined based on the essence of the theme and the data is captured. Each theme was defined and named based on what data is captured and named themes were ordered coherently. At this stage, overlapping expressions that gave evidence to the identified themes were determined. The expressions were selected based on their ability to form theoretical connections across and within cases.
6. During data analysis, it became evident that data saturation was reached at 7 participants.
7. Once all transcripts had been analysed and the final themes had been identified, the write-up of the results was conducted. This stage involved providing a narrative account of the themes that emerged from the data by using an overarching comment for each theme and providing direct statements from the transcripts to illustrate and provide evidence for it.

3.8. Ethical Considerations

Prior to the commencement of the study, ethical clearance was granted by the University of Cape Town Human Research Ethics Committee. An official request was sent to the Neurodiversity Centre seeking permission to access males with late-diagnosed autism at the centre and the request was approved (see Appendix B). In addition, each potential participant received an informed consent form when the request letters for participation were issued (see Appendix C). The informed consent form stated the study's objectives and participants' rights during the study.

Voluntary participation was secured by ensuring signed consent forms from all participants. Participants were assured that the information they provided during the interviews would be kept confidential. Interviews were conducted in a private room, however, upon request, participants had a family member present in order to provide them with additional support so as to minimise their discomfort and /anxiety. Participants who consented to take part in the study, were asked to sign an informed consent and they received a duplicate of the signed form. Counselling services from the Neurodiversity Centre were also made available for anyone who experienced psychological distress. The identity of the participants was protected by omitting their names and pseudonyms were used. Electronic and printed formats of the information gathered during the study were stored in password-protected files and secure files in order to secure the coded information. All data gathered will be kept safe for five years succeeding the study and will be disposed of thereafter. All findings will be presented in an authentic manner in all research outputs (that is, thesis and possibly journal articles).

3.9. Reflexivity

In reflecting on my experience in the fieldwork, various factors such as my professional history in research and positioning as a qualitative researcher, influenced my approach to the data collection process. My lack of familiarity with engaging with adults with autism may have also influenced the process. Given that one of the core impairments in autism is related to social engagement and reciprocity (Mash & Wolfe, 2005), my lack of clinical experience may have resulted in various disadvantages, such as my lack of knowledge on how to approach the interview and how to interact and respond to adults with autism. Having a role play of the interview with a clinician from the Neurodiversity Centre, specializing in autism, assisted me in this regard.

Another key element that may have influenced the quality of the data I collected is linked to the variability of my demographics compared to those of the participants in this study. Being a young black isiXhosa speaking woman interviewing older white predominantly Afrikaans speaking men may have had immediate implications for the content that was explored during the interviews. Given that the history of South Africa is characterised by racism and the power differences that still exist, the participants' perceptions of me as an interviewer may have limited the extent to which they were willing to discuss intricate details of their experiences. In addition, my tendency to be overly cautious and avoiding the further probing of responses given by participants that contained sensitive information (that may or may not have been in line with the objectives of the study) in avoidance of crossing boundaries, may have limited the richness of the data I gathered. Furthermore, language related issues may have impacted the quality of the data I collected as the interviews were conducted in English. This may have limited the participants' ability to express themselves, as several participants' first and/home language was Afrikaans.

CHAPTER FOUR: RESULTS

This chapter presents the findings that emerged from a thematic analysis of data collected. Four main themes emerged during the study, namely, diagnostic trajectory, perceived implications of adulthood diagnosis on early life, self-perception and being an adult with late diagnosed ASD. The first section of this chapter will look at process issues that influenced the data collection process and which were thought to be important as they contribute to the understanding of the challenges adult males diagnosed with conditions on the autism spectrum might struggle with. This will be followed by findings on the diagnostic trajectory leading up to diagnosis and the implications of receiving a diagnosis in adulthood. The next section will look at issues related to self-perception, which explores how they perceived themselves at various stages leading up to their diagnosis, and lastly, factors related to their experiences of being a late diagnosed adult with ASD will be presented.

4.1. Process Issues

The process leading up to, and the actual data collection process of this study did not come without any challenges. The very nature of autism is characterised by qualitative impairments in social communication and interactions. Bearing this in mind, it is important to highlight anecdotal accounts of what was observed during the data collection process and some of the challenges that were encountered while interviewing the participants. When participants were initially recruited, eighteen males who were suitable candidates showed interest in participating. However, it was impossible to schedule an interview with most of them (reasons for this included a lack of response when contacted by the researcher or difficulties negotiating where and when the interview will be conducted) and their withdrawal may have been a result of anxiety about the interview, as experienced by some of those who did participate.

> “I'm sorry. I'm quite anxious now. I’m finding it hard to, to concentrate... my mind has just gone blank. I really want to answer your question” (Luke)

The anxiety that participants experienced manifested in different ways as shown by the adaptations that had to be made for the interviews to proceed. Some participants requested to be interviewed in familiar settings. For example, one participant was contacted via email by the researcher and a follow-up text message was sent two weeks later due to the lack of response. He called the Neurodiversity Centre stating that he was eager to participate in the study but driving to the interview venue was anxiety-provoking for him and he would rather

be interviewed either in his residence or surrounding areas. Some participants requested to be interviewed at their workplace:

> "I will prefer Neurodiversity for my interview unless you want to do it at my place of work" (Hugo)

> "I'd prefer if you could come this way (referring to his workplace)" (Francois)

While the reasoning implicit in the above-mentioned quotes is that it was more convenient for them, it is also likely that being interviewed by a stranger in an environment they were unfamiliar with may have further increased their anxiety.

Three participants arrived with their partner and one participant arrived with his mother. While this may indicate logistical issues that contributed to the difficulty of getting the participants to come for interviews, it could also have been a way for them to reduce their anxiety by being accompanied by someone they had a close-knit relationship with. One participant insisted that he would like his wife to be present during the interview, stating that:

> "She is also coming in, she knows all the answers… I won't be able to answer all the questions; my English is not good" (Mendel)

The remaining participants arrived at the interviewing venue alone but two of them showed a great deal of anxiety. For example, one participant arrived 30 minutes late for the interview and this severely impacted his experience. Upon his arrival, he seemed to be panicked for arriving late without giving any notification. Although he seemed to have calmed down after being reassured that his arrival will not in any way affect his interview, the combination of being late and being interviewed by a stranger increased his anxiety levels to the point where he could no longer answer the questions. He started sweating and fidgeting with his hands and this resulted in the interview being postponed and rescheduled for another day. The high anxiety that was noted during the data collection is not unusual, given the social interaction difficulties that are a key feature of conditions on the autism spectrum, and is in line with findings reported by DePape and Lindsay (2016), and Mash and Wolfe (2005).

4.2 Diagnostic trajectory

This theme includes the participants' description of their initial autistic difficulties and how they were ignored and misunderstood. The participants described various childhood difficulties that were suggestive of autism but which for one reason or another were not

attended to by parents or broader society. Most participants described that, generally, parents did have concerns about their early childhood development, reporting that they were perceived as “No ordinary child”. These concerns varied from having a child that was extremely shy and withdrawn to a child who was perceived as being socially inappropriate.

> *“...*when I was still very small there was this period in which my mother and father told me about that I couldn't really talk to people and I only started talking later… *”* (Hennie)

In addition to this, some participants reported that parental concerns revolved around unusual behaviours, as described in the quotes below:

> “If someone falls off their bike, I'll start laughing because I think it's funny. Um, other people will be like shocked, like geez, how can you laugh at that, while to me it's funny” (Boris)

> “… not really giving people a chance to speak because I'll be getting into whatever I was talking about” (Anthony)

Participants also described having had behavioural problems such as temper tantrums and restlessness, which lead to them being labelled as a “difficult child”

> “I was a hyperactive child, difficult. I was way more difficult than my brother and sister who followed me, many times. Um, I was difficult at school… the standard sort of report would be I’m a disruptive influence and it’s not fair to the children who, who want to, uh, want to learn in the class. So that was a common thread through, through my education. I was disruptive” (Nicholas)

> “When I was younger I didn't like, my father always told me to do this and this and this, but I want to do it differently” (Mendel)

For some participants, parents were concerned by their child’s regression in development, such as when a child who had developed age-appropriate speech began to lose the skills around the age of five to eight years. Participants seemed to view this as problematic because even with such severe challenges, the difficulties were not addressed:

> “I mean I started stuttering at eight, but they never really took me for counselling or helping or anything like that. They kind of just, I don't want it to sound rude, but maybe

they turned a blind eye or I'm not quite sure but if they were concerned they didn't show it." (Luke)

In a few instances, even when parents, suspected that such developmental regressions were indicative of autism, no action was taken to address the matter. However, some participants speculated that their parents' inaction was due to there being no support services specifically for people with autism or an adequate understanding of the disorder:

"Around about 5ish or so if I'm not mistaken…There was a strong suspicion that I could have been autistic um… my father was also a [professional]… remember in the past there wasn't really an emphasis on the whole subject so they, they didn't really go into autism and in the past, they will just say there's something wrong with you sort yourself out… unfortunately, you know I think these days a lot of people, I know somebody personally whose son is also on the spectrum and they do a lot more for the children these days" (Hennie)

"I think due to lack of experience from, from doctors and psychologists and stuff like that, they aren't able to pick that up…" (Boris)

Some participants reported that their symptoms or behaviours, such as the tendency to be withdrawn or different from other children, were not of much concern to their parents. While some parents were "accepting", participants perceived this as problematic as it contributed to parents not seeking professional help and getting a diagnosis during their early childhood.
Duquette et al. (2011) state that, some parents view their child's autistic traits as not being problematic but rather perceive the child as being gifted or intellegent, therefore, no professional help is sought.

"My dad would frequently ask me things like what is wrong and what not because you know, my normal face, is not a smiling happy face… So, Um, I think, I don't think there was much concern about it like I said, my family's really fairly accepting. They don't really push me out of my comfort zone" (Anthony)

"I did well at school and I had a few friends and stuff like that. So they were happy with my, umas a child growing up." (Francois)

The majority of participants attributed their parents' inaction to reasons such as lack of knowledge on how to address the issues, a general passivity and neglect towards their children, and as in the first quote below, not having primary caregivers due to varying circumstances. In addition, several participants speculated that these concerns were not addressed due to parents possibly struggling with their own challenges related to autism:

> "My dad… He left when I was about five, with three kids. So, there was no relationship from his side and then my mom, she passed away when we were quite young as well, so I think all in all up into 10 different schools…So nobody's ever picked it up. It's just like, you know, if I wasn't coping in the school, then I moved to another school… I was in many different schools with severe learning difficulties reading, writing and counting… When I was walking, I had bad knock-knees. So, my legs were quite sort of wobbly." (Boris)

> "I mean the father took very little notice of me possibly because he had the same condition" (Philip)

> "We have a sneaky suspicion that my mom might be autistic as well, so she's been handling it, controlling stuff very well." (Albert)

On the other hand, teachers were also regarded as professionals whose knowledge of conditions on the autism spectrum was very limited. Many of the participants described exhibiting peculiar behaviour at school which was regarded as either "difficult" or "shy". In one instance, the participant reported being ridiculed by the teacher for the difficulties he was experiencing rather than receiving assistance.

> "I also had a lot of anxiety and that caused me to find it hard to express myself in class. I would literally turn red in the face when the teacher asked me a question to the extent that the teacher wouldn't ask other kids questions and would joke to the whole class and say let's ask Philip a question and see how red he will get. That made me even more vulnerable to bullying." (Philip)

Another key diagnosis-related issue that emerged from the data was the confounding presence of other mental health problems. Majority of the participants described having experienced at least one or more mental health difficulties, with ADHD, depression and anxiety being the

most frequently reported conditions. Most of the participants received medical treatment for these disorders while conditions on the autism spectrum were missed by the health practitioners.

> "Over a period of years, I've always figured out that I'm different I, I, I sense things differently and see things differently and so, I mean I've always known there is some kind of variation, so basically they just said it's just depression and so they, they, they treating depression but nobody was aware of, of, of the Asperger's" (Boris) Interestingly, a few participants stated that they had never experienced any form of mental health difficulties prior to their autism diagnosis and as such, no prior mental health services were sought.

For some participants, they only received a diagnosis of autism through seeking help for their children's difficulties, only to discover that they also had a condition on the autism spectrum. In addition, they indicated that they had seen several health professionals regarding their children's difficulties without any success and only got a successful referral when someone, who knew an individual diagnosed with autism:

> "my daughter was 18 at that stage and we've been through psychiatry, psychologist, everything because we had problems with her, she, she didn't cope in the normal or function well in normal circumstances…And then somebody told us that her brother was diagnosed with Asperger's and that [therapist name] was the leader in the field… then we took my daughter there and we had the first session and he sat and he talked and while we're talking, everything that he said fell into place... I knew that was exactly as he was describing it. And then the next moment he turned to my partner, he said, but he wants to ask a few questions about me and he asked the questions and as he was asking it I just started smiling because I knew, I knew that what it means…he called us back and he said, listen…he wants to see me the next, the next week. So, then I waited for my session and then it was discovered." (Hugo)

Others stated they self-diagnosed after conducting research on their presenting symptoms due to feeling that the diagnosis that was given to them by their mental health practitioner was incorrect.

> "I got diagnosed with generalized anxiety and then I went to the psychiatrist for three, four, five years and then he started diagnosing me with OCD and I said, wait a minute, that doesn't fit, then I did research and then I diagnosed myself. Then I went to the psychiatrist and he confirmed it… but I went to him and he made me do a test and he confirmed it as well." (Albert)

> "I worked at the company and everything got a lot. We were moving from one place to another and there was a lot of stress at work and everything got overwhelming and as you would say I got a meltdown and then we said no we have to make a plan this can't carry on…I struggle to deal with crisis and things like that… my wife is also a psychometrist in psychology…she did a better read up on the subject and realised that there might be a form of autism in me… that's when I was diagnosed by [mention's therapist's name] and his team" (Hennie)

In the last quote, it appears that the quest for a diagnosis of ASD might be heightened during a time of crisis. Similarly, another participant reported having sought out a diagnosis under similar situations.

> "And I think it was through a struggle of that and was a lot of strain on our marriage and everything. It was really a tipping point or breaking point. It just sort of dawned on me because my awareness of autism or Asperger's had improved, it had increased a lot during this time. So it dawned on me, I thought maybe I've got that, you know... And then I phoned [therapist name], and almost on the phone I knew" (Nicholas)

Interestingly, once they received a formal diagnosis and became more knowledgeable about autism, participants reported noticing others who display autistic traits. In such instances, they generally make recommendations to others, urging them to seek help, especially for their children while they are still at a young age.

> "(mentions one of the participants) wife told my wife, um, that she thinks my son might be Asperger's" (Francois)

Some participants indicated that gender stereotypes, such as men not being as social as women, make it even more difficult for men to receive a diagnosis of autism and for it to be accepted

by others once it is received. Disruptive behaviours they might manifest were perceived as being normal and dismissed as ‘boys just being boys’.

> “My sister works with children with autism and when I told her she said that there is no way I have autism she knows what autism looks like and I don’t have it so I must stop looking for attention. All men are like that, if that’s the case then all men should have autism” (Philip)

The diagnostic trajectories described were similar for most participants. It was evident that early indicators of autism were present, however, they were either missed, misinterpreted or ignored. The instances where these initial indicators were observed and perceived as being problematic, was when participants exhibited extreme behavioural challenges or engaged in unusual behaviour; yet these concerns were not addressed even when they were perceived as concerning. The inaction of addressing the above-mentioned concerns was attributed to various reasons, such as lack of knowledge around the disorder, lack of support services, passivity and personal challenges primary caregivers were experiencing. On the other hand, some participants described their families as being accepting of their uniqueness and did not perceive it as problematic, which also led to not seeking professional help for their autism-related presentations. When mental health services were sought, being misdiagnosed with other conditions, without autism being considered as a primary diagnosis, also contributed to late-diagnosis. Participants described that a formal diagnosis was only made through help-seeking for their children’s difficulties and self-diagnosis which led to seeking confirmation of diagnosis. In instances where an active search for a diagnosis was sought out, it was during times of crisis and participants desperately needed answers for why they were experiencing these challenges. Once a formal diagnosis was made, they reported becoming more knowledgeable about the disorder, being able to recognize symptoms indicative of autism in others and making recommendations that they seek a formal diagnosis especially for their children who they suspected as having a condition within the autism spectrum.

4.3. Perceived Implications of Adulthood Diagnosis of ASD on Early Life

Receiving a diagnosis of autism in adulthood had serious implications for the early life of participants in this study. This theme describes the perceived impact that not receiving a diagnosis of autism in childhood had on participants’ early stages of life, as described by their

narratives in this study. This impact was two-fold, as some participants described positive aspects of receiving a late-diagnosis while others described negative aspects that were perceived as being detrimental to their life outcomes.

As can be seen from previous quotes (for example, Nicholas states that: "I was a hyperactive child, difficult… I was disruptive"), the behavioural challenges of participants that manifested in various settings and being labelled as a 'difficult child', seems to have been internalized by participants as being descriptive of them. This was found to negatively impact their self-perception and reduced the likelihood that these challenges would be addressed. In instances where actions were taken to address the concerns, it generally involved discipline, which is not surprising given that participants reported being labelled or perceived as "difficult":

> "Well, the way to address those concerns in those days would be discipline" (Nicholas)
>
> "I have some difficulties… they must know how to deal with, with, with us… I can do what I want… If I want to go to China, I go to China, then that person has to stop me… Actually, there's no borders. So, for me I need to have a border or be disciplined" (Mendel)

Without understanding the cause of their challenges and the underlying reason for being "different", participants described experiencing distress from a young age. In thinking about and talking about their childhood sources of stress, they indicated how the main source of stress at school was mostly due to being bullied and experiencing physical harm from classmates.

> "I had difficulties making friends and as a result, I was severely bullied. I've been cut on my back with a razor, I've had my head pushed into a toilet, I've been physically beaten. I experienced bullying at school and I also experienced bullying at home from my father and all that made things even more difficult to bear." (Philip)

As can be seen from the above quote, the bullying was not only limited to students but was also inflicted by adults as well. This may have further isolated the participants and resulted in them being withdrawn and finding ways to independently cope with some of their challenges. Participants also described experiencing academically related challenges that they typically would attempt to solve on their own, rather than asking for help. These difficulties included:

> “My biggest challenge is a lack of, a lack of concentration. So, so I jump from here to there to there” (Hugo)

> “I struggle with like writing neatly and quickly. So basically, what I did is I like sat in class and ignore the teacher and slept and read a book or something then I did the work myself at home and then that's how I passed” (Albertus).

This draws attention to the significant impact of a late diagnosis of autism. Without a formal diagnosis and an understanding of their challenges, participants were forced to navigate through their school career without receiving the necessary support.

Although participants suspected that there was something different about them, with all of them using the phrase “I always knew I was different”, no formal diagnosis of an autism spectrum disorder was made during consultations with health professionals, with some having spent years seeking professional help. Instead, they described having received multiple misdiagnoses and expressed how not knowing what was wrong with them contributed to serious emotional distress, including feeling suicidal.

> “I recognize there was something wrong back in 82… I drove to my GP… she said that they were fully booked until the following week and I made a point to her that if she didn't see me now, I may not be around next week because of the way I was feeling. She recognized the urgency. She saw me. She gave me some medication and referred me to the Tavistock Centre in north London, which specializes in psychoanalysis. I went to see a Freudian therapist, um, that marked my journey of 20 years, seeing that, a psychotherapist…I’ve been formally diagnosed with depression in the past… And I had some suicidal tendencies and I had some just general frustrations because I couldn't quite understand what was happening inside. I felt isolated and anxious and felt like I couldn’t take it anymore.” (Philip)

During an interview with one of the participants, while narrating his story and reporting on thoughts he had as a result of his isolation and lack of insight into his challenges, he wrote a note to the researcher stating:

> “No parent should have to bury their child. I was going to kill myself after my parents had died” (Luke)

It is important to note that, this is not only reflective of the extent of distress these participants may have been experiencing but it may also be indicative of the ways in which they employed strategies to manage their anxiety.

Misdiagnosis was found not only to negatively affect their psychological well-being, but participants also described other ways in which it severely impacted them. While the treatments for the disorders they were diagnosed with work for some participants, most reported the negative outcomes, including severe side-effects, that sometimes resulted from these:

> "I was diagnosed with ADHD… At first I was put on Ritalin, eventually I went off it because I found myself getting into, you know, I'll sit there and people would talk to me and I wouldn't um, you know, I don't know, I wouldn't register the fact that they're talking to me because I was too focused on whatever I was doing" (Anthony)

> "I can't sleep then so I got medication that helps me deal a bit better with insomnia…The pills work but it gives you a massive headache" (Hennie)

Many of the participants were diagnosed between the ages of 30 and 50. Some expressed how they felt that receiving a diagnosis in their adulthood had a profound and detrimental effect on their life, especially with regards to their education, social life and overall wellbeing.

> "I mean, education would have been different. Schooling would have been different. Just, everything would have been different, you know, and not forced" (Boris)

> "… a lot of the things I'm having to learn in terms of like socializing stuff and picking up social cues and stuff, it's so difficult now as an adult with a lot of other worries and other things to take note off." (Anthony)

> "I mean I've missed so many milestones in my life. I mean I'm almost 40 now and I'm stuck maybe in my twenties. You know what I mean? I've missed out so much on life" (Luke)

In contrast, some participants expressed they were glad that they were diagnosed during adulthood as they felt that having received a diagnosis earlier may have completely altered the course of their life.

> "I'm glad I didn't because I wouldn't want to change my life… I developed coping, ways to cope with them." (Nicholas)

While most participants expressed feeling a sense of relief in knowing that there was an explanation for their peculiarities, there were also feelings of anger and regret for having wasted time and resources without any success, and feelings of devastation that they have a lifelong condition that cannot be cured.

> "I cried. And then I felt very frustrated and angry about all of the hard work I'd put into psychotherapy, etc. In London, the amount of money I'd spent on, the time I spent on it when clearly they were barking up the wrong tree with me...but also I felt very relieved that I'm hopeful, finally somebody has told me, actually, I'm suffering from a condition that I could do nothing about" (Philip)

While some participants expressed having neutral feelings about the late diagnosis, they reported that it gave them insight as to how they can manage some of their challenges.

> "You see I think, uh, we like have autism don't actually have emotional feelings…but after my wife's, that she killed herself I got more emotional, but I was never emotional [referring to diagnosis] … I think when we heard it [diagnosis], I think we can put it in a frame that we have some problem and that will help us in the future how to work, how to deal with it... So now we've got a name so now we can maybe help that the doctor can help treat us how to be normal or try to be normal and for [says wife's name] to understand me and understand [says son's name] and the other children" (Mendel)

The ways in which participants expressed their perception of and the implications of receiving an adulthood diagnosis varied. Some participants expressed that it had a significant effect on them. The lack of understanding of the underlying cause of their behavioural challenges led to ineffective measures, such as discipline, being used as a strategy to correct the "difficulties". In addition, the lack of knowledge about their challenges caused distressed and made them vulnerable to being ostracised. These feelings of isolation further led to emotional and psychological distress with a few participants reporting suicidal ideations. The challenges extended beyond their social world, but also affected their academic work forcing them to navigate through their schooling career without adequate support. In instances where

professional help was sought out as an attempt to address their difficulties, they were misdiagnosed which further had negative implications for them. Many of the participants reported that receiving a diagnosis during childhood may have positively changed their trajectory and life outcomes. They expressed feelings of loss in terms of all the support and interventions they could have received during childhood that are no longer available or are not as effective during adulthood. While a few participants expressed being happy about receiving adulthood diagnosis as they wouldn't want to alter the course of their lives, others expressed deep feelings of regret and loss yet remained hopeful as they began to understand their challenges and how they could best manage them.

4.4. Self-perception

This theme describes the way in which participants perceived themselves compared to others as well as how they understood and made meaning of their difficulties prior to and following their ASD diagnosis. It also includes some of the challenges they experienced and the strategies they employed to cope.

Participants described how getting an ASD diagnosis has had a wide range of effects on their sense of self. Most participants reported that their diagnosis formed an integral part in their identity as it shed more light into some of the difficulties they experienced and helped them understand themselves better.

> "it has helped me understand why I find it difficult building connections with people. I struggled with certain things, especially with a PDA [Pathological Demand Avoidance] diagnosis, it helped me to understand like, why I struggled to get things done, why it takes me a lot longer to get things done… so yeah, it has, it has helped me understand all those things in the past and has given me fuel for future actions" (Anthony)

> "There's more accepting of who I am…. you don't try and copy other people and try and fit in. You trying to be yourself… It's almost every time it's like you're wearing a mask, or you play a character around people. But I've kind of stopped trying to do that" (Luke)

As can be seen from the last quote, some participants spoke about how receiving a diagnosis allowed them to gain a sense of acceptance of who they are. In addition, some viewed it as a

gift that they took pride in and which made them want to be affiliated with people with the same diagnosis.

> "Finding that out, in January, is a huge gift… I was trying to piece myself together, in a way, understand myself, but it was like I was putting a jigsaw together that was upside down, you know, the cardboard that was facing up. And then when I got that one piece, it was like the centrepiece. And it was the first time there was actually a picture and I put that piece in and all of a sudden you flipped the whole thing over". (Nicholas)
>
> "I'll tell them like I'm like Sheldon Cooper from Big Bang and everyone is like yeah that's a cool guy, yeah there's another character House from the series on the autism spectrum… I actually use it as a bragging feature these days" (Hennie)

For other participants, the diagnosis not only gave them a better understanding of themselves but also allowed them to gain more insight into their children's difficulties. This realization was integral for their role as parents as it enlightened them as to how they can best assist their children to manage their difficulties while being cognizant of their own challenges.

> "I've learned to be more patient with my daughter… you see things differently and you understand more. It's a little bit clearer now, you know, why would you say, you know, why do you do the things you do? It is because of that. So, you understand now, you, you put things into context." (Boris)

From the above, it appears that for the majority of participants, getting a diagnosis was helpful in how they understood or viewed themselves and others like them. However, a minority felt indifferent stating that being diagnosed with autism has not influenced how they perceive themselves.

> "I'm not really going to change who I am. I've, I've adopted and adapted my life through the years to fit in more socially... So, yeah. It, it, it, it made me think more about certain stuff. I do if I do something and then I realize, I could be doing something that way because I am Asperger's, but that doesn't. it didn't really change me or the way I do stuff." (Francois)

Interestingly, some of the participants felt more inclined to distinguish between themselves and the diagnosis, stating that they may possess autistic traits but there is a part of them that falls outside that diagnosis and is within their control, as shown by the excerpt below:

> "but it's kind of difficult because like, I'm actually at a bit of a phase at the moment when I'm trying to actually work out how much of this, of what I'm experiencing is, is uh, is out of my control as a result of Asperger's or autism and how much of it is within my control because I don't really want to fall into the trap of explaining to people, oh, I'm not doing this because I'm autistic and using it as a crutch or an excuse… I kind of fear that people will see me differently if I start to bring it up and that they might have to act in a certain way when they're dealing with me. So, I try and avoid that" (Anthony)

From the above, it seems likely that the separation of self and diagnosis may also be a strategy to avoid labels and possibly stereotyping. Participants also spoke of some of the positive traits they have because of autism, with some describing themselves as diligent and loyal people, and being more intelligent than neurotypicals and taking pride in that:

> "just like being this full-on genius, you know, you're incredibly good at certain things in the workplace and creativity and problem-solving and strategic. Um, that's, um, um, I suppose I'm proud of it in that respect." (Philip)

> "If you have your own business or if you ever strive to do something, you will do it. So, you will put everything in it to make it work. Um, and I'm lucky that I can do quite a lot of things…we're very loyal" (Mendel)

Lastly, participants spoke of how their family's acceptance of who they were before and after their diagnosis made them feel like they can be themselves even with the knowledge of their condition:

> "my family's very accepting… Um, I mean my family for a start have been a big help. I think if they were less supportive of it, I know some parents with Aspie or autistic children are either not invested or they almost against the diagnosis itself and I think that can make a lot more difficult but I'm fortunate enough that a lot of my friends tend to and my family as well they're very accepting they don't they don't perceive it as

anything wrong. And because of that acceptance, it kind of made it easier for me to accept myself" (Anthony)

Another key issue that emerged from the data related to how participants had to pretend to be normal. They described experiencing ongoing anxiety and engaging in various strategies to cope. They also reported feeling the need to be more self-aware and having to often regulate their behaviour and responses.

> "when I was a kid, I would say stuff to people without thinking what I was saying, sometimes hurting people's feelings because I would say something negative without realizing it and I definitely over the years… I would really think hard before I say something" (Francois)

Participants reported engaging in various strategies to camouflage their qualitative social impairments, such as putting on a persona or a mask. They described using different media sources, such as movies, books, documentaries, novels etc., to learn how to behave in different social settings.

> "I can be very charming. I can be well spoken. Uh, I think those are the, probably the main, the main factors or the main tools… I would imagine, it's like acting... you watch movies, maybe you watch documentaries, you watch whatever. You take bits and pieces and you put them together." (Boris)

> "My whole life has been a strategy on hiding it, mainly through reading novels about characters and watching films, watching tv shows, to try and get a sense from those, how people behave in certain situations and adopting some of those characteristics to be my armour, if you'd like it, to protect me from autism." (Philip)

A number of participants described how they would mask their difficulties by making jokes about some of their behaviour in order to appear typical and fit in. This masking was not only used in social situations, with some participants describing how the "professional image" they created for themselves as a façade to hide some of their challenges, as shown in the second quote:

> "I think through the years, I've. I've built up or I've, what can you call it, but I've learned to adapt so I will either make jokes to fit in. (Hugo)

> "My sense of identity was wrapped up in this, in this role I grew into... So, you can do that by being a successful businessman and you can also do that by living the lifestyle that Mick Jagger. It's only when, it's only when you can't go any further with those two ways of living that you have some sort of death, some symbolic death. Yeah. And then through that does some sort of search begins for yourself" (Nicholas)

Interestingly, one participant stated that the career he chose allows him to act out a role which camouflages his impairments.

> "Even the role I played at work allowed me to put on an act because you would go to a pub after work to network with potential clients and you would sit and recite a script to them that tells them what you do and how it will be beneficial to them. So, in those settings, my difficulties were not that obvious." (Philip)

While the above suggests that participants actively and thoughtfully engaged in masking behaviours, others indicated that it happened at an unconscious level. One participant described how upon reflecting on the past, he tends to observe others and re-enact the way they behave in social situations to appear normal.

> "consciously, no, subconscious, yes… I've researched a lot about, you know, uh, in terms of socializing… like, pickup artist stuff and that sort of stuff to try and help me understand how things work so that I can try and fit that more or try and apply that so that people don't see me as different. Um, but even though it doesn't, it's not always that successful" (Anthony)

However, it appears that such superficial attempts to adapt to social situations did not come without a cost, with some participants describing feeling exhausted at constantly putting on a front when interacting with others. Thus, some participants reported withdrawing, avoiding social settings and spending more time alone, while others relied on alcohol to relieve their distress. One participant further described how his reckless lifestyle; that was characterised by alcohol, drugs and women; was a strategy to relieve stress and all the pressure he was experiencing.

> "I become obsessed with movies because they helped me make sense of things and taught me how to act in certain situations. It is very exhausting." (Philip)

> "I think in my coping mechanisms, they have been a cost like alcohol, drugs, sex and women, you know, all these types of things" (Nicholas)

It is important to highlight that amongst these participants, masking was two folded. Firstly, some participants engaged in masking as an adaptive way to navigate through their social environment. For example, following career paths where they could use their professional image and duties to make their challenges less "obvious". This can be regarded as an adaptive use of camouflaging of autism-related challenges as participants did not describe being distressed by it. On the other hand, participants who described using masking to "hide" their challenges found it to be exhausting and distressing. This draws attention to the fact that masking autism-related traits can be both adaptive and maladaptive.

Overall, receiving a formal diagnosis of autism in adulthood and the impact it has on self-perception was viewed differently by various participants. Generally, it was reported that gaining an understanding of their challenges allowed them to find ways of managing them and to be more accepting of who they are. In instances where participants had children who also had conditions on the autism spectrum, they described how the knowledge and understanding of their diagnosis helped them understand their children's difficulties and how they could best manage and support them. It also became evident that although the majority of the participants reported that getting a diagnosis was helpful, a minority felt indifferent stating that being diagnosed with autism has not influenced how they perceive themselves. Participants also described regulating behaviour, masking, using substances and leading reckless lives as some sort of the coping strategies they employed prior to receiving their diagnosis. Some of the coping strategies that they employed were adaptive while others were maladaptive, however, without an adequate understanding of their challenges and the necessary skills training and support, these participants were left with very limited options.

4.5. Being an Adult with Late Diagnosed ASD

This theme describes participants' experiences as adults with autism and some of the challenges and benefits their diagnosis has afforded them. The participants described various challenges they experience during adulthood, particularly, autism-related challenges that played out in the workplace, which lead to them being perceived as "No ordinary employee" as described by some participants. Furthermore, it reports on participants perceptions and expectations regarding their future following receiving their diagnosis.

Some participants described how the lack of understanding of their difficulties, resulting from receiving a late diagnosis of autism, has had a detrimental effect on their employment. Many participants describe how they have struggled with the application and selection process which has profoundly impacted their employability. These challenges may be associated with the crippling anxiety that they experience in novel or uncertain situations (Mash & Wolfe, 2005) and the pressure of social communication which they further struggle with.

> "I can't just walk in and start a job. I need time to climatize and get used to all the people and things like that… also going into the interviews, I just couldn't deal with interviews"
> (Luke)

In instances where employment was attained, difficulties sustaining it were reported, as problems with supervisors or customers emerged, which participants had no way of explaining, thus making them disposable. These challenges were centred around qualitative impairments associated with autism, such as rigidity – also referred to as restricted and/ or repetitive behaviour – and social interaction and communication difficulties (American Psychiatric Association, 2013) as seen in the quotes below:

> "I haven't been able to keep a job… I worked there for about three months now this was before my diagnosis, um, and they couldn't understand why I wouldn't, you know if I was struggling with something, why I wouldn't communicate with them… on top of, on top of that, I started getting tired after a while so I can keep, I can keep a job going for a couple of weeks or months… And that's what happened with [mentions company name] um, eventually they let me go. They used the probationary period to let me go, at the end of the probation they let me go, um, because I couldn't quite understand why I wasn't doing so well why I wasn't communicating when something went wrong or anything like that. It might have been different say if I had my diagnosis at that point though, I think they would have understood a lot better" (Anthony)

> "If they tell me you have to do it like this, I wanted to know why can't I do it this way because this is easier for me… after three years they couldn't handle me anymore. They get the union in and the union told me that I have to listen to the boss and that is the way that it should be and if I'm not listening they can fire me." (Mendel)

As can be seen in the first quote mentioned above, a qualitative impairment in social interaction and communication has profound implications for these individuals, such as difficulties in communicating and feeling exhausted by social interactions even within the work context where such interactions are not only necessary but also mandatory. Similarly, several participants described feeling exhausted by working with other employees and tend to avoid social interactions within the workplace.

> "I hate groups… that's the thing I hate it, it really makes me livid… working with people is exhausting" (Hennie)

> "I don't, I'm going to say waste my time, talking to a lot of people or chit chatting or doing small talk with other people. I'd rather when I have lunch…I'd rather have it at my desk, like work while I have lunch… whereas, other people, they would sit in the rec area and have lunch with other people and talk about stuff..." (Francois)

On the contrary, other participants managed to choose career paths that would allow them to avoid constant interaction with others, thus, decreasing their levels of anxiety. These career choices may have been informed by an understanding of their challenges and following career paths that would best accommodate their needs, however, they may also have been informed by their restricted interests and rules that allow them to be expert within a specific area.

> "at school, I was always good at accounting and math… I switched over to BSC mathematics … If you're focusing on writing software, as soon as you have a break in concentration, it actually takes you more time to get back into that zone before that…. my job allows me to function on my own most of the time… working here, the environment allows me to function more normally" (Francois)

This quote suggests that, even with the challenges they do experience, participants strive to achieve some sort of normalcy in their daily lives. With this being said, some participants described how some of their traits associated with autism have proven to be a strength within their careers. While others expressed how their work ethic, the ability to separate their emotions from work, their need for structure, and a clear understanding of rules (which are characteristics of conditions on the autism spectrum), allowed them to thrive in their careers.

> "There was a definite structure. There were rules to the game. Those rules of engagement that I could actually pick up quite quickly and to not get emotionally involved in stuff and tied into that web is, it is a plus... Business was like… understood the rules of engagement. I understood when I was interested in it…I learned, and I was successful" (Nicholas)

Upon being diagnosed, some participants chose to disclose their diagnosis, describing the positive impact this disclosure has had on their overall work experience, such as having accommodations being made for them within the workplace and receiving some of the disability benefits; while others felt disclosure would further disadvantage them.

> "… it's the first company that I've actually disclosed that I'm on the autism spectrum. I even told the HR about it… they've been very accommodating in the workspace. So, they know how to work with me… My work colleagues also know about it so we've now built-in measures to accommodate for my needs" (Hennie)

> "I know a lot of jobs and businesses, they wouldn't hire you if they find out that you are on the spectrum." (Anthony)

Although the above comments suggest that there are differences of opinion as to whether or not disclosing their diagnosis within the workplace has advantages, the general consensus was that having employment played an integral role in participants' lives as it provided a sense of identity and afforded stability, independence and some sort of 'normalcy'.

> "I've found I become more, more confident. Especially having to hold on a job. Because if you ever meet someone and they ask, you know, what do you do for a living and where do you live? I was so embarrassed to say I don't have a job and I live with my mom." (Luke)

Another key implication reported by participants in this study is the feeling of having to "wander towards a better future". This was a combination of conflicting feelings, such as that receiving a diagnosis gave them the impression that it will help them better navigate into the future. However, they were offered very little guidance as to how to move forward into the future with this new diagnosis.

Participants reported that the knowledge of their diagnosis has allowed them to equip themselves with tools to improve their lives.

"Working with psychologists on how to deal with situations and getting the necessary training makes the future look more brighter… I work a lot with my psychologist and psychiatrist to give me the guidelines on how to work with or how to deal with situations" (Hennie)

This highlights how receiving a diagnosis, regardless of when it happens, can be helpful. Furthermore, participants expressed how, following their diagnosis, they are continuously learning that, although they may share the same diagnosis with others, they are all unique. When employing strategies aimed at managing and coping with their challenges, individually tailored approaches are essential, given that what works for one individual may not work for another:

"I'll do my routine and I do my stuff" (Albert)

"I've tried doing things like work on a routine which a lot of Aspies tend to thrive on. That doesn't work for me. Routine actually has the opposite effect on me… So instead of working by routine, I tend to follow more of a moment by moment" (Anthony).

Participants also described how they are learning to embrace their differences and not have to hide the fact that they have autism.

"I think it would be actually more damaging to actually hide it in general, what would be ideal would be able to just be okay with being autistic and then, uh, be able to lead a relatively normal life within society and staff because, you know, unfortunately, the society isn't geared around people on the spectrum." (Anthony)

The above quote emphasizes the need for more positive ways to cope with the qualitative impairments associated with conditions on the autism spectrum, and how the tendency for society to promote conformity as a standard for normalcy while reprimanding those who are different, is problematic for those who are atypical or nonconforming.

On the other hand, some participants expressed how their new diagnosis is not without challenges as it comes with the pressure to change themselves, however, they would not succumb to it.

> "I told the psychologist… I told him I'm not, I'll go to the sessions… but I said I'm not really going to change who I am. I've, I've adopted and adapted my life through the years to fit in more socially" (Francois)

This draws attention to the fact that, although no formal diagnosis was made during early stages of development, it is possible to adapt and adjust to some of the challenges these participants experience and improve their overall life prospect and outcomes. However, even with the diagnosis, there were various concerns participants voiced regarding the future. They felt that others were not understanding of their diagnosis and in disclosing their diagnosis, they realized the lack of awareness surrounding it.

> "You won't believe it, but most people, well the majority of the people, will say it um as actually like what is Asperger's or autism?... So, I think from my perspective we have to, the only way we going to build awareness is that we have to say that we have the thing but we are getting help to deal with this thing." (Hennie)

Several participants felt that they were merely handed the diagnosis with nothing to navigate into the future. They also expressed how they've found it difficult getting support services for adults with autism.

> "I find it is difficult finding services for adults with autism. I have contacted people who work with children with autism 2 or 3 times before, and they could not refer me to any services for adults. I finally found some services through my psychologist, who actually knew the person personally." (Albertus)

This further draws attention to the need for creating awareness around the disorder and the need for support and services for adults with conditions on the autism spectrum. Without any guidance and support, they were concerned that the future may not be any different from the past. Their needs such as those for close intimate connections with others may never come to pass.

> "I find it very difficult to create a connection with people because I don't always… our brains don't register the social cues I'd say because our brains are so busy trying to process all this huge amount of information that it takes a lot longer to get to certain revelations I suppose. So, I don't always I can't always pick up things in real time… so that's, that's my biggest challenge. Because of that, because I miss those cues and stuff

it’s difficult for me to actually build up interaction with people, connections with people.” (Anthony)

This suggests that, although support services have been proven to be beneficial during early childhood, there is also a desire and a need for adult support services.

With this being said, one participant made an intriguing closing remark. He expressed that autism is more of a gift than a curse. It is a form of a protective shell that protects them as they are sensitive people. It allows them to nurture their specific talents and become experts in their areas of interest. Their sensitivity allows them to be one with nature and their immediate environment. It should not be regarded as something that needs to be “treated” with medication, but rather, people need to become more aware of it and accommodating to those who have it.

> “I think it's as of much a gift as a curse. I think it might be more of a gift. I think even when I look at my son, my son's incredibly sensitive with a lot of love and I think he needs some sort of shell to protect him and I think that's what it is. It's like a protective shell in a way. He's, if it's something that he's interested in, he's extremely bright and will take information in and you’ll be amazed... so if it's something in his space, you'd be amazed and he's very sensitive so it's very specialized and very sensitive and that's where the future of the world's going… I think there's more to it… typically, they will try and medicate it and I've never had medication in my life, but we live on a farm that backs up onto the Franschhoek mountain and I've seen that nature has a massive impact.” (Nicholas)

The above-mentioned quote highlights an important point. In having the first-hand experience of the disorder, it can be expected that individuals with ASD are highly knowledgeable about the challenges they experience and draws attention to the need to involve them in the development of interventions and support services for individuals with conditions on the autism spectrum.

This theme shows that the lack of understanding, of parents, professions and the general public, regarding participants’ challenges hindered them from obtaining and retaining employment, which played an integral role for them in maintaining ‘normalcy’. Without understanding their challenges, participants reported being disadvantaged as they had no way of explaining or defending their idiosyncrasies, such as not being able to follow instructions and meeting

deadlines, which led to them getting laid off. This negatively impacted them because, without employment, they could not be independent. In some instances, participants managed these difficulties by finding jobs that would allow them to obtain some sort of normalcy, such as working in environments where they would not have to engage with others, which minimized the likelihood that they would have any miscommunication with others. On the other hand, some of the participants described their autism-related traits as being an advantage within the workplace allowing them to thrive. Following receiving a diagnosis, those who chose to disclose to their employers described having advantages such as being accommodated where necessary, while others chose not to disclose in fear of being discriminated against. Although receiving a diagnosis has helped them understand their challenges and develop effective ways of managing them, participants reported feeling as though the future will not be any different from the past, as they were given the diagnosis without any guidelines as to how to move forward and get the necessary support and interventions.

4.6. Chapter summary

The findings of this study highlight four key features of the experiences of males who were diagnosed with autism during adulthood. Firstly, it is evident that initial presenting symptoms were noticeable during early childhood, however, the way in which they were perceived, lack of knowledge in how to address them and various other factors, resulted in these challenges being overlooked. Similar results were found by other authors (Kishore & Basu, 2011; Mandell et al., 2009; Rosenberg et al., 2011; Zeleke et al., 2017). Secondly, the lack of a formal diagnosis impacted their early life forcing them to navigate through their childhood with challenges that were not being adequately addressed. These challenges (and the inability to understand them) may have further shaped not only how participants perceive themselves but also their future prospect. Without these challenges being adequately addressed and understood, participants were forced to adapt and find coping strategies (some of which were maladaptive) to navigate through life and maintain some sort of "normalcy". Lastly, it is evident that even following their diagnosis, the lack of support services and guidance for adults with ASD has left the participants feeling that the future does not look any brighter than the past.

CHAPTER FIVE: DISCUSSION AND CONCLUSION

This chapter will discuss the themes that emerged around the experiences of late diagnosed males in relation to the objectives of the study and provide concluding remarks. The first section will present the process issues that emerged during data collection and how these may have impacted the content of data gathered from the participants. This will be followed by a discussion on the diagnostic trajectory leading up to gaining an ASD diagnosis and the ways in which receiving an adulthood diagnosis impacted their early life. This will be followed by a discussion of how the changes in participants' self-perception at various stages of the diagnostic process can be understood. In addition, factors related to their experiences of being an adult with ASD will be discussed. These findings will be integrated and discussed in relation to previous literature. This will be followed by the conclusion section which will summarise the aims of the study and provide reflections on the limitations of the study and make recommendations for future research.

Autism is a complex disorder and the way in which it presents itself differs from person to person. According to Wall (2004), the presentation of each individual's autism is unique and may evolve over time which further exacerbates the complexity of the disorder. This variation in the presentation of the same condition amongst different individuals became evident within the study in various ways. For example, the social interaction and communication challenge presented itself through differing levels of anxiety that participants experienced leading up to and during the data collection process. This anxiety was managed by providing the participants with the interview questions prior to the commencement of the data collection process to familiarize themselves with what would be asked and remove the ambiguity of the process. However, because of the variation and/or heterogeneity of the disorder as well as qualitative impairments and/or elevated anxiety levels, some of the participants needed to be accommodated even further. As a result, some were not only accompanied (by either their relative or spouse) to the interview venue but further requested that they remain present during the interview. This evidences, to some degree, the variation of the disorder and extent of the challenges of individuals with ASD experience. More importantly, these turn of events may have potentially affected the data gathered from participants, as the anxiety or the presence of a family member or spouse may have limited the content discussed and hindered the expression and exploration some of the intricate details of their experiences.

Symptoms of autism and its presentation vary in their intensity and severity (Baghdadli et al., 2003; Mandell et al., 2005), which makes it challenging to identify. The participants in this study reported presenting with initial symptoms that were indicative of ASD within the first five years of life, which is in line with The United States Centers for Disease Control and Prevention's (2009) report that indicators of autism are evident before the age of five. Several participants described exhibiting social impairments, loss of language and extremes of mood lability within the early stages of development. Interestingly, social impairment was the most prominent early indicator of autism that most participants identified with. For some, it manifested as inappropriate social responses such as laughing inappropriately when someone got hurt or not being able to give others a turn to talk during conversations. These symptoms are in line with the atypical behaviour described by Welton (2004) as being indicative of the impairment in the social interaction domain amongst individuals with ASD. Furthermore, the symptoms described by the participants in this study are in line with the findings of other studies which describe such difficulties as being early concerns of parents of children who were later diagnosed with autism (De Giacomo & Fombonne, 1998; Ozonoff et al., 2010; Young et al., 2003; Zeleke et al., 2017). This suggests that some of the delays in identifying early symptomatic features described by the participants may reflect parents' difficulty in understanding them, rather than the absence of symptoms per se. The complexity of autism is further increased because in some cases periods of apparently typical development were followed by stagnation, regression or loss of skills that were already developed (Goldberg et al., 2003; Moolman-Smook et al., 2008; Ozonoff et al., 2010).

From the participants' reports, signs of autism were present but due to various factors, these symptoms were unrecognized or overlooked. Issues reported by the participants as causing their symptoms to be overlooked included lack of awareness about the condition, personal challenges of caregivers, in some instances absence of caregivers for one or other reasons, and cultural factors that influence the perception and understanding of atypical development. This misperception of lack of an understanding is not unusual and was reported in a number of other studies (e.g. Aggarwal & Angus, 2015; Kishore & Basu, 2011; Mandell et al., 2009; Rosenberg et al., 2011; Zeleke et al., 2017). In addition to symptoms being misperceived or not understood by parents, participants also reported a lack of knowledge by professionals who were consulted, including health professionals and teachers. This was not surprising, given that Franz et al. (2017) and Zeleke et al. (2017) suggest that knowledge of

ASD in Africa is limited. Lastly, it was also not surprising that participants in this study attributed factors, such as cultural understandings of ASD symptoms, as contributing to their late diagnosis, as this was also observed in other studies (Bakare et al., 2009; Mthmobeni & Nwoye, 2018), where autism was perceived as resulting from supernatural causes. In these studies, professional help was either not sought or considered as a last resort.

It was also found that when professional help was sought, participants' difficulties were misunderstood and were not considered as being symbolic of autism spectrum disorders. This had a detrimental effect on the participants as it led to receiving multiple misdiagnoses (with the common misdiagnoses being ADHD and anxiety) and being administered various treatment methods which were mostly ineffective and resulted in severe side effects. This was in line with Bargiela et al.'s (2016) finding that females who were diagnosed with ASD in their adulthood had received similar misdiagnoses and, in some cases, no diagnosis was given at all. This tendency to misdiagnose individuals with autism has been linked to its co-morbidity with other conditions, such as ADHD and anxiety (Davidocitch et al., 2015; Hendrickx, 2015; Hurlbutt & Chalmers, 2002; Leyfer et al., 2006), as other psychological conditions tend to mask it. However, it can also reflect the characteristics of the systems that are designed to identify and assist individuals who have ASD, as health professionals and the diagnostic tools that are currently being used for diagnosing ASD may contribute to the number of individuals who are misdiagnosed and/or whose diagnosis is missed (Abubakar et al., 2016; NICE, 2012).

Another element that the study elucidated was the phenomenon of masking social difficulties. Participants described making deliberate efforts to learn and use neurotypical social skills to fit in, referring to it as "putting on a mask". Many studies have argued that this tendency to disguise autistic traits was common in females with autism and was one of the contributing factors in the gender differences evident in the prevalence rate of the disorder (Bargiela et al., 2016; Gould & Ashton-Smith, 2011; Hiller et al., 2015; Mandy et al., 2011). Some participants described engaging in masking at an unconscious level, through observing others' behaviour and mimicking it without being aware of it. This effort to camouflage social challenges was widespread but not universal. Based on the results, it can be inferred that these skills are self-taught through various strategies such as imitating characters in films, reading novels and observing others. This can be understood as a coping mechanism employed to hide social difficulties and manage stress and anxiety. While masking is typically seen in females (Bargiela et al., 2016; Gould & Ashton-Smith, 2011; Hiller et al., 2015; Mandy et al., 2011), a

number of males in this study also reported masking their difficulties and may suggest a need for caution when making such gendered assertions.

Another key issue was the finding that engaging in camouflaging efforts also had disadvantages. Participants expressed feeling exhausted by their constant attempts to put on a façade and described how it caused further confusion in terms of their identity. Again, this is similar to what Bargiela et al. (2016) described among females with autism. In addition, Hull et al. (2017) state masking cause individuals to develop negative attitudes and emotions towards themselves, feeling that their relationships are based on deception, as they are forged through portraying a false self-presentation. Similarly, participants reported how relationships they formed while camouflaging their ASD characteristics would collapse when they could no longer put on a mask resulting in negative emotions and feelings of being deceptive. This may have further negatively impacted their self-perception, with several participants reporting that masking made them less accepting of who they were as they felt compelled to hide in order to fit in. Interestingly, in novel situations where strategies to hide autism-related impairments could not be employed, such as participating in a research study like this, heightened levels of anxiety were experienced (American Psychiatric Association, 2013; Bargiela et al., 2016). This highlights the extent of the impairment in social imagination amongst individuals with autism, as they lack an ability to imagine an alternate sequence of events and employ strategies of avoiding ambiguity and uncertainty of situations that are anxiety provoking (Mash & Wolfe, 2005).

The findings of the study also suggest that the challenges that males with ASD experience are not a result of their autistic difficulties alone, with cultural expectations influencing the way in which these difficulties play out within various social settings. For example, several participants described longing for, but finding it difficult, to build intimate relationships with others due to social expectations regarding interactions and the courtship process. This was in line with the findings of Attwood (2007) and Van Hees et al. (2015), who state that the inability to understand social rules, such as the oscillating nature of conversations, and the inability to read subtle social cues, contributed significantly to not being able to meet social demands. In keeping with what was reported by DePape and Lindsay (2016), participants in this study reported that the anxiety induced by feeling different from others resulted in maladaptive behaviours, like relying on alcohol and social withdrawal. This points to the need for these individuals to develop adaptive coping strategies.

The findings of this study further suggest that some of the participants' autism-related traits, for example, engaging in repetitive behaviour and fixed narrow interests, were an asset and contributed to success when applied within the workplace. As reported by DePape and Lindsay (2016), restricted and repetitive interests of individuals with autism shape their identity and more critically, when those who were employed used these interests within their workplace, they tended to be successful. It appears therefore that some characteristics of the disorder which may be problematic in some settings can also be useful skills that may be harnessed in exploring possible career paths that those with ASD may thrive in and enjoy. However, it is important to note that situations in which autism-related characteristics contribute to success are anecdotal. Most of the work-related success and/or satisfaction described by participants were based on finding a good match in their careers, interests and characteristics; which was also in line with the findings of DePape and Lindsay (2016).

Overall, participants in this study expressed that receiving a diagnosis had significant positive benefits for them, such as a better understanding of their challenges allows them to develop tools that will help them move forward. They expressed how they now understand the underlying cause for their difficulties in forming relationships and other challenges they had, but most importantly, how gaining this understanding has enabled them to be more accepting of who they are. This acceptance was found to also be influenced by the decision to disclose the diagnosis of autism or not. According to Hurlbutt and Chalmers (2002), the level of acceptance that individuals with autism have of their diagnosis is influenced by whether family and friends are accepting of the diagnosis. In this study, it was found that participants whose families and friends were accepting, and supportive following disclosure of the diagnosis resulted in them being more accepting of their diagnosis and finding adaptive ways to manage some of their challenges. On the contrary, participants who chose not to disclose due to various reasons, such as the possibility of being labelled and the stigma attached to conditions on the autism spectrum, did not express the same level of acceptance of their diagnosis as those who had disclosed and received support from their families and friends.

Lewis (2016) talks about individuals who receive a late diagnosis progressing through three phases of conflicting identities, namely pre-identity alignment, transitional identity alignment and lastly, post-identity alignment. Participants in this study described feeling uncertain about who they were prior to their diagnosis. Through the process of receiving a diagnosis, they reported progressing to gaining an understanding of who they were and their

challenges. Lastly, they developed a sense of acceptance in who they are following their diagnosis. This suggests that receiving a diagnosis of autism plays an integral role in individuals' identities as it can improve self-esteem and confidence, through gaining a better understanding of themselves and the condition (Hendrickx, 2015). More importantly, discovering that their challenges and feelings of being different are a result of autism can bring about, for some people, a sense of relief (Hendrickx, 2015; Lewis, 2016) which may lead to being more accepting of who they are. Similarly, participants reported that receiving a diagnosis has allowed them to understand and identify with those who share a similar diagnosis. Furthermore, those who had children diagnosed with ASD expressed how their diagnosis has allowed them to be more patient with their children which further allows them to be better parents.

The results also point to how receiving a diagnosis earlier may have made a significant positive impact on participants' experiences and life outcomes. It has been suggested that socially oriented skills and developmental behaviour, which are impaired in individuals with autism can be developed, especially through intervention at a young age. Early interventions have been found to reduce developmental gaps that individuals with ASD experience compared to neurotypical individuals (Aldred et al., 2008; Ozonoff et al., 2010; Rogers et al., 2014). A late diagnosis means that they missed the critical period in which interventions could be administered and improved their developmental trajectory (Hendrickx, 2015; Khan et al., 2012; Koegel et al., 2014; Wong et al., 2015). Furthermore, it has left them feeling helpless as there are limited support services available for adults with autism (Lewis, 2016). This suggests that an adulthood diagnosis makes it difficult for individuals to gain access to support services that may have potentially improved the quality of their lives had they received a diagnosis during childhood.

Conclusion

The purpose of this study was to explore the experiences of males who were diagnosed as having conditions within the autism spectrum during adulthood. It explored their initial presenting symptoms, challenges and perception of the impact that late diagnosis had on their developmental trajectory by employing a qualitative research design to generate ideas and to gain an in-depth understanding of emerging themes. The themes that emerged during the study include the diagnostic trajectory they experienced leading up to their diagnosis, including their

perceptions of what contributed to late diagnosis. A second theme was related to the ways in which receiving an adulthood diagnosis impacted early life, including some of the challenges they experienced and how the lack of a diagnosis impacted their life experiences. The third theme was related to their self-perception describing how they perceived themselves and their identity at various stages leading up to and following their diagnosis. Lastly, a theme that presented factors related to their experiences of being a late-diagnosed adult with ASD was presented and it includes their experiences as adults with autism prior to and following the diagnosis. This section will present some reflections on the study, including a summary of the key findings and their implications. This will be followed by a presentation of the limitations of this study and make recommendations for future research. Finally, the main contribution of this study and concluding remarks will be presented.

In this study, it was found that initial indicators of autism were evident during the early stages of development. However, for various reasons, professional help was only sought during their adulthood which, was mostly to no success. This had a significant impact on the overall life experiences and outcomes for these males as they were forced to navigate through their lives without understanding their difficulties. In addition, as these individuals progressed through life, they encountered numerous challenges and learned various strategies to cope with some of their autism-related difficulties. Some of these coping mechanisms were maladaptive, while those that were considered as being adaptive, further had unintended negative implications. Furthermore, due to limited availability and/or access to support services for adults with autism, participants felt that the future, following their diagnosis, does not look any brighter than the past. With this being a subject area that has not been greatly explored, these findings highlight the importance of creating more knowledge and understanding around adults with autism, as these individuals experience major life challenges (especially without a formal diagnosis) and desperately need support, both professionally and personally, in managing their difficulties.

Based on the findings of this study, one can begin to understand the important role the training and proficiency of health professionals play in these individuals' life experiences and life outcomes. It also draws attention to the need for health professionals to be trained in understanding and diagnosing the spectrum nature of autism, as their inability to diagnose individuals during early stages of development, while interventions can yield improved life outcomes, has significant effects on families and individuals with autism in a number of areas,

such as economic, social, emotional and psychological areas. Furthermore, the scarcity in support and services for adults with conditions on the autism spectrum further has paralysing effects on those who attain a diagnosis in adulthood.

Limitations

The study was limited in that the findings were based on data collected from ten participants who were not representative of the demographics of South Africans in terms of race and socio-economic status. It consisted of participants who were white middle-class males, due to the fact that the Neurodiversity Centre can only offer services to individuals with their own financial means or medical aid. This is a minority of South Africans, as most of the local population relies on public health services (Statistics South Africa, 2017) due to economic constraints. This has additional and immediate implications as autism is described as one of the most expensive conditions to treat during early years (Horlin et al., 2014) and lack of access to diagnosis has developmental and economic implications for individuals. Although these are findings from global north countries, it is possible (if international prevalence figures are considered) that most South African males will not access either diagnosis or intervention services. The implications of this – not just on these individual's mental health, but general well-being and progress – deserves further research and investigation in the present context. This is critical - as understanding the experiences of adults with autism should be done with reference to context and environment.

In addition, this study was a snapshot and did not explore all the experiences of individuals with autism and focuses on certain facets. This study also did not explore the long-term experiences of the participants, following diagnosis, as all participants had received a diagnosis at least several months prior (with exception of a few participants) to the commencement of the study. Although this study was limited, it aimed to explore an area that has limited research and can provide insights that may be pertinent to the field of autism.

Recommendations

Future research should further investigate how parents of individuals who were diagnosed with ASD in their adulthood, understood the aetiology of their children's presenting symptoms and why a diagnosis of autism (during earlier stages of development) was not sought. Furthermore, an exploration of their current understanding of autism, including their awareness of the condition and knowledge of support services available, should be conducted. This will provide insights into the extent of awareness there is around autism and how a lack

of awareness can potentially be addressed. It is also suggested that health professionals become trained at being able to recognize and diagnose those who are symptomatic upon initial referral. More research should be conducted on developing assessment instruments and diagnostic tools for adults presenting with conditions on the autism spectrum and how they can be adapted to multiple contexts.

Considering that this study does not depict a definitive picture of masking, it is suggested that research be conducted that derives a precise and coherent conceptualization of the construct, both at the conscious and unconscious level. By operationalizing this concept and developing a measure, the extent to which it is used and whether there are positive and/or negative aspects to it among individuals with ASD can be quantified. This could inform how educational programs and workshops can be developed to minimise camouflaging and encouraging the expression of one's authentic self. Conversely, the ways in which the functional aspects of masking, such as being used adaptively and to learn social cues, can be explored an integrated into educational programs. This will ensure that some of the adaptive functional skills adopted by adults with autism are acknowledged, refined and enhanced rather than being overlooked. Future research should further investigate the various coping mechanisms employed by individuals with autism, so as to provide more adaptive alternatives. The extent (if any) of the gender differences when engaging in masking and how this affects the likelihood of being diagnosed with autism should be explored.

With this being said, this study may have potentially drawn attention to the critical importance of future research being conducted among adults with ASD, as little is known about this developmental period among individuals with these conditions. However, this study has raised further questions that still remain unanswered. One of these questions is that, if white middle to upper-class males do not receive a formal diagnosis of autism during early stages of development (when interventions have the potential to improve functionality), what then is the trajectory of black marginalized individuals (who are constantly confronted by struggles to gaining access to material resources) making up the majority of the current South African population?

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APPENDIX A: ACCEPTANCE OF MASTERS PROPOSAL LETTER

Faculty of Humanities
Postgraduate Administrrtion
University of Cape Town

Room 110, Beattie Building
Private Bag X3, Rondebosch 7701
Tel: +27 (0) 21 650 2693
E-mail: sylvia.chauke@uct.ac.za
Website:http://www.humanities.uct.ac.za/hum/postgraduate/studies/aboutus/overview

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23 April 2018

Miss Marinos Lupindo
E-mail: LPNMAR002@MYUCT.AC.ZA Student
no.: LPNMAR002

Dear Miss Lupindo

ACCEPTANCE OF MASTERS PROPOSAL BY HUMANITIES FACULTY BOARD

I have pleasure in advising that your research proposal as detailed below has been approved by the department and the Faculty of Humanities in the Dean's Circular HUM 01/2018.

Kind regards
Sylvia.chauke@uct.ac.za
Miss Sylvia Chauke
Faculty of Humanities: Postgraduate office

cc Supervisor/s: Dr N Shabalala
Co-Supervisor: Dr A Maw

CANDIDATE	STUDENT NO.	DEPT	SUPERVISOR	CO-SUPERVISOR	TITLE
Lupindo, MB	LPNMAR002	PSY	Dr N Shabalala	Dr A Maw	Exploring the experiences of males diagnosed with high functioning autism in their adulthood

"Our Mission is to be an outstanding teaching and research university, educating for life and addressing the challenges facing our society."

APPENDIX B: LETTER REQUESTING TO CONDUCT MY STUDY AT THE NEURODIVERSITY CENTRE University of Cape Town

Child Guidance Clinic
Chapel Road
Rosebank
Cape Town
7700
24 April 2018

Neurodiversity Centre
Lekkerwijn Estate
Groot Drakenstein
Stellenbosch 7680

REQUEST TO CONDUCT MY RESEARCH STUDY AT THE NEURODIVERSITY CENTRE

To whom it may concern

My name is Bomikazi Lupindo, I am a Master's student in Clinical Psychology at the University of Cape Town. One of the requirements for the degree is for me to conduct a research study.

I am interested in conducting a study that explores the experiences of males diagnosed with high functioning autism during their adulthood. I am looking to recruit participants from the Neurodiversity Centre (NDC).

I would like to requested that the Neurodiversity Centre assist me in identifying and connecting with individuals who meet the criteria for this study. To be considered for participation, the participants have to have received a formal diagnosis of ASD and self-identify as autistic males. They have to be between the ages of twenty-five and sixty-five years. In addition, participant selection is limited to those males who received their diagnosis within twelve months prior to this study being conducted. This was to ensure that participants have had enough life experience following diagnosis and, thus will be able to provide rich data that will be pertinent to the study, about their experiences before and after diagnosis.

I would like to request that I conduct my study at the Neurodiversity Centre as the centre specializes in providing services for social communication challenges and autism spectrum disorders. This means that participants recruited for the study who met the inclusion criteria would be easily accessible. Please note that participation in this study is voluntary and participants will be notified that the participation in the study or lack, thereof, will not in any way influence their current relationship with the centre and the current services they receive at the centre will continue whether or not they choose to partake in the study. Participants will also be informed that they will be able to discuss any concerns that they may have about the research with the NDC staff or me.

It would be an honour to conduct my study within the organization.

Thank you in advance for taking the time to read this letter.

Looking forward to hearing from you.

Kind regards

Bomikazi Lupindo

APPENDIX C: LETTER REQUESTING PARTICIPATION IN RESEARCH STUDY

University of Cape Town
Child Guidance Clinic
Chapel Road
Rosebank
Cape Town
7700
26 April 2018

Neurodiversity Centre
Lekkerwijn Estate
Groot Drakenstein
Stellenbosch
7680

REQUEST TO PARTICIPATE IN MY RESEARCH STUDY

To whom it may concern

My name is Bomikazi Lupindo, I am a Master's student in Clinical Psychology at the University of Cape Town. One of the requirements for the degree is for me to conduct a research study.

I am interested in conducting a study that explores the experiences of males diagnosed with high functioning autism during their adulthood. I am looking to recruit participants from the Neurodiversity Centre.

We have requested that the Neurodiversity Centre assist us in identifying and connecting with individuals who meet the criteria for this study. Therefore, if you are receiving this letter, the Neurodiversity Centre has identified you as a potential participant.

I would like to extend my invitation to you to participate in this study. Please note that participation in this study is voluntary and your participation or lack, thereof, will not in any way influence your current relationship with the centre and the current services you receive at the centre will continue whether or not you choose to partake in the study. You will also be able to discuss any concerns that you may have about the research with Ben or other NDC staff or me.

It would be an honour to have you as one of my participants.

Thank you in advance for taking the time to read this.

Looking forward to hearing from you.

Kind regards

Bomikazi Lupindo

APPENDIX D: INFORMED CONSENT

UNIVERSITY OF CAPE TOWN

Masters Research Study

Exploring the experiences of males who were diagnosed with high functioning autism during their adulthood

Information Sheet and Consent to Participate in Research Date:

Dear Participant

My name is Bomikazi Lupindo from the University of Cape Town, Department of Psychology, contacts: 08267683844 or Lbomikazi@yahoo.com

I hereby request you to be a part of the study I am conducting, pursuing a Master's degree in Clinical Psychology, under my lecturers' supervision. The study will be conducted amongst males, diagnosed with autism in their adulthood, currently attending the Neurodiversity Centre. The study will look at the experiences of males diagnosed with high functioning autism (what is often described as Asperger's syndrome) during their adulthood. In specific terms, the study intends to obtain information from you regarding your experience of first beginning to consider, and then confirming, that you have a diagnosis in the form of a condition on the spectrum of Autism. It is intended that this can assist myself as a researcher to draw attention to the experiences and needs of adults with Autism in South Africa. In doing so, it is my intention that this can draw attention to the training needs for professionals working in the mental health, psychology, psychiatry and related fields.

This study will particularly be concerned with obtaining and collecting information regarding your experience of your diagnosis of a condition on the spectrum of Autism – and specifically, your experience and understanding of any mental health or psychological difficulties or challenges that you may have experienced prior to your diagnosis.

The study intends to enrol twelve participants who will be interviewed by the researcher, who is currently a masters student.

The study does not ask for harmful questions or information that might evoke depressing emotions or discomfort. However, in the event that you experience any psychological distress, during or after the study, resulting from the study, psychological services will be provided to you, by clinicians at the Neurodiversity Centre, without any costs being incurred.
This study has been ethically reviewed and approved by the UCT Human Research Ethics Committee.

In the event that you encounter any problems, concerns or questions, you may contact any of the following:

Researcher:

Bomikazi Lupindo

Contact number: 082 676 83844

Email: Lbomikazi@yahoo.com

Supervisors

Dr N. Shabalala

Contact number: 021 650 3908

Email: Nokuthula.shabalala@uct.ac.za

Dr A. Maw

Contact number: 021 650 3904

Email: Anastasia.maw@uct.ac.za

Postgraduate Programmes Administrator

Rosalind Adams

Contact number: 021 650 3417

Email: Rosalind.adams@uct.ac.za

Participation in this study is voluntary, and your privacy and confidentiality will be maintained at all times. You will be allowed, without any discrimination or prejudice, to withdraw from the study at any given time should you so wish or feel uncomfortable to continue. It is important to highlight that your participation or lack of participation in this study will not in any way affect your current relationship with the Neurodiversity Centre. The services you currently receive at the centre will continue regardless of your participation or lack thereof, in this study.

I am aware that face to face interviews with myself could possibly prove both anxietyprovoking and stressful, and because of this, I intend to provide you with all of the questions in a written format beforehand, in order to give you time to consider the precise content and context of each question – so that you feel both comfortable and satisfied with your answer.

The information provided (by you) will be stored for no less than five years succeeding the study being conducted and will be disposed of thereafter. This information will also be stored in a manner that protects your identity at all times.

The study does not carry any costs, incentives or reimbursements for participation.

CONSENT

I (Name)………………………………………………………… have been informed about the study entitled (**The experiences of males diagnosed with autism during their adulthood**) by Bomikazi Lupindo.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at 082 678 3844 or Lbomikazi@yahoo.com.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

Postgraduate Programmes Administrator

Rosalind Adams

Contact number: 021 650 3417

Email: Rosalind.adams@uct.ac.za

I hereby provide consent to:

Audio-record my interview YES / NO

______________________ ______________________

Signature of Participant **Date**

APPENDIX E: INTERVIEW SCHEDULE

The aim of this study is to explore the experiences of males who were diagnosed with high functioning autism during their adulthood. The questions in this interview schedule are aimed at capturing your experiences prior to receiving a diagnosis of autism, your journey towards receiving a diagnosis and your personal experiences following receiving a diagnosis. The interview is estimated to be approximately thirty minutes; therefore, may I please request that your responses be as short and concise as possible. If at any stage of preparing for the interview during the interview you may be unsure of anything, please feel free to request me to clarify anything you may be uncertain of.

Mental health

1. Prior to your diagnosis, have you ever had any mental health difficulties? If yes, are you able to briefly label, describe or classify those mental health difficulties?
2. Have you ever received a diagnosis of any other psychological condition? If so, what was the diagnosed condition and course of treatment? Did this course of treatment help you in your opinion?

Diagnosis

1. Can you identify or recall a process that led to you getting diagnosed?
2. Can you identify any emotional reaction you had when you found out about your diagnosis? You may describe this reaction in any way that you feel is appropriate.
3. How did other people around you react when you received the diagnosis? How did this reaction influence your own perception and acceptance of your diagnosis?
4. What do you feel has changed as a result of receiving a diagnosis of autism? Has receiving a diagnosis of autism influenced your experience of your own identity in any way? Specifically, has your awareness of having autism assisted you in understanding some of your past experiences with new insight?
5. Are you comfortable sharing your diagnosis with others? Why or why not?
6. If you can recall, did your parents have any concerns about your general development in terms of your social interaction and social communication prior to you receiving a

diagnosis? If yes, what caused these concerns for your parents? Can you recall what they did to try and address these concerns?

7. What difference (if any) do you feel getting a diagnosis of autism earlier in your life would have made?
8. What do you perceive as being an advantage of having autism?
9. What are some of the challenges you experience as an individual with autism?
10. How did you manage the challenges you experienced prior to your diagnosis, such as difficulties with social interactions?
11. Have you engaged in any strategies to hide your autism?
12. How has being a male with autism made things easier or more difficult for you?

<u>Life outcomes</u>

1. Have you ever been employed? If yes, how long were you employed and how would you describe your experience in your workplace?
2. Have you experienced barriers to being able to fulfil your work or do your job in the work environment? Were these sensory, social or demand-related? Your opinion would be welcomed.
3. Do you feel that your diagnosis can be linked to the difficulties you experience at work? Which of these difficulties you experience at work do you feel are linked to your diagnosis?
4. Are you still dependent on your parents? If yes, in what sphere are you dependent on your parents and what is the extent of your dependence on your parents?

<u>Summary</u>

1. Is there anything you would like us to know that would help us understand your experience with autism and receiving a diagnosis during your adulthood?
2. Is there anything you would like to know about me?

APPENDIX F: HANDWRITTEN NOTE FROM PARTICIPANT (Luke)

No parent should have to bury their child. I was going to kill myself after my parents had died.

APPENDIX G: DEMOGRAPHIC INFORMATION RELATED TO PARTICIPANTS

Table 1.1. Table Representing the Demographical Information of the Participants

Participant's Pseudonym	**Age at time of interview**	**Age at time of diagnosis**	**Year of diagnosis**	**Marital/ partnership status**	**Number and age of children**	**Living arrangements**	**Highest level of education**	**Qualifications**	**Employment status**
Albert	35	32	2015	Single	None	I live in my parent's flat. They assist me with minor housework and transport.	Bachelor's Degree	Bachelor of Science: Computing	Unemployed, student
Anthony	28	26	2016	Single	None	I live with my parents. I am dependent on my parents as I am unemployed and also on my friends for	Information not available	Information not available	Unemployed

						things like transportation.			
Boris	47	47	April 2018	Married	Children: 1; Ages: 9	I live with my wife and child, no assistance	Information not available	Information not available	Selfemployed
Francois	41	40	Feb 2018	Married	Children: 3; Ages: 2, 7 and 9	I live with my wife and kids in our own home, no assistance	National Diploma	National Diploma: Information Technology	Employed
Hennie	35	33	2016	Married	No children	I live with my wife, I do receive advice from psychologist and wife in dealing with people	Project Management NQF8. MBA Essentials NQF8.	I do not have a degree but have a lot of certificates. I am planning to do my BCOM – Financial Management.	Employed
Hugo	44		2017	Married	Children: 2;	I live with my wife and	Technicon qualification	Technicon qualification	Employed

					Aged: 16 and 19	children, no assistance			
Luke	39	35	2014	Single	None	I live alone, I receive financial assistance from my mother	National Diploma	National Diploma: Information Technology	Employed
Nicholas	56	56	2018	Married	Children: 3; Ages: 23, 14 and 8	I live with my wife and children, no assistance	Honours degree	Undergraduate degree: Marketing Management Honours degree: Business	Selfemployed
Mendel	48	44	2014	Married	Children: 4; Ages:	I live with my wife and children, I get assistance from my wife	Grade 12	High School certificate	Selfemployed
							Post		

Philip	64	64	February 2018	Married	Children: 1; Age/s: 18	I live with wife and son. Don’t receive or need assistance yet	Graduate Diploma, Post Graduate Certificate and MSc equivalent.	Degree in Engineering, Media, Film & Television, Marketing and Humanities	Unemployed