A sociological investigation of the lived experiences of people with Androgen Insensitivity Syndrome (AIS) in South Africa

L Loubser

orcid.org/0000-0003-2333-6992

Dissertation accepted in fulfillment of the requirements for the degree *Master of Arts in Sociology* at the North-West University

Supervisor: Ms C Cilliers

Co-Supervisor: Prof J Rothmann

Graduation: May 2022

Student number: 24160563

DECLARATION

I, Lize-Marié Loubser, declare that this dissertation and the work presented in it is my own and has been generated by me as the result of my own original research.

I further declare that:

i. This work was done wholly or mainly while in candidature for the MA degree in Sociology at the North-West University (NWU), Potchefstroom;

ii. Where any part of this dissertation has previously been submitted for a degree or any other qualification at the NWU or any other institution, this has been clearly stated;

iii. Where I have consulted the published work of others, this is always clearly attributed and referenced;

iv. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this dissertation is entirely my own work;

v. I have acknowledged all main sources of assistance;

vi. Where the dissertation is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

vii. None of this work or its parts have been published or submitted before.

Signed: L Loubser

Dated: 10 Dec 2021

ACKNOWLEDGMENTS

Completing this master's degree has been a journey in many different respects. I have learned so much about myself and my abilities and have gained so many valuable new skills as a researcher. There have been days where this was a steep mountain to climb, but also days where I have looked at my work with pride, feeling honoured to contribute to such a special and important area of research. This research would, however, not have been possible without the support and contributions of the following people:

- Above anyone else, I would firstly like to thank my incredible primary supervisor, Ms Carolé Cilliers, who have also grown to be a friend over the course of this study. She was a constant source of motivation and encouragement, words of wisdom and guidance.

- Secondly, I am very grateful for my fantastic secondary supervisor, Prof. Jacques Rothman, for being an extra pair of eyes and for always checking in to see if I was coping.

- Thirdly, I would like to thank my participants for their time and contribution to this study.

- Fourthly, I must give credit to my boyfriend, Lohann du Preez, who has given me endless support and encouragement (and snacks in the last month before submission).

- Fifthly, there is the rest of my "Potch family" – Antoinette, Zander and Renier. Thanks for all the chats, coffee, philosophy, and ranting sessions.

- Last, but certainly not least, there are my parents, Riaan and Antoinette Loubser, who have patiently been waiting for me to finish this study and who have cheered me on and have motivated and supported me throughout this journey.

ABSTRACT

Androgen insensitivity syndrome (AIS) is an intersex variation where a person is born with male chromosomes (XY chromosomes), but as a result of their body not responding to androgens, they develop and are born with a phenotypical female body. Individuals with AIS usually identify and live as women and the variation is often only diagnosed when they are medically investigated as a result of delayed puberty. Although AIS comes with specific health concerns that may require medical attention and intervention, it has been increasingly medicalized over the last 50 years, with gendered assumptions guiding medical protocols. Medicalized practices include medically unnecessary surgeries in many cases and also a conviction that individuals should not know the full truth about their variation as this would result in gender dysphoria. These medical practices of promoting secrecy and silence have contributed to the stigma surrounding an AIS variation. As a result of the shame that individuals have been made to feel about their variation, their experiences have been hidden and knowledge on AIS has until recently been limited to medical studies on the variation. Little is therefore known about the lived experiences of people with AIS worldwide and specifically in South Africa.

This study aimed to contribute to sociological investigations on the lived experiences of people with AIS in South Africa. This was done by providing a review and analysis of the existing literature and by making use of gender structure theory as a theoretical position. To gain access to the subjective views of people with AIS, data were gathered by making use of in-depth data collection methods. These methods included online written or face-to-face interviews with South African women with AIS. The findings of this study confirm findings in the intersex literature and show that medical practices and interactions with medical professionals over the years have contributed to the stigma of having AIS and to feelings of shame, objectification, and difference among participants. This contributed to negative health outcomes in participants' lives. Negative feelings of shame and difference were also reinforced by gendered expectations in everyday interactions with family and friends. Nevertheless, most participants had come to terms with their AIS with the support of an intersex community and supportive family, friends, and partners. There were also positive accounts of interactions with medical professionals where honesty, transparency and bodily autonomy were at the centre of interactions. This contributed to participants

understanding their conditions, making informed choices, and living healthy and happy lives.

Keywords: Androgen insensitivity syndrome (AIS), intersex, difference in sex development (DSD), biological sex, gender, medicalization

ACRONYMS

AIS	Androgen Insensitivity Syndrome
PAIS	Partial Androgen Insensitivity Syndrome
CAIS	Complete Androgen Insensitivity Syndrome
MAIS	Mild Androgen Insensitivity Syndrome
AR	Androgen Receptor
DSD	Disorder/Difference of Sex Development
IAAF	international Association of Athletics Federations
HRT	Hormone Replacement Therapy
ISSA	Intersex South Africa
ISNA	Intersex Society of North America
LGBTQI+	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex and others
IGLYO	International Lesbian, Gay, Bisexual, Transgender, Queer & Intersex Youth
NWU	North West University
GP	General Practitioner

Table of Contents

CHAPTER 1: INTRODUCTION AND PROBLEM STATEMENT

1.1 INTRODUCTION

In her book "Sexing the Body: Gender Politics and the Construction of Sexuality", Professor Anne Fausto-Sterling (2000) states that it is estimated that approximately 1.7% of any population are born with an intersex variation[1]. Despite it being more common than most people think, what it means to be intersex is still widely misunderstood. A major reason for this is that silence still surrounds intersex variations. Some people also may not know that they are intersex unless they undergo genetic testing (as is the case for athletes). There are individuals who do not identify with the term intersex and would not describe their sex variation as such. Intersex is also an umbrella term that includes several conditions, which results in many different experiences of what it means to be born as intersex.

One type of intersex condition is androgen insensitivity syndrome (AIS), which is one of approximately 40 different types of intersex variations (Maquba & Sehoole, 2018). According to Batista *et al*. (2018), AIS is the most common type of intersex variation in people with XY chromosomes. AIS affects the androgen receptors (AR) in a person's body (Geethika *et al*., 2016). This means that the body of someone who is genetically male

[1] Historically the term "intersex" was used to classify people who are born with internal or external sex variations. Over the last ten years the term "Disorder of Sex Development" (DSD) was selected by the international Consensus Conference on Intersex people as the overarching term to be used for congenital variations in the development of chromosomal, gonadal and anatomic sex, replacing terms such as 'intersex' and 'hermaphroditism' (Bennecke et al., 2020:1). There are however debates about whether it is still an offensive term as it labels people with atypical, sexed bodies as having a "disorder". Although the intersex participants of the European study by Bennecke *et al.* (2020) did not feel offended by the term "Disorder of Sex Development" and perceived it as a descriptive and neutral term, some people avoid the word "disorders" and rather use the word "difference or divergence" (Bennecke *et al*., 2020:2). For the purposes of this study, the terms "Intersex", "intersex variation" and "variation in sex development" were used as all of the participants identified with and were comfortable with these terms.

(they have XY chromosomes), responds either partially to androgens or not at all[2]. This leads to the atypical development of primary and secondary sex traits (Gulia *et al*., 2018). There are also different types of AIS, depending on the extent to which the affected person's androgen receptors can recognize and respond to androgens[3]. People with AIS are therefore born with bodies that do not follow the typical XY development pattern (Mendoza & Motos, 2012).

Over the last few decades, essentialist views on gender strongly dominated decisions regarding the sex and gender assignment of people with intersex traits and variations[4]. Because their bodies do not fit the distinct binary categories of male and female, variations like AIS were regarded as an abnormality, something shameful that had to be hidden from the child and others (Lev *et al*., 2006). This consequently led to medical procedures and surgical outcomes aimed at "correcting" atypical bodies as quickly and secretly as possible to fit a binary view of sex and gender (Fisher *et al*., 2016). This secrecy contributed to the general global population being relatively uninformed about what intersex, and more specifically AIS, is. What is known from studies and the documented lived experiences of people with AIS globally is that people with intersex variations, including AIS, often grow up with higher levels of inner conflict, shame, confusion, and insecurity since doctors and

---

[2] Patroa et al. (2009) define androgens as follows: "Androgens are steroid hormones that play key roles in the development and maintenance of male phenotype and reproductive function. These hormones also affect the function of several non-reproductive organs, such as bone and skeletal muscle."

[3] There are three types of AIS. The first type is complete androgen insensitivity syndrome (CAIS) where infants are born with bodies that developed according to a typical female pattern. People with CAIS are generally brought up and identify as female. They typically only learn during puberty that they do not have internal female reproductive organs, such as ovaries or a uterus, but that they have internal gonads consisting of testicular tissue. The second type of AIS is partial androgen insensitivity syndrome (PAIS) where infants are often born with genital variations (their external genitalia didn't develop according to a typical male or female pattern). In the majority of cases people with PAIS are assigned a male gender, but this gender assignment is problematic for some people with PAIS. The third type is mild androgen insensitivity syndrome (MAIS) where infants' external genitalia developed according to a typically male pattern, but they have defective spermatogenesis and are infertile (Batista *et al*., 2018). They are usually assigned a male gender and typically continue identifying as male.

[4] For McKeown (2014:6) essentialism is to have a perfect, simple, and functioning template and design of everything. In this context an essentialist view of sex and gender implies that all bodies belong to one of two categories – either male or female.

their parents or guardians deceive them or lie to them about their variations (Danon & Yanay, 2016). Their lived experiences are influenced by the fact that they must undergo various medical procedures (Tamar-Mattis, 2014) and grow up "differently" from their peers (Feder *et al*., 2009). However, as is evident from the content of the informal sources and literature found on social media sites, including Facebook and Instagram, and disseminated by AIS support and advocacy groups such as InterAct[5], some people with AIS live full and content lives regardless of their diagnosis (InterConnect, 2021).

Medical studies such as the South African study by Kemp (2013), the Brazilian study of Batista *et al*. (2018) and the British study by Hughes *et al*. (2012) largely dominate the research on intersex. However, there are limited sociological studies on intersex itself globally, with the majority focusing on intersex as a broad theme rather than on the different types of intersex. Some examples of sociological studies on intersex are the English study by Jones (2019) on intersex and infertility and the American study by Kelly (2007) which primarily focuses on intersex challenging the gender binary divide. These types of studies have been criticized as being too broad and not contributing to an understanding of different experiences of being intersex. An example of this is found in the twitter feed of intersex XOTurner (2021). Furthermore, in her blog post Clarecais (2021), a person who has complete androgen insensitivity syndrome (CAIS), has criticized the University of Sussex for its efforts to support young people born with intersex traits through a resource they created. Clare believes that there are no resources that successfully meet intersex needs while there are various resources that contribute to the fetishization and misinterpretation of intersex bodies. The discourse on intersex has also been criticized for being too focused on the issue of gender identity at the cost of other issues being raised by intersex activists. It is often used in gender studies courses as evidence that sex, and therefore gender, is not binary, at the cost of truly understanding the lived experiences of intersex individuals. Clarecais (2021) provides an example of this by further criticizing the University of Sussex for using the bodies of people with intersex variations "as props in debates about gender." XOTurner (2021), a person who has Turner syndrome, which is

[5] InterAct is a US advocacy group for intersex youths. This group was founded in 2006 by an attorney, Anne Tamar-Mattis. The aim of this group is to put a stop to any medical interventions on children with intersex variations that might have a negative impact on their lives (InterAct, 2020).

another of the various other types of intersex that exist, also criticized the University of Sussex for categorizing congenital intersex variations like Turner's syndrome as part of queer studies. She states that intersex variations have to do with the body and can lead to problems with the heart, senses, fertility and learning disabilities, and that specific support is needed for individuals, not just framing it as an identity issue.

It is then perhaps not surprising that very few sociological studies are done on the lived experiences of people with intersex, and on specific experiences like having AIS. One such sociological study on the lived experiences of people with AIS was conducted by intersex scholar Georgiann Davis *et al.,* (2016), who incorporated her lived experience as someone who has AIS into her sociological study. She raised several issues important to the experience of having AIS, including being lied to by doctors when she was told that she had underdeveloped ovaries that might be cancerous and had to have surgery to, in her words, "remove the supposedly dangerous organs" (Davis *et al*., 2016).

While there is limited sociological studies on intersex and on AIS specifically in the global context, there is even less in South Africa. While there are South African studies on intersex, like the study on activism for intersex and transgender groups by Klein (2009) and a study on the medical ethics of intersex surgeries by Behrens (2020), South African studies on AIS are mostly medical studies. These include, among others, that of Kemp (2013) on the prevalence of AIS among family members, or the clinical molecular investigations done by Scott *et al*. (2006). Furthermore, there has also been popular interest and publications on the suspected intersex variation of the South African athlete Caster Semenya, although Semenya has never publicly confirmed that she has an intersex variation[6]. As the majority of the South African AIS studies are medical, there is a gap on how South Africans with AIS experience various aspects of their lives with AIS. An investigation into the lived experiences of people with AIS in South Africa is thus important

[6] It is usually only stated that Semenya has a variation called hyperandrogenism, by which her body produces higher levels of testosterone than the bodies of other women – the reason for the hyperandrogenism has not been confirmed publicly. Her testosterone levels are higher than what are allowed for women to compete in international competitions of between 400 meters and 1 mile. This is argued to improve her performance as an athlete. To be allowed to compete, she has to undergo artificial hormone treatment to lower her testosterone levels to what the international Association of Athletics Federations (IAAF) see as an acceptable level (Katwala, 2019).

as it can shed light on the ways in which it is potentially different from the lived experiences of people with AIS globally. It can also reveal truths about their medically lived experiences, which can provide feedback to the medical sector and health care professionals in South Africa with respect to the care of people with AIS. This will hopefully lead to improved care. Knowledge of the lived experiences of South African people with AIS may also create awareness and contribute to better information among groups of people with AIS and those without AIS to potentially help to combat discrimination, challenge the stigmatization of those with AIS, and support people with AIS in managing their variations.

From the discussion, it becomes clear that the authority of medical professionals has had a profound impact on the lives of those living with AIS. It highlights the often harmful effects of medical advice on their identity construction, mental health, and relationships. This study focuses on the lived experiences of people with AIS in South Africa. The section to follow provides further background to the study, followed by the problem statement, research questions and objectives, and an overview of the methodological choices and theoretical framing of the study.

1.2 BACKGROUND

This section offers the background to this study by shortly summarizing the existing academic and informal literature on what is known about the lived experiences of people with AIS globally. The first subsection provides a detailed conceptualization of AIS. The second subsection provides a brief orientation to the medicalization of intersex variations and the influence of social science on intersex over the last century (to be discussed in more detail in Chapter 2). The third section briefly discusses the literature on the lived experiences of people growing up and living with AIS (also to be discussed in more detail in Chapter 2).

1.2.1 What is androgen insensitivity syndrome?

This section provides a detailed discussion of AIS to contribute to a clearer understanding of the variation that affects the lived experiences of the participants in this study.

During the first eight weeks of gestation, male and female embryos typically develop along a similar path (Geethika *et al*., 2016:1016). After week eight, however, the AR gene is expressed in male embryos[7]. This gene causes the development of testes, which start to produce testosterone from the ninth week of gestation. Gulia *et al.* (2018:3876) state that in AIS, there is a mutation on the gene that provides the information that is used to make the AR. The purpose of the nuclear receptor, AR, is to bind testosterone with dihydrotestosterone to, in effect, enable the cells in the tissues of the body to respond to androgen. If there is a defect in the assembly of the AR, the tissue cells show insensitivity to androgens in various degrees of severity (Gulia *et al*., 2018). AIS is medically classified according to three types, based on the degree of insensitivity to androgens. These types are complete androgen insensitivity syndrome (CAIS), partial androgen insensitivity syndrome (PAIS), and mild androgen insensitivity syndrome (MAIS) (Pritsini *et al*., 2017).

In CAIS, the phenotype body and external genitalia of the person are completely female without any visible variation, even though genetically they have XY chromosomes. Although their external body develops according to a female pattern, internally they have variations of sex development. Instead of developing ovaries, their internal gonads are made up of testicular tissue. These gonads produce the anti-Mullerian hormone that obstructs the development of female internal reproductive organs like the uterus, cervix, ovaries, the womb, and sometimes, vaginal development (Batista *et al*., 2018). People are usually only diagnosed with CAIS during puberty when they do not start a menstrual cycle or do not show other visible signs of puberty like growing breasts or pubic hair. They will then often be referred for a consultation with a gynaecologist to investigate the reasons for not experiencing normal pubertal changes (Batista *et al*., 2018). When the diagnosis is made, it is usually recommended that these young women with CAIS undergo a gonadectomy to remove the internal gonads. It is normally regarded as a necessary procedure due to a cancer risk if the gonads are not removed. Hormonal oestrogen

[7] YG (2016) explains gene expression as follows: “Gene expression is the process by which the instructions in our DNA are converted into functional products, such as proteins.” According to Davey and Grossman (2016) the AR can be defined as a “ligand-dependent nuclear transcription factor and member of the steroid hormone nuclear receptor family.” The purpose of AR is to enable the actions of androgens like testosterone (Davey & Grossman, 2016).

treatment is additionally prescribed to make breast development possible if the gonadectomy was performed before puberty. If the gonadectomy is performed after puberty, the gonads will have allowed breast development. While hormone replacement therapy (HRT) is important for the development of sex characteristics, it is also necessary to prevent osteoporosis, which may occur because of the insensitive nature of the androgens necessary for skeletal development. Taking HRTs can also help to prevent cardiovascular disease, which might occur in people with AIS (Ko *et al.,* 2017).

In PAIS, the AR functions partially (Geethika *et al*., 2016). For this reason, there are various possible genital variations in PAIS (Mazur, 2005)[8]. One of the most common PAIS variations is hypospadias[9]. According to Keays and Dave (2017), statistics indicate that hypospadias, which is a congenital variation of male genitalia, occurs in 1 out of 200 live male births. Batch *et al*. (1993) state that roughly 10% to 50% of PAIS males have abnormalities on their androgen receptors and it is these abnormalities that can cause hypospadias. The gender assignment of babies with PAIS as either male or female is usually determined by the degree of hypomasculinization (Mazur, 2005:412). It is usually recommended that gender reconstructive procedures like correcting hypospadias be done before the child reaches two years of age (Batista *et al*., 2018:231). This is done to successfully raise the child in a gender binary category of either male or female (Danon & Yanay, 2016). During puberty, boys with PAIS might develop gynecomastia (the development of breasts) due to an imbalance of oestrogen and androgen (Soliman *et al*., 2017). At this point they often require mastectomies. Due to a hormonal imbalance, boys with PAIS may take testosterone to promote penal growth and virilization (Batista *et al*., 2018). There are also people with PAIS who are raised as girls. They must undergo medical procedures such as gonadectomies and genitoplasty and have to take oestrogen supplements for the rest of their lives (Batista *et al*. 2018:231).

---

[8] According to Mazur (2005) some of the variations of PAIS entail perineoscrotal hypospadias, with or without cryptorchidism, to a micropenis, with or without hypoplastic labioscrotal swellings and remnants of female internal reproductive structure.

[9] Keays and Dave (2017) define hypospadias as follow: “Hypospadias is a variation where the urethra opens on the underside of the penis with associated ventral penile curvature.”

In MAIS there are also mutations in the AR gene (Batista *et al*., 2018:229). This leads to MAIS. The phenotype body of someone with MAIS is, however, male and there are no genital variations (Batista *et al*., 2018:22). People with MAIS usually have defective spermatogenesis and it is therefore usually diagnosed in patients seeking medical help for infertility (Kapoor *et al*., 2016:815). It can also be diagnosed when gynecomastia develops during puberty, which often leads to surgeries to have a mastectomy done. According to Batista *et al*. (2018:231), presenting with gynecomastia and infertility are usually indicators of MAIS.

Given the above context of common AIS variations, I now discuss some key points regarding the medicalization of intersex [10].

1.2.2 The medicalization of intersex

In the early 19th century, the birth of babies with atypical bodies gave rise to a division between those with 'normal bodies' and those with 'abnormal' bodies in biomedicine (Karkazis, 2008). Intersex posed a social dilemma for the society of the time as people who were born this way did not neatly fit into the sex categories of either male or female. This, along with fears that they might resort to homosexuality since their bodies are so different, became the driving force behind doctors at the time coming up with a treatment protocol and optimal gender assignment of these patients (Reis, 2009). Due to underdeveloped medical knowledge and technology at the start of the 19th century, intersex variations were difficult to diagnose. In the Victorian medical model, the presence or absence of gonads determined what the 'true' or 'best' sex of the person was (Kennedy, 2016). From the 1930s, however, psychology began to play a bigger role in intersex diagnosis.

According to Kennedy (2016), the work of psychologist John Money greatly influenced medical protocols on the management and treatment of intersex variations from the 1950s

[10] According to Conrad (2003), the term "medicalization" refers to ways in which something is, in his words, "made medical." This term emerged in the 1970s within the context of social science. It was used to critique how medicine asserted power and authority over problems of a nonmedical nature by defining and treating these problems as medical problems.

until recently. Money's theories argued that a person is not born with fixed gender identity, but that it develops during the first two years of a child's life – it is therefore somewhat flexible before this age. A stable male or female gender identity, according to Money, develops when a child is raised according to their assigned gender (assigned according to their external sex traits), which is repeatedly reinforced during the first two years of life. The gender assignment of infants with intersex variations, according to Money, therefore, has to be done as soon as possible for children to be raised in one of the gender binary categories. He also advised that genital reconstructive surgery takes place as soon as possible so that a child would visually fit into a male or female category that corresponds with the gender assignment. The gender assignment surgeries usually depended on whether the baby had an adequate penis. Since it was considered easier to construct a vagina than a penis, many intersex babies were assigned as females[11] (Kennedy, 2016). While Money's protocols entailed gender assignment and reconstructive treatment, there were also protocols for the social treatment of a child with intersex variations. Money and his colleague Joan Hampson advised parents to fully understand their child's variation, but to keep this information from the child and other people, especially if the child had undergone genital reconstructive surgery (Reis, 2009). Parents were also advised to relocate to a place where no one would know of their situation. Oakes *et al*. (2009) from the Department of Obstetrics and Gynaecology University of Michigan Health system state that in 1953 American gynaecological researcher John Morris advised that adults with CAIS should not know about their true genotype and should only be told that they are unable to have children. This was an ethics implementation called "therapeutic privilege" (Conn *et al*., 2005). This validified the non-disclosure of some details about a patient's diagnosis if it was believed not to be in the best interest of the patient to know all the aspects of their diagnosis (Conn *et al*., 2005).

While this treatment protocol remained unchanged for forty years, the emergence of the internet in the 1990s brought about changes as intersex people were able to search for

[11] There is a sexist bias in considering a vagina easier to construct than a penis, and there was a "striking lack of attention to the size and shape requirements of the female genitals" in medical literature (Kessler, 2002: 26-27).

answers about their variations (Zieselman, 2020). They were also able to form online support groups where they could interact with other people who had similar variations. As more people began to share their stories, the optimal gender theory and standard intersex treatment protocols faced great criticism (Kerry, 2011). Over the next twenty years, intersex patients, their parents, and some healthcare workers criticised the treatment protocols and called for an end to unnecessary genital reconstructive surgeries on infants (Leidolf *et al*., 2008). While the original treatment protocols are still largely in place, there are signs that some positive changes are happening (Jenkins & Short, 2017). These include transparency and full disclosure to patients, the availability of psychological counselling, and the fact that intersex patients can choose whether they want to have genital reconstructive surgery performed when they reach puberty (Kemp, 2013).

The medicalization of intersex had and still has a profound effect on the lived experiences of many intersex people globally. From the literature, I was able to gather that some of the greatest areas of impact were their experiences of medical and familial authority over their bodies, their gender identity and identity construction as people who have AIS, and the influence that AIS has had on their different relationships and mental health. In the next section, I briefly introduce these aspects.

1.2.3 Growing up and living with androgen insensitivity syndrome

1.2.3.1 The authority of medicine and family/guardians

Parents of intersex children often look to doctors to give them answers about what to make of their children's atypical bodies and they trust these professional and medical opinions. In many cases however, this has an irreversible effect on the lives of people with AIS.

Money's treatment protocols included genital reconstructive surgery, but also the nondisclosure of the truth about an intersex child or person's diagnosis. While doctors and parents regarded these treatment protocols as being in the best interest of patients, people with AIS globally expressed feeling objectified, feeling as if doctors speak over them, being confused by medical jargon, not giving consent, being subject to uninformed decision making, etc. (Davis & Preves, 2019). While parents did trust doctors to perform invasive surgeries on their children and keep these procedures a secret, they were often also subject to uninformed and hasty decision making due to doctors' emphasis on the urgency

to operate and confusion about the medical jargon (Danon & Yanay, 2016). Doctors' emphasis on secrecy also created feelings of shame in parents and caused them to hide their child's variation from others and the child (Danon & Yanay, 2016). As a result, many intersex people experienced feeling lied to by their parents, being angry, feeling rejected by parents, gender dysphoria, immense feelings of shame, feeling freakish, etc. (Davis *et al*, 2016).[12] Over time there have been changes in the medical management of AIS in some contexts. In response to what many health professionals now consider to be mistakes in the AIS management of the past, for example keeping information secret, there are now efforts to ensure that patients have a full understanding of the medical procedures and give consent. This entails thorough information and counselling of parents by a psychologist who is educated in AIS variations. Furthermore, it is now generally considered important that children with AIS are fully aware of their variations before adulthood (Kemp, 2013).

In the next section, I touch on what global literature has to offer on how a diagnosis of AIS may influence the gender identity construction of people with AIS.

1.2.3.2 Gender identities

Since people with AIS do not have typical male or female bodies, they often experience challenges regarding their identity and gender identity construction.[13] This section provides a brief overview of the gender identity construction of people with AIS and the lived experiences with respect to how a diagnosis of AIS has shaped their gender identities. Categories like sex and gender are commonly recognized and are used daily by people to make sense of and create order in the complicated construction of the social world[14].

---

[12] Mazur (2005:412) defines gender dysphoria as "a feeling of dissatisfaction with one's assigned or legal gender." According to Tamar-Mattis (2014), this happens to 8.5%-20% of people who undergo gender assignment surgery.

[13] Wood and Eagly (2015:109) state that "from a social role perspective, gender identity reflects the different placements of men and women into societal roles."

[14] Sex is a term that is used to refer the biological primary sex characteristics of a person. Gender is a term that is used collectively for the social meaning, values, roles and traits that people ascribe to and associate with a certain sex (Blackstone, 2003:335).

Essentially, sex is placed into the binary categories of male (being born with a penis) and female (being born with a vagina). Most people see sex/gender as something that is fixed and *"*natural, inevitable and biologically determined*"* (DeLamater & Shibley Hyde, 1998:10). However, people with intersex variations such as AIS, challenge this "neat" and "simple idea" of sex which, in the words of Mckeown (2014:6*), "*rejects the idea that we can all fit*."*

While some of these experiences overlap between the different types of AIS, people with PAIS, who are born with atypical bodies, more often experience gender dysphoria. There is the possibility that they would develop traits of the opposite gender from their assigned gender (for instance where boys grow breasts or start to menstruate when they reach puberty). They experience embarrassment, confusion, and shame (AIS Australia Support Group, 2019). Due to lengthy hospital visits and secrecy, some also feel like they are missing out on important social and gender identity shaping events (considered as "normal" gender behavior) that their peers experience (Feder, 2009). People with PAIS also have a higher risk of psychological challenges including anxiety and depression compared to adults with CAIS (Hughes *et al*., 2012:1426). People with CAIS, on the other hand, are born with the phenotypical bodies of women and usually live and identify as women. They often only become aware of their variations during adolescence. They can feel isolated from other women, experience a fear of not being normal, feel inferior due to their infertility and experience depression and mental health problems because of their feelings of inferiority. Hughes *et al*. (2012) argue that it is important in current AIS management that the disclosure of an AIS diagnosis is done carefully and with psychological support. This is necessary as the diagnostic disclosure may provoke emotional responses from patients and their parents. If this is done correctly, people with AIS can orient themselves and their identities better around the fact that they have an intersex variation and be spared much of the identity confusion.

While people with AIS globally experience challenges with their identities and gender identities, AIS also has an impact on their mental health and various relationships. This is shortly discussed in the next section.

1.2.3.3 The influences on mental health, relationships, and intimacy

Growing up with AIS can have a significant effect on one's mental health, relationships, and potential for intimacy. This section engages findings in academic and informal literature on the influence a diagnosis in AIS may have on the mental health and relational lived experiences of people with AIS.

Yellappa and Venkatesh (2015) found that people with AIS often have negative lived experiences such as trauma and physical and psychological discomfort regarding sex and intimacy. According to a US study by Tamar-Mattis (2014), some people with AIS may display suicidal and self-harming behaviour. This might be partly attributed to medical practices where children with AIS variations undergo various medical procedures from a young age that they do not necessarily understand or give consent for and, as a result, they suffer trauma (Tamar-Mattis, 2014). Due to negative medical lived experiences, some remain asexual (Davis *et a*l., 2016:11). People with CAIS often experience great distress when they find out that they cannot menstruate and will thus not be able to bear children of their own one day. Infertility might in some cases challenge relationships. As seen in the sections above, older medical protocols for the treatment of AIS often entailed that the truth about a patient's variation be kept a secret from them. Thus, some people with AIS have difficulty trusting others.

Although a diagnosis of AIS can entail various challenges, formal and informal literature such as articles written by Davis *et al*., (2016) and representatives of InterConnect (2021) and the AIS Support Group (2019), has shown that some people with AIS experience talking and being open about their variations as a healing experience. Honesty and openness about their lived experiences have also helped people with AIS to form better relationships with their families and the people around them (Davis *et al*., 2016). Some people with AIS experience that they can use their variation to find acceptance of their body and self and have a full, normal, and rewarding life despite their variation.

The preceding section foregrounds the fact that a diagnosis of AIS has a definite effect on people's romantic, familial, and friendship relationships, both positive and negative. With this background in mind, I subsequently discuss the problem statement of this study.

1.3 PROBLEM STATEMENT

This section presents the problem statement for this study. I do this by firstly visiting the general problems surrounding the lack of global intersex research and reasons why it is important to conduct studies on specific forms of intersex like AIS and the lived experiences of these people globally. Thereafter, I provide the central problem statement of this study, which focuses on the South African context specifically.

Despite its common occurrence, there is "a global silence around intersex lives" (Karaca & Macauly, 2017). The global silence on intersex has resulted in numerous problems with how people understand (or fail to understand) intersex. Some of these include the following: As a result of this silence, intersex is often confused with individuals who are transgender and who also suffer secrecy, silence, and stigmatization (InterAct Advocates for Intersex Youth, 2016).[15] While intersex and transgender groups share the fact that their members would like to choose their own gender identity and often require hormone replacement therapy, it is very important to distinguish between these groups since they are not the same (ISNA, 2008). Most intersex people prefer to live with either a male or female gender identity and are less prone to experience conflict with their gender identities, while most transgender people identify as transgender or transsexual and are prone to experiencing problems with their gender identities (ISNA, 2008). Subsequently, they have different experiences and face different forms of stigmatization, which means that generalizing their experiences is damaging to both groups (ISNA, 2008). It is therefore important to conduct studies that focus on the lived experiences of people who have an intersex variation specifically, and to not just group intersex with research on LGBTQI+ (lesbian, gay, bisexual, transgender, queer/questioning, intersex and others) people without specifically focusing on the needs and interests of intersex people.

[15] There is some confusion regarding the difference between intersex variations and being Transgender. InterAct Advocates for Intersex Youth (2016) differentiates transgender from intersex as follows: "A person who is transgender has a gender that is different from the one traditionally associated with the sex they were assigned at birth, a person who is intersex was born with a variation in their sexual or reproductive anatomy such that their body does not fit typical definitions of male or female."

Despite the existence of multiple different intersex variations, intersex people are often grouped into one category and their experiences are generalized. This is exacerbated by the fact that, in general, social research on the experiences of intersex people are lacking, which compounds the misinformation and lack of understanding of what it means to have an intersex variation. This lack of information is partly due to the secrecy and shame connected to the topic of intersex (ISNA, 2008). The general shortage of studies on intersex and grouping intersex as one homogenous category contributes to misinformation about intersex as a whole and can further the stigmatization and shame that often accompany the different intersex types. This underscores the importance of studies that specifically focus on the experiences of people with a specific type of intersex, like AIS, to ensure that there is growing first-hand knowledge on the differences between intersex people and their unique needs.

In the world in which we live today, people have easy access to social media platforms like Instagram, Facebook, TikTok, Twitter, etc. Various forms of online activism can take place using this medium (Khiry, 2020). However, it can be harmful when people use intersex lives to make arguments about gender identities without considering whether it has value to intersex communities or merely contribute to stigmas. Clarecais (2021), a person who has CAIS, states that there are few resources that meet intersex needs, while there are various resources that contribute to the fetishization and misinterpretation of intersex bodies. Academics have also been accused of using the existence of intersex people as evidence in their academic arguments and teachings (to, for example, challenge heteronormativity based on binary views of sex and gender), without creating any further awareness of intersex lives and issues (such as infant genital surgery) that are important to the intersex community (XOTurner, 2021). This contributes to the misinformation and lack of understanding of intersex lives (Clarecais, 2021). The Interact Media Guide (InterAct Advocates for Intersex Youth, 2017) points out that it is crucial when writing about or discussing intersex that a person speaks to or uses information from people who have one of the intersex types themselves “to bring in other experts who can provide accurate, fact-based information.” A study like this on the lived experiences of people with AIS can enable people who want to help the intersex community to understand specific areas where they can help to bring forth a change that would truly benefit and have value for the

intersex community, rather than to make generalized assumptions that cause more harm than good.

While limited, there are some South African studies on intersex. Some of these include the study on activism for intersex and transgender groups by Klein (2009), a study on the medical ethics of intersex surgeries by Behrens (2020), Van Jaarsveld's (2018) master's dissertation on the lived experiences of women with Turner syndrome in South Africa and online articles like "Growing up Intersex in a Country where it is Believed to be Bad Luck" written by Salaudeen (2019), Lock Swarr's (2012) "Sex in Transition: Remaking Gender and Race in South Africa" and Magubane's (2014) article "Caster Semenya, Intersex Studies, and the Problem of Race in Feminist Theory". While these studies do provide some information about intersex variations, there are some gaps. Salaudeen's study provides insight into the lived experiences of people with intersex in South Africa where there is a stigma around intersex variations. Her article, however, addresses the experiences of people with different intersex variations and does not focus on AIS. The study of Lock Swarr focusses on problems of gender and race specifically and intersex only forms a small part of her study. She addresses intersex in broad terms and does not focus on AIS specifically. Like Lock Swarr's study, the study of Magubane focusses on intersex as a broad concept in relation to race and feminism and not AIS. In this study I aim to fill some of these gaps by providing the narratives of the lived experiences of people who have AIS in particular to contribute to the very limited information in this area.

The South African studies on AIS are mostly medical studies. These include, among others, that of Kemp (2013) on the prevalence of AIS among family members, or the clinical molecular investigations done by Scott (2006) and Scott *et al*. (2006). There is also an interest in the speculated intersex variation of the South African athlete, Caster Semenya. The problem in the South African context specifically is thus that little is known about the personal lived experiences of people with AIS in South Africa. It is claimed that South Africa is a country with one of the highest intersex numbers in the world as 1 in every 1000 babies South African babies are born with an intersex trait (Collison, 2018). South Africa is also a country with a history of racial juxtaposition which was visible in South African medicine and science. Healthcare professionals claimed that black people are more prone to have intersex bodies than white people. Before South Africa became a democratic party it was protocol in the South African healthcare system to not include the

medical statistics of black people into the medical overall statistics of the country. This was to give the impression that healthcare professionals had control over the healthcare challenges of black people while it was protocol to withhold healthcare from these groups as a means of population control. Subsequently it can be argued that the racialization of intersex was also fabricated and linked to people of a certain class group. (Lock Swarr, 2009). It is therefore important to investigate the lived experiences of people with AIS from different demographic areas like race.

Some of Intersex South Africa (ISSA), a non-governmental organisation (NGO), main missions include ending non-consensual intersex surgeries and to ensure that intersex people have the right to full disclosure, information, and access to their medical records (FRIDA, 2021). One of the great areas of importance is thus people with AIS' interactions with medical practice and health professionals. This study may gain insight into what medical reforms people with AIS would like to see in their treatment in the future in South Africa. South Africa still experiences high numbers of discrimination against people based on their gender identity, gender expression, and body diversity (Mokoena, 2015). Another of ISSA's missions is thus the removal of the stigma and secrecy around intersex people and the ending of infanticide and intersex killings due to religious or traditional beliefs. It is, therefore, necessary to see what effect a diagnosis of AIS has on the identity construction of people and how it affects their familial, friendship, and intimate relationships. ISSA also wants to spread knowledge of intersex and provide support for intersex people. By doing this study, the researcher aims to emphasize the lives and lived experiences of people with AIS in South Africa. This will help other South Africans with AIS and South Africans in general to form a better understanding of what AIS and a life with it entails.

With this problem statement in mind, I put forward the most suitable research question(s) and research objective(s) for this study in the next section.

1.4 RESEARCH QUESTIONS

The main research question was formulated as follows:

What are the lived experiences of people with AIS in South Africa?

Research sub-questions were formulated as follows:

a. What do literature and theory state about the lived experiences of people with AIS?
b. What methodology will be useful when studying the lived experiences of people with AIS?
c. How has the medicalization of AIS affected the lives of people with AIS in South Africa?
d. How do people with AIS experience their interactions with health care professionals?
    - In what ways have interactions with medical professionals helped or hindered living with AIS?
    - What recommendations would people with AIS make about the practices of health care professionals surrounding their healthcare?
e. How has the diagnosis and treatment of AIS shaped ideas and experiences of gender of persons with AIS?
f. How has the diagnosis and treatment of AIS influenced family and other relationships?
g. What conclusions and recommendations can be drawn from the study?

1.5 RESEARCH OBJECTIVES

The main research objective was formulated as follows:

To investigate the lived experiences of people with AIS in South Africa.

Sub-research objectives were formulated as follows:

a. To indicate what the literature and theory state about the lived experiences of people with AIS
b. To explore the relevant research design and methodology used for the study
c. To investigate how the medicalization of AIS has affected the lives of people with AIS in South Africa
d. To show how people with AIS experience their interactions with health care professionals
    - To understand the possible ways in which interactions with medical professionals have helped or hindered living with AIS

- To explore the recommendations that people with AIS would make about the practices of healthcare professionals surrounding their health care

e. To understand how the diagnosis and treatment of AIS have shaped ideas and experiences of the gender of persons with AIS
f. To explore how the diagnosis and treatment of AIS have influenced family and other relationships
g. To draw conclusions and recommendations from the study.

1.6 CENTRAL THEORETICAL ARGUMENT

This study adopted a gender structure theoretical position as conceptualized by Barbara Risman (2004). This position views gender as a social structure to "better analyze the ways in which gender is embedded in the individual, interactional, and institutional dimensions of our society" (Risman, 2004:429). Such a conceptualisation places the same emphasis on gender as on the economy or political sphere in structuring society and influencing the lives of individuals. The use of Risman's theoretical schema follows its use in the work of sociologist and intersex scholar, Georgian Davis (2015). She used the schema to analyse the shift to the new intersex terminology and how intersex activism has disrupted medical authority and how intersex individuals, their parents and medical professionals make sense of an intersex diagnosis.

Davis' research shows how the justification of medical protocols related to the care of people with intersex variations (including those with AIS) are related to gendered norms and expectations. This does not mean that the experiences of AIS is only relevant in as far as it relates to gender, but it demonstrates how gender is ubiquitous and influences every aspect of our lives.

1.7 RESEARCH METHODOLOGY

This section describes the design and research methods that used in the study. I provide a brief discussion of the philosophical foundations of this study, namely constructivism and interpretivism. I also discuss the qualitative research design and provide an overview of the methodology. An in-depth discussion of the methodological aspects is provided in

Chapter 3; this discussion is therefore an orientation towards the most suitable methods to conduct this study.

1.7.1 Philosophical findings

As this study sought to investigate the lived experiences of the people with AIS in South Africa, the ontological position that was taken was social constructivism, while the epistemological position was interpretivism. Both these approaches view reality and knowledge as socially constructed and something that stems from the lived experiences of people in the social world (Tuli, 2010). These philosophical foundations correlate with the central theoretical stances of this study, which is gender structure theory. Contemporary gender theory can be seen as a criticism of the modernist and structuralist beliefs that reality and knowledge are rigid and fixed (Calafell & Nakayama, 2016). These beliefs contributed to the medicalization of intersex variations like AIS, as people who have atypical bodies challenge the gender binary divide. The main assumption of social constructivism and interpretivism is that the gendered reality is socially constructed as people form an understanding of it as they interact with each other and the social world (Payne *et al*., 2008).

Next, I discuss the qualitative research design used in this study as an approach that complements the philosophical findings.

1.7.2 Research design

The research design that best suit the philosophical foundations of constructivism and interpretivism is a qualitative design (Pryce *et al*., 2014). In this study, it was important to make use of a research design that would allow me to gain insight into the lived realities of my participants. As opposed to quantitative research, a qualitative research design is not interested in explaining phenomena, but rather to describe and understand them. Using a qualitative research design, I was best able to get access to the unique beliefs, lived experiences, and worldviews of my participants (Haradhan, 2018).

The following section includes a discussion of the different components of the methodology that used in this study.

1.7.3 Methodology

The participants in this study included five people who have been diagnosed with AIS by a medical practitioner and who were over the age of 18. I made use of non-probability-based sampling and sampling methods such as purposive and snowball sampling.

After establishing the sample that would be used for this study, I had to collect data from the participants in this sample. I made use of life history methods to collect the data for this study as it follows the principles of qualitative data collection and, as the term suggests, entails participants telling their life stories. This was done by means of an in-depth, online, face-to-face or written interview with each participant. The interviews aimed to get each participant to tell the story of their life in their own words (Ssali *et al*., 2015). To give some structure to the interviews, an interview guide with potential themes and questions was sent to participants beforehand. I also kept it at hand during the interview. This ensured that the same broad topics and questions were introduced to each participant, but it allowed enough flexibility so that each participant could determine the direction of the interview. The questions in this guide were categorized under the following themes: Diagnosis, Childhood, Adulthood, Relationships, Support, Mental health, Relationships with the medical establishment.

After the data had been collected, it had to be analysed. The process of data analysis entailed the transcription of each interview, after which I made use of open coding to identify themes in the raw data. After this, I made use of axial coding to indicate certain themes. These included stigmas of an atypical body; the social consequences of having an atypical body; the impact of medical interventions on stigmas experienced; and coping with an AIS diagnosis.

In the next section I discuss the important ethical considerations that were considered in this study.

1.7.4 Ethical considerations

As this was a qualitative study, I interacted closely with research participants to enable them to tell their life stories and experiences living with AIS through life history research methods. The topic of discussion was sensitive, so I had to remain aware of the necessary

ethics. According to Aluwihare-Samaranayake (2012:65), ethics entail that a researcher strives to always do good and avoid doing any type of harm to their participants, whether it is mentally, physically, or psychologically. Some of the ethical considerations relevant to this study include that the participants gave informed consent through an informed consent form and were all willing to participate out of their free will. I ensured confidentiality, anonymity, and privacy by using pseudonyms for the participants instead of their real names. I also refrained from discussing the content of interviews with anyone and always attempted to not deviate from the real narratives of the participants during the analysis and writing of findings. I avoided inflicting any physical, mental, or emotional harm to participants by not pressuring them to talk about a topic if I saw that it made them uncomfortable. I also arranged with a psychologist to be available for counselling if one of the participants would require it. Furthermore, throughout the interviews, I regularly asked participants if they were alright to ensure that the duration of the interviews did not exhaust them.

With an overview of the literature, problem statement, research questions and goals, central theoretical arguments, and most suitable methods to conduct this study in mind, it was important to provide some of the significances of this study. This discussion followed.

1.8 SIGNIFICANCE OF THE STUDY

Intersex variations like AIS have been met by silence and shame in the past and in some cases, still today. By participating in this study, participants were provided with the opportunity to tell their life stories and to share their lived experiences as people living with AIS in South Africa. As seen in the Chinese study by Suen (2015) and the US study done by Noland (2012), perceived “vulnerable groups” often find participating in research to be a positive and empowering experience. The initial email contact with the convenors of support groups for AIS in South Africa also indicated this to be the case, as they were enthusiastic about participating in the study and saw the academic focus on intersex in South Africa as “long overdue”.

There has only been limited social research on intersex variations in South Africa with examples provided in the problem statement. In the problem statement I also referred to some of Intersex South Africa’s missions, of which the first entails the spreading of knowledge regarding intersex. This study contributes to this knowledge and aims to help

organizations like ISSA to combat issues like secrecy and shame, discrimination, killings, violence against intersex people in South Africa, unnecessary surgeries, and misinformation. In her memoir, XOXY Zieselmann (2020) indicates that people with intersex variations are also eager to share their experiences with the medical sector to enable reforms. Although the findings of this study will not be distributed to the medical sector directly, the completed dissertation will be available online on the NWU repository. In this manner both the public, academics and medical workers can gain access. The findings provide insight into the relationship of people with AIS with medical professionals and contribute to the knowledge about this relationship. This could potentially be used to facilitate better communication and relationships and further influence protocols on the medical management of AIS.

This study acted as a means by which people with intersex variations could distribute information and insight to the medical sector. They also stood the chance to potentially help facilitate better communication and relationships between members of the intersex community and doctors regarding intersex treatment and protocols. This study has the opportunity to create awareness of people with intersex variations by revealing their own lived experiences and incorporating that into the existing knowledge of intersex variations rather than only relying on what is known about intersex variations through the works of people with gender-typical traits.

1.9 CHAPTER LAYOUT

Chapter 1: Introduction, background, and problem statement

This chapter provided the introduction and background to the study. It included an overview of the topic, the research problem, and research questions and objectives.

Chapter 2: Literature review and theoretical orientation: The lived experiences of people with AIS

This chapter evaluates the existing literature on the lived experiences of people with AIS in South Africa and abroad. It also includes a discussion of the central theoretical assumptions of sex and gender.

Chapter 3: Research methodology

In the chapter on research methodology, the most suitable research approach, research design, sampling procedures, data collection, and data analysis for the study are discussed. Furthermore, it emphasizes the ethical considerations for the study, providing the possible limitations of the study, and comments on the significance of the study

Chapter 4 and 5: Findings

These chapters offers an in-depth discussion of the empirical findings and analysis according to the existing literature on the lived experiences of people with AIS globally and theoretical assumptions of sex and gender.

Chapter 6: Conclusion and recommendation

Chapter 6 concludes the research by answering the general and specific research questions posed in Chapter 1. The final section of the chapter offers a concluding overview of the main findings and conclusions. Furthermore, it foregrounds particular recommendations for further studies or ways in which the research problem and other problems related to the topic can be addressed by future research.

CHAPTER 2: THE MEDICALIZATION OF INTERSEX VARIATIONS – A LITERATURE REIVEW

2.1 INTRODUCTION

Medical authority plays an important role in the decision-making and treatment of people with intersex variations such as AIS. Doctors are trusted to guide parents and individuals with AIS towards the best potential options and decisions for the treatment of AIS variations. The treatment decisions doctors and parents make affect the lives of people with AIS in various ways and ultimately contribute to their lived experiences. In this chapter, I provide a review of the academic literature on the lived experiences of people with AIS. This literature review helped me to answer the first research question: What do literature and theory state about the lived experiences of people with AIS? This was done by showing that the medicalization of intersex has contributed to the lived experiences of people with AIS in a variety of ways. This chapter furthermore provides a theoretical foundation for meaningful data analysis.

The chapter consists of two parts. In the first part, I offer a review of the literature to contextualize the lived experiences of intersex people, in particular those born with AIS. I firstly provide a historical timeline of the medicalization of intersex variations. Secondly, I provide a discussion of the formal (academic) and informal (as found on social media and support groups) literature on the lived experiences of people with AIS. This discussion demonstrates how the following research questions of this study fits into the existing literature and research: How do people with AIS experience their interactions with health care professionals? How has the diagnosis and treatment of AIS shaped ideas and experiences of the gender of persons with AIS? And, how has the diagnosis and treatment of AIS influenced family and other relationships?

The second part discusses the theoretical literature on the understanding of the sex/gender distinction. I discuss the academic use of the term gender. However, there are arguments that the importance of the body and gendered experiences should not be disregarded. I conclude this chapter by discussing how gender structures theory. An understanding of the different levels at which gender structuring takes place helped me to better interpret the lived experiences of people with AIS in South Africa during data analysis.

2.2 A TIMELINE OF THE MEDICALIZATION AND DE-MEDICALIZATION OF INTERSEX

According to Conrad (2003), the term “medicalization” refers to ways in which something is, in his words, “made medical.” This term emerged in the 1970s in the context of social science. It was used to criticize how medicine asserted power and authority over problems of a nonmedical nature by defining and treating these problems as medical problems. Medicalization played a great role in how variations in sex development were viewed and treated in society over the years and had a direct effect on the lived experiences of people with intersex variations like AIS. It is therefore important to provide a timeline of the medicalization and later attempts to de-medicalize intersex variations to contextualize the experiences of people with AIS in South Africa.

The medicalization of intersex can be categorized into three time periods. The first era is the era before the 1950s. This era is marked by the search for “true sex.” Physicians believed that hidden within each person with a sex variation was the sex that they were destined to be born into. They viewed it as the responsibility of physicians to “interpret patients’ lives and decide on a treatment” (Reis, 2009:90). The second era spanned from 1950 to 1970 and was heavily influenced by the psychologist John Money and his contributions in shaping the treatment protocols for people with intersex variations. This era is associated with the notion of “best sex” (Kennedy, 2016). According to Germon (2009:35) “best sex” referred to “whichever sex seemed most appropriate in light of the person’s genital appearance, psychological makeup, and familial environment.” The best sex approach attempted to offer a person the possibility to live “the best kind of life” with an atypical body in a society where one had to be either male or female (Germon, 2009:35). The last era stretches from the 1990s until the current time. It is the era in which activism has played a great role in the de-medicalization of intersex variations. This entailed directly challenging the intersex treatment protocols of the John Money era, re-evaluating the necessity of intersex reconstructive surgeries, and combatting the secrecy, shame, and stigma that has surrounded sex variations over the last century. In the following section, these three eras will be discussed in more detail.

2.2.1 Intersex before the 1950s: Before the John Money era

At the beginning of the 20th century, a shift of the birthing process to hospitals staffed by male doctors replaced midwives and home births. Although this change was deemed a

better option in terms of safety and comfort for both expectant mothers and their doctors, it made children born with noticeable external variations exceedingly accessible to doctors (Karkazis, 2008). As people born without external variations appeared to be gender-typical males and females, they were assigned a gender according to the binary appearance of their genitals. If later in their lives they experienced gender dysphoria, they would be treated on a case-to-case basis as there were no standard treatment protocols for intersex variations (Karkazis, 2008). Those born with visible external variations, however, gave rise to a differentiation between the natural categories of male and female and supposed abnormal males and females in the world of biomedicine over the next few years (Karkazis, 2008). According to de Paula and Viera (2015), the term "hermaphroditism" was used to classify people born with intersex variations during this period early in the 20th century. In 1922, physicians were eager to treat intersex variations with operations despite being aware of the limitations of doing these surgeries (Reis, 2009). Two doctors at the time, F.R. Hagner and H.B. Kneale, admitted that most of these operations were reported as unsuccessful. Regardless of this, these "risky" operations were believed to benefit the social world of binary gender categories. It offered a way in which deviant bodies could be "corrected" to fit the categories of gender-typical male and female bodies (Reis, 2009:86). In Reis (2009:86), the following quote from the British physician Dr. Arthur Edmunds illustrates some of the context of intersex variations during the 1920s: *"*I venture to think that there is no deformity for which treatment is more urgently called*."*

Intersex variations posed a social dilemma for early 20th century society. The idea of a person living "in the wrong sex" was unsettling to doctors and became their driving force in deciding on treatment and the optimal sex assignment of intersex patients in the 1920s and 1930s (Reis, 2009). Doctors believed that hidden in each intersex patient lay their "true sex" and that their bodies just had to be moulded towards this true sex. According to Reis, the sexual desire of a patient played an important role in what doctors considered to be their "true sex" (Reis, 2009:53). In 1934, the definition of heterosexuality as we know it today emerged as "a manifestation of sexual passion for one of the opposite sex; normal sexuality" (Ambrosino, 2017). The second part of this definition illustrates the modernized view that started to form on the binary nature of sex and sexuality (Fausto-Sterling, 2000). According to Freud and Krafft-Ebing, heterosexuality was "normal" and homosexuality "abnormal" and with this notion came the idea of the binary divide – a division that resulted

in the dominance of the “natural” and a subordinate of anything that did not fit into the category of “normal and natural” (Ambrosino, 2017). The preservation of heterosexual relationships and marriages was thus regarded as very important. The bodies of intersex people therefore had to have the capacity for “normal” heterosexual sex as it was feared that an atypical body might lead to, in the words of psychiatrist Albert Ellis, “resorting to homosexuality, bisexuality, or psychosexual immaturity to meet the exigencies of an unusual external and internal situation” (Reis, 2009:123). Furthermore, when confronted with intersex treatment methods and surgeries, doctors emphasized the fact that it was the own will of patients to undergo said treatment and genital altering surgeries as they wanted to be able to engage in “normal” heterosexual sex. Doctors, however, took it upon themselves to educate people on family matters like marriage and childbearing to combat the possibility of homosexuality. They also provided stereotypical heterosexual descriptions of the interests, dreams, and ambitions of males and females, which influenced how children were raised (Reis, 2009).

The practice of determining someone’s true sex based only on a person’s biological features was regarded as the standard treatment protocol at the time and deviations from this protocol were met with scrutiny. There were, however, some physicians who challenged these protocols. An example of such a case occurred in 1904 when an American gynaecologist adhered to the wishes of the patient by performing a surgery that stood in contradiction to what was believed to be her “true sex” (Karkazis, 2008). Another challenger to the idea of “true sex” as something determined only biologically was the British surgeon William Blair Bell. In 1910 he argued that a person’s gonads might not necessarily correlate with their phenotype and that the presence of gonads does not necessarily have any correlation with the physical appearance or gender identity of a person. Over time this thinking process led to the realization that a person’s biological sex traits should not be the only considerations when determining a person’s sex. In the latter half of the 1930s, psychology began to play a growing part in determining the “true sex” of a person (Kennedy, 2016), and in the late 1940s it became common medical practice to include psychological as well as emotional factors when considering the diagnosis of a person with intersex traits rather than only the presence or absence of gonads (Reis, 2009).

From the above discussion it is clear that the world of medicine gained more control over people's bodies, sex assignments, and gender roles in society in the early 20th century. There was, however, no standard treatment protocol for people with sex variations at the time and it was dealt with in a case-by-case manner (Karkazis, 2008). This changed in the 1950s with the development of what was regarded as the main approach to the treatment and management of intersex variations for many years to come. The American sexologist John Money and two of his colleagues, Joan and John Hampson, at the Johns Hopkins Hospital played an essential role in the development of this approach (Kennedy, 2016). The next section elaborates on this period.

2.2.2 The medicalization of intersex from the 1950s to the 1980s: the John Money era

To ground this discussion, I begin by providing a short historic overview of John Money, one of the most significant role players in the medialization of intersex. John Money was born in New Zealand and moved to the United States of America where he did his Ph.D in psychology on the topic of intersex. He pursued his career as a psychologist at the Johns Hopkins University Hospital's endocrinology department, where he worked until his death (Goldie, 2014). Money and his colleagues, the married psychiatrists John and Joan Hampson, were key figures in the development of sexology and gender after the 1950s (Bullough, 2003). The trio created a new theory to explain human sexual development, which would greatly contribute to the development of intersex treatment and management protocols in the years to come (Eder, 2012). Although Money later faced great criticism for his unconventional theories and methods, he also advocated and worked towards changing opinions on the LGBTQI community in the latter half of the 20th century (Goldie, 2014). With this orientation in mind, I continue to discuss the medicalization of intersex during the time between the 1950s and 1970s.

By the beginning of the 1950s, intersex births were still treated as a medical emergency as sex variations were regarded as a threat to what society considered as normal and acceptable (Karkazis, 2009). Preves (2001) states that researchers like John Money believed in the importance of swift genital sex determination of a baby with a sex variation to alleviate social stigma. In formulating his optimal gender theory, Money promised to cure intersex variations (Kennedy, 2016). This theory was built on his belief that the

gender identity of a person is not something they are born with, but rather something that develops over time per the gender-specific rearing of a child. He believed that the gender of a child could be shaped and moulded to agree with their genital appearance (Kennedy, 2016). For Money, it would be less strenuous for parents to raise their child as a certain gender if the child's genitals had as close to a gender-typical appearance as possible. These ideas led to the advice towards the end of the 1950s that deviant bodies should be corrected in early childhood rather than in adulthood.

According to Karkazis (2008) and Kennedy (2016), a shift away from the earlier "age of the gonads" and search for "true sex" to the "age of the genitals/penis" and creating the "best sex" took place in the 1950s. Kessler (2002) argues that despite knowledge about hormones and chromosomes, the external genital appearance and presence of an adequate penis were seen as the most important factor in the gender assignment and surgery decisions of a child. Kennedy (2016) states that Money believed that if the child had an adequate penis, he could be raised as a boy, but if not, it was advised to raise the child as a girl to avoid gender confusion and an unstable gender identity.

Apart from the gender assignment and reconstructive treatment protocols, there were also protocols for the social treatment of a child with a sex development variation. Money and his Hampson colleagues advised parents to fully understand their child's variation, but to keep this information from the child and other people, especially if the child had undergone genital reconstructive surgery (Reis, 2009). Parents were also often advised to relocate to a place where no one would know of their situation. This was also the case with AIS. Oakes *et al.* (2009), from the Department of Obstetrics and Gynaecology of the University of Michigan state that in 1953 American gynaecological researcher John Morris advised that adults with CAIS should not know about their true genotype and should only be told that they are unable to have children. This was a view of ethics called "therapeutic privilege" or "therapeutic non-disclosure" where withholding some details about a patient's diagnosis was considered to be justified if it was believed not to be in the best interest of the patient to know all the aspects of their diagnosis (Conn *et al*., 2005). At this time numerous other doctors regarded non-disclosure of a patient's variation as part of the treatment protocol. This was also the case in South Africa. In a 1959 journal article on AIS, non-disclosure of patients with AIS's DSD status is seen as essential in the avoidance of

psychological trauma for the patient (De La Harpe, 1959). De La Harpe (1959) stated that full disclosure of a patient's variation will only confuse the patient.

The 1950s set the tone for new ideas and protocols for the management of intersex variations, and these protocols were refined and implemented over the next decade (Laubscher, 1969). John Money had the opportunity to apply his optimal gender theory to a real scenario in 1966. In 1965 identical twin boys with typical male bodies were born in Canada. They were uncircumcised and within their first year, both developed a condition characterized by the tightening of the foreskin, which required surgery. Due to an accidental burn, the penis of one of the twins, John, was badly damaged during this procedure. His brother's surgery was subsequently cancelled (Preves, 2001). John, raised as a boy before the accident in which he lost his penis, still possessed the hormones, chromosomes, and internal sex organs of a typical male. Money's notion that children are born as blank slates and that an adequate penis is essential for stable male gender identity lead him and his colleagues to advise gender reassignment surgery and for John to be raised as a girl (Preves, 2001). As is discussed later on, the John/Joan case was unsuccessful, and Money's theory was eventually discredited.

Apart from Money's social experiment, Dewhurst created set principles for the management of sex development variations that were influenced by the ideas of Money and his colleagues (Laubscher, 1967). These surgery and management principles were created with an emphasis on childbearing options, the possibility of "normal married life" with heterosexual sex, and the avoidance of homosexuality. Furthermore, it was important to consider the simpler surgical procedure between constructing a sufficient penis or vagina. Another important factor was the avoidance of factors like malignancy, early menopause, and gender and psychological maladjustments as a result of delaying sex assignment surgery (Laubscher, 1967). However, small cracks started to appear in the idea that biological factors are the sole determinants of a person's gender identity late in the 1960s (Karkazis, 2008). The medical scholar Hirscowitz (1969) argued that a patient's psychological sex should also be considered in their gender assignment. Hirscowitz (1969:26) states that "disasters have occurred in the past where the new sex has been determined by the karyotype rather than the patient's psycho-sexual orientation."

According to Preves (2001), medical sociologists began to investigate the human experiences of people who had been deemed medically problematic in the 1970s. This offered a first chance for intersex people to share their narratives. It was also during this time that the term “medicalization” was first used by Irving Zola (1972) to describe the act of “viewing natural phenomenon in a medical framework where the medical view is seen as the authoritative, if not hegemonic view” (Preves, 2001:532). In the context of this study, this was relevant where a healthy intersex baby was born, but the fact that the baby’s appearance was atypical seemingly called for immediate and emergent medical intervention. According to Preves (2001), social movements like homebirth movements began to take shape to keep medical professionals from intervening after birth. The world of medicine was, however, able to resist this movement as there is merit in medical authority and people regard medical practitioners as having the power to cure illnesses and save lives (Preves, 2001). The world of medicine retained control over births, enabling doctors to provide sex assignment for intersex babies as prescribed by Money and his colleagues. In 1975, Money stated that the gender assignment of John, who now lived as a woman, Brenda, had been successful. In his view clear sex assignment of a baby before 18 months along with associated gender-rearing would lead to normal gender identity development (Preves, 2001). Money’s theories and ideas greatly influenced the treatment protocols for sex variations for a long time. These practices were, however, questioned over time, leading to a further revolution in people’s perception of intersex variations and its management. This is discussed in the following section.

2.2.3 Intersex from the 1980s to the current day: after the John Money era

According to Karkazis (2008), the treatment protocols for difference in sex development variations as recommended by Money and his colleagues were standard and remained unchanged for almost 40 years. While the principle of therapeutic privilege eventually received less favour from the 1960s onwards, Oakes *et al.* (2009) state that the protocol itself persisted through the years. In 1988 doctors were still advised to not disclose the truth about a patient’s diagnosis as it may only confuse the patient, or the family of the patient and they may not receive the diagnosis well. This protocol of secrecy continued through the 1990s, especially in the context of AIS where it was still regarded as unwise to disclose a patient with AIS’s genotype to them (Conn *et al*., 2005; Oakes *et al*., 2009).

According to Reis (2009), medical students in the 1990s were taught that it was their “ethical responsibility” to only tell patients half-truths about their diagnoses and variations.

The emergence of the internet in the 1990s played an important role in the lives of people with sex variations like AIS. For many years, people with intersex variations were made to believe that their variations were extremely rare, leaving them feeling alienated and alone (Zieselman, 2020). With the advent of the internet, they were able to do research on their variations and gain answers they could not necessarily find from doctors. Online support groups and movements like the Intersex Society of North America (ISNA) also enabled people to meet others with similar variations and to share their stories, experiences, advice, and knowledge, shaping the “intersex narrative” (Kerry, 2011). Adult intersex patients who had been treated as children began to voice their dismay about the dishonesty of doctors towards their parents and themselves about their diagnosis and treatment. They also questioned the urgency to surgically correct the variating bodies of infants. In the words of Karkazis (2008:3) “the desire to erase gender atypicality in the name of the care”. As more people with intersex variations started to share stories and experiences of medical harm during the treatment and management of their variations, the previously unchallenged management and treatment protocols began to face their first opposition (Karkazis, 2008). This led to the investigation of Money’s research and his optimal gender theory was met with great criticism (Kennedy, 2016). In 1996, Morgan Holmes, an intersex scholar, voiced her view of the harmful medicalization of sex development variations amidst various medical professionals and offered them guidance towards possibly less invasive alternatives (Davis, 2015). It was also in 1997 that it became known that David Reimer never accepted a female identity and transitioned back to a male gender at the age of 14 after finding out about his past (Preves, 2001). He committed suicide in 2004 at the age of 38 (Davis, 2015).

Despite treatment protocols being challenged, doctors held on to the fact that medical intervention in intersex bodies was essential to avoid the alienation of people in a society of gender-typical people. Ironically enough, people with sex variations revealed that secrecy, silence, and the continuous drive by the medical establishment to correct and alter their bodies were the very things that left them feeling “isolated, freakish, monstrous and stigmatized” (Preves, 2001:541). During the early 2000s these treatment protocols were challenged by intersex patients and some healthcare practitioners. They

foregrounded the view that intersex patients themselves should have a say in their treatment (Leidolf *et al*., 2008). This contributed to a re-evaluation of the treatment practices and protocols and a decline in the perception that surgeries on infants born with a sex development variation should be done promptly before the age of 18 months (Jenkins & Short, 2017).

A year of great development with respect to the medicalization of intersex variations was 2005. Firstly, numerous international experts from different medical fields related to the treatment of intersex gathered in Chicago. The purpose of this meeting was to seriously reconsider treatment and surgical protocols (Karkazis, 2008). Furthermore, the ISNA arranged a group meeting between medical practitioners, intersex activists and scholars, parents, and intersex patients. This meeting aimed to propose ways in which treatment and the management of sex variations could happen in a manner that focused on the patients and their experiences (Jenkins & Short, 2017). During this meeting a new term for intersex variations was adopted – disorders of sex development (DSD). Davis (2015:2) argues that with this linguistic shift, the medical fraternity "reclaimed their authority and jurisdiction over the intersex body". This is possible as DSD language "reifies the essentialist understanding of sex, gender and sexuality held by many medical experts on intersex traits" (Davis, 2015:84–85). The word "disorder" in the term indicates that there is something wrong with the development of the bodies of intersex people, which makes it different from that of other people. It is therefore yet again in the hands of doctors and surgeons to rectify this "problem."

Although the activist Cheryl Chase introduced this term to the intersex community with prospects of better healthcare and treatment for intersex people, it was met with mixed reactions. Some groups accepted the term as a type of peace offering and an invitation to unite with medical professionals towards better care. Other groups, however, strongly criticized this term as they saw it as another way in which the medical world established authority over them. The fact that this new term contains the word "disorder" implies that intersex bodies are "abnormal" and that intersex people are at the mercy of doctors to "fix" them and allow them to live "normal" lives (Davis, 2015:88).

While guidelines such as the Consensus Statement on Management of Intersex Disorders by Hughes *et al*. (2006) still promote genital reconstructive surgeries on children to

contribute to a more “normal” genital appearance, these were done with “more caution and less urgency” (Kennedy, 2016:820). This was, however, barely an adjustment as genital normalizing surgeries in children were still occurring worldwide and were regarded as the recommended and typical procedure for babies born with DSD traits (Kennedy, 2016). Based on data collected as part of the KIDS Inpatient Database Agency for healthcare research and quality of the United States Department of Health and Human Services, Tamar-Mattis (2011) states that in 2009, 680 hypospadias repairs and 59 surgeries of the clitoris were performed on children in the United States. There was also evidence in a 2013 article in *The Age*. It showed that up to 15 genital normalization surgeries are performed yearly at the Royal Children’s Hospital in Melbourne (Carpenter, 2013). These surgeries are usually performed on children under the age of two (Kennedy, 2016).

According to Jenkins and Short (2017), the global treatment protocols for sex development variations have not changed much despite clear protests and dissatisfaction. Subsequently, the medicalization of intersex variations began to gain social interest in terms of why it was regarded as such a social necessity to correct these bodies (Jenkins & Short, 2017). Over the next decade, the effect of this social interest can be observed in small but significant changes to treatment protocols. Hughes *et al.* (2012), for example, point out that the functionality of sex organs and the sexual and psychological aspects of a person, are important considerations when treating AIS. They also emphasize the importance of holistic, individual, and flexible care. According to the South African scholar Kemp (2013), the new treatment protocol entails full disclosure and psychological counselling to the patient once the patient is of an appropriate age. If the patient is still a child, doctors should be completely open with the parents and recommend psychological assistance to help them process their child’s diagnosis. According to Ko *et al.* (2017), the current treatment protocol for patients with AIS recommends that they have gonadectomies after they have reached puberty. However, HRT is then necessary after a person has reached puberty, as the gonads produces hormones. Life-long HRT is needed for the development of sex characteristics, but also to prevent osteoporosis. People with AIS are more at risk for osteoporosis because they are insensitive to androgens, which are necessary for skeletal health. Taking HRTs can also help to prevent cardiovascular disease, which may occur in people with AIS (Ko *et al.,* 2017).

This timeline shows how intersex as a biological variation was historically treated under the strong authority of the medical sector. Underlying much of this intervention by medicine is the gendered norms in society, which require all individuals to fit into one of two sexes and to conform to the gender roles and heterosexuality expected from these two sexes. For the longest time, treatment protocols remained unchallenged and as a result, many people underwent harmful procedures (Karkazis, 2008). When the affected population started to voice their dissatisfaction and concerns, however, the medical fraternity was challenged and was forced to adjust. An example is when Morgan Holmes, a scholar with an intersex variation, shared her personal views on less invasive treatment protocols with a room full of doctors in 1996. Some of her main points were that doctors and parents should let go of the notion that they have ownership and power over their patient/child's body and that patients with sex development variations should be free to own their sexualities (Davis, 2015). Although there are still harmful medical practices, intersex people and activists breaking the silence and sharing their lived experiences have greatly contributed to the de-medicalization of intersex variations. As this section has created a foundation for this chapter in terms of a medicalization timeline, the next section focuses on the literature on the experiences of people with AIS.

2.3 LITERATURE ON THE EXPERIENCES OF PEOPLE WITH ANDROGEN INSENSITIVITY SYNDROME

2.3.1 The authority of medicine and family guardians

Lev *et al*. (2006:29) state that "medical protocols have been guided by attempts to determine the 'optimal' gender assignment for those born with intersex variations with the hope of assisting in the development of stable gender identity". However, people born with an intersex variation had to undergo various medical procedures to determine this optimal gender assignment. A review of both the academic literature and informal literature on the lived experiences of people with AIS shows that this also applies to their medical experiences. Davis and Preves (2019:254) state that people with sex development variations such as AIS "are treated as 'passive objects' in need of medical attention to fix their deviance." This is evident from the US study by Davis *et al*. (2016), which provides an overview of the personal stories of people with intersex variations. In one account of a person with AIS from their study, the participant noted:

> I remember the doctor always spoke as if I wasn't right there, and I did not always understand everything the doctor said when I was young, because of all the medical terms he used (Davis *et al*., 2016:11).

Over the last few decades, the use of medical jargon and the emphasis on the urgency of surgeries has led to parents of and people with AIS being subject to uninformed decision making (Danon & Yanay, 2016). This persists today. Parents do not fully comprehend the implications of surgeries and medical procedures that may be irreversible and life changing. It is still sometimes regarded as part of the medical protocol for doctors to selectively exclude some of the details regarding the child's variation from parents as medical professionals are afraid that it may negatively influence the way a child is raised in his/her assigned sex (Danon & Yanay, 2016). The fear is that parents may treat the child differently from their assigned sex and that the child, as a result, may grow up to experience gender dysphoria.

An AIS diagnosis, in the last few decades, therefore usually entailed that parent trusted the advice of doctors when it was recommended to keep their child's variation a secret from the child and other people. This was regarded as in the child's best interest (Conn *et al*., 2005:629). A review of published literature like the important work of intersex scholars Davis (2015, 2016 and 2019), Zieselman (2020), Karkazis (2008), Preves (2001), and informal literature on the lived experiences of people with AIS (as found on social media, YouTube, online support groups, and blogs that detail the lived experiences of people with AIS), indicate that secrecy and shame about their variation were common when they grew up. One person with AIS said the following about her experience: "In retrospect, my whole experience was veiled in lies, fear, and shame. Being lied to give me immense anger and that anger was something I did not know how to handle" (Davis *et al.,* 2016:9). Furthermore, the secrecy and shame associated with variations such as AIS often left people with AIS feeling rejected by their families.

Conservatism and pressure to adhere to the authority of doctors also contribute to secrecy and shame. Families may not want to discuss the truth of their children's variation due to a fear of embarrassment, shaming and mistreatment by their extended community (Danon & Yanay, 2016). Parents often tell others lies about their child's variation as it is an easier alternative than dealing with the consequences of sharing the actual truth about their children (Feder, 2009). In a US study of the personal stories of people with intersex

variations, a person with AIS included the following as part of her narrative: “What added to my inner turmoil is that outside family members like aunts, uncles, and cousins were told I was in the hospital for an ‘appendectomy’” (Davis *et al.,* 2016:9). The following is also an account from a person with AIS who experienced rejection from family members:

> My father visited on rare occasions only, it was as if he could not bear the shame of having a son that was not perfect. It must have been hard for them to accept, but the least I could have expected was some kind of explanation or an attempt to explain. (AIS Support Group Australia Inc., 2019).

Accounts such as these have led to changes in the medical management of AIS in some contexts. In response to what is now considered by many health professionals to be mistakes in AIS management of the past to, for example, keep information secret, there is now an effort to ensure that patients have a full understanding of the medical procedures and give consent. Kemp (2013:161–162) provides evidence of this in a South African case study of a patient with AIS by stating the following:

> The patient was extensively counselled before surgery regarding her diagnosis and the implications of this variation concerning fertility. She demonstrated very good insight into the variation. Full disclosure now forms part of the management plan.

The protocol now includes thorough information and counselling of parents by a psychologist who is educated on AIS variations. Furthermore, it is now generally considered important that children with AIS are fully aware of their variations before adulthood. Apart from positive changes to the treatment protocols for intersex variations, positive stories include those of parents fighting for their children to not fall victim to medicalization. One such story is found in an online article by Pikoli (2021). She spoke to Nthabiseng Mokoea, an intersex person from South Africa, about their experiences. In this interview Nthabiseng emphasized the fact that their mother was their greatest support throughout their life. Nthabiseng was born with an atypical body and although they were born in a small town, their mother was referred to a hospital where a surgical procedure was advised. Nthabiseng shared the following narrative of their mother’s protective instinct: “and even at that point, my mother, with the little information that she had, what she had was this innate wisdom and she said, I don’t want this” (Pikoli, 2021).

In this section I reviewed the literature on the authority of medical professionals and parents/guardians and how it influences the lived experiences of intersex people. The following section elaborates on gendered experiences.

2.3.2 Gendered identities

As is evident from the preceding discussion, medically there are three different types of AIS, of which PAIS and CAIS are the most common. Although both are forms of AIS, people with PAIS more often have experiences where they feel like they had been assigned the wrong gender compared to people born with CAIS. For both these types of AIS, a diagnosis of AIS had a definite impact on their gender identity construction. This section provides a brief overview of the lived gendered experiences of people with AIS.

As is discussed in more detail in the theoretical section of this chapter, categories such as sex and gender are commonly recognized and are used daily by people to make sense of and create order in the complicated social world. Essentially, sex is placed into the binary categories of male (being born with a penis) and female (being born with a vagina). Gender identities are seen as mapping neatly onto these biological categories. Most people see sex/gender as something that is fixed and it is described as “natural, inevitable and biologically determined” (DeLamater & Shibley Hyde, 1998:10). However, people with intersex variations, such as AIS, challenge this “neat” and “simple idea” of sex as it, in the words of McKeown (2014:6), “rejects the idea that we can all fit into one of two categories.”

For example, the bodies of people with PAIS partially respond to androgens and they may, therefore, be born with genital variations. It is therefore often difficult to assign a definite sex to the baby, as an assignment is done according to biological characteristics (Gulia *et al*., 2018). As seen in the earlier discussion, from the 1950s onwards, medical professionals argued that gender assignment should ideally take place very soon after birth. According to Danon and Yanay (2016), a three-step process was used, and these steps entailed *diagnosis* (where it was decided whether the biological sex traits of the child leaned more towards a male or female side), *design* (where gender reconstructive surgery was carried out) and *follow-up* (to see if the reconstructed genitals of the person appeared and functioned as normally as possible). The follow-up process, however, rarely included interventions that sought to address the mental or emotional wellbeing of the person (Danon & Yanay, 2013). This is attributed to, among other things, the fact that the main

purpose of the surgical procedure was to make the genitalia of children function and appear as normal as possible to ensure that the child can be raised according to the supposed binary gender categories of either male or female and that the child would not develop gender dysphoria later (Danon & Yanay, 2016). Although the main concern in countries such as the United Kingdom is currently still the adequate functioning of sex organs, the focus has now expanded to address sexual as well as psychological issues (Hughes *et al*., 2012). This is also apparent in South African studies like that of Kemp (2013). Furthermore, it is ideal to use a multidisciplinary approach in the treatment of people with AIS variations, meaning the involvement of medical doctors, psychologists, and therapists. The implementation of this approach can improve both clinical management and the education of doctors (Hughes *et al*., 2012:1423).

A diagnosis of PAIS may present challenges with respect to a person's gender identity. It should be clear from the preceding discussion that one of the issues is that gender dysphoria may occur when a child grows up rejecting the gender that they were assigned at birth. In Pikoli (2021), South African intersex person Nthabiseng stated that their mother raised them as a girl, but during their adolescence they started to identify more with a masculine gender identity and started to express this through their outward appearance. While their mother was always acceptant of them, their masculine gender expression confused some members of the community. In some cases, people with PAIS develop traits of the opposite gender from their assigned gender (for instance where boys grow breasts or start to menstruate when they reach puberty), which may result in embarrassment, confusion, and shame (AIS Australia Support Group Inc., 2019). Also, due to medical procedures and surgeries, children with PAIS may miss out on several important social and gender identity shaping phenomena (considered as 'normal' gender behaviour) that their peers experience (Feder, 2009:297). For example, boys with PAIS may have to hide their variational or scarred genitalia or breasts, which can make competing in sports or even taken-for-granted activities such as urinating standing-up, difficult (Davis & Preves, 2019:531). Adults with PAIS also have a higher risk of psychological challenges, including anxiety and depression compared to adults with CAIS (Hughes *et al.,* 2012:1426).

As opposed to people with PAIS, people with CAIS have the phenotypical body of women and are are therefore usually raised to adopt female gender identity practices and gender

roles (Hines *et al*., 2003). They typically only suspect an abnormality in their teenage years when they do not go through the same gender-typical puberty changes as their peers in terms of getting pimples, growing pubic hair and starting menstruation (Davis *et al*., 2016). Based on the findings of Davis's *et al*. (2016) study, some of the personal accounts of people with CAIS indicate that they would try to imitate these pubertal changes by "faking it". As a result of not going through these pubertal milestones, these girls would seek medical help as parents or doctors had often concealed the truth about their variations from them (Davis *et al*., 2016). Davis *et al*. (2016) further argues that doctors, over the last few decades, would tell parents and persons diagnosed with CAIS that they have no cervix and that "people like them" should have their cancerous ovaries removed immediately. Even once she found out the truth about her CAIS, the account of one woman indicated that she felt "isolated" from other women (Davis *et al*., 2016:8). For this reason, Hughes *et al*. (2012) argue that it is important in current AIS management that the disclosure of a CAIS diagnosis is done carefully and accompanied by psychological support. This is necessary as the diagnostic disclosure may provoke an emotional response from patients and their parents. Research has shown that disclosure before the age of 15 is advised since women who are aware of their variations at a younger age are better informed than people who only learn the truth about their variations later in their lives (Hughes *et al*., 2012). In an online AIS DSD support group (2017), a woman with CAIS wrote the following: "As a niece with CAIS matured, she was the one who educated me. The first in our family not to shy away from the facts, she introduced me to the new AIS terminology and directed me to the website." Other CAIS women have expressed similar views that they wished to have known the facts about their variation at a young age rather than finding it out later in their lives (Hughes *et al*., 2012). In the case of CAIS, AIS support groups also play an important role. For some people, a diagnosis of an AIS variation has helped them to come to terms with certain aspects of their lives in a positive way or helped to strengthen family relationships. This is evident in the post of a member of an online AIS DSD support group (2017): "Confiding my story to friends and family has only deepened and improved my relationships with them."

According to Davis and Preves (2019), biological factors and fertility play a large part in a person's gender identity and gender role. People with CAIS are most often infertile as they do not possess internal reproductive organs, including a womb, ovaries, or a cervix.

However, for people with PAIS, who may initially be fertile, gender assignment surgeries and treatments can do permanent damage to their reproductive systems, leaving them infertile as well (Tamar-Mattis, 2014). Knowledge about their infertility often affects the mental health of women, but also men with AIS variations. In an online AIS support group (2017), a woman with CAIS wrote the following: “A day doesn’t go by without my thinking about AIS, and being childless”. According to Tamar-Mattis (2014), medical procedures were frequently done without the consent or full understanding of people with AIS. During these procedures, the fertility of the person was not always considered a priority since the main priority at hand was to “normalize” the functioning of a person’s genitalia. A woman with CAIS described her infertility as “the fear of not being a normal woman” while a man with PAIS talks about the shame and depression he experienced when his wife wanted to have a child and he could not impregnate her (AIS Support Group Australia Inc., 2019). Although infertility results in people with AIS not being able to have children of their own, there is the option of adoption for people with AIS who want children. This possibility is expressed by a woman in an online AIS DSD support group (2017) post: “Happily, I have been married for nearly 20 years and have beautiful, adopted twin daughters!” She further wrote:

> If someone offered me a magic wand to wish away my AIS, I would absolutely NOT do it. Without my AIS, I may not have met my wonderful, caring husband; I may not have my two beautiful loving daughters, and I definitely would not have met all the amazing women in this amazing group.

In this section, it is clear that the gender identity construction of people with AIS is influenced by their intersex variation. It also influences their relationships and intimacy. This is discussed in the next section.

2.3.3 The influences on mental health, relationships, and intimacy

People with AIS are often greatly affected by early lived experiences; these include medical procedures and living in a society with gender-typical people. Growing up with AIS may have a significant effect on one’s mental health, relationships, and potential for intimacy. This section engages findings in academic and informal literature on this theme.

Tamart-Mattis (2011) and Yellappa and Venkatesh (2015) found that people with AIS often have negative experiences such as trauma and physical and psychological discomfort

when it comes to sex and intimacy. This may even lead to severe depression. According to a US study by Tamar-Mattis (2014), some people with AIS may display suicidal and self-harming behaviour. In an Indian case study on the psychological effects of AIS on patients, Yellappa and Venkatesh (2015:2) note the following regarding a female patient with CAIS: “Then she started feeling sad because of her inability to fulfil the personal and societal roles of a woman. Because of intense sadness and anxiety, she started making repeated attempts of suicide in a span of about six months.” This may be partly attributed to medical practices where children with AIS variations undergo various medical procedures from a young age that they do not necessarily understand or give consent to and, as a result, they suffer trauma (Tamar-Mattis, 2014). Due to negative medical experiences, some remain asexual. In an online article, Salaudeen (2019) reports on conversations with South African women with AIS. She learned from the narratives of these women that people with AIS can also experience post-surgical depression. People with CAIS often experience great distress when they find out that they cannot menstruate and will not be able to bear children of their own one day. This is also evident from an online AIS DSD support group (2017) where a woman wrote the following: “There are many hard parts of having AIS…for me, the hardest part of having AIS is not being able to have biological children.” Infertility may in some cases challenge relationships. In a South African case study on people with AIS, Kemp (2013:161) states the following: “Unfortunately, her husband left her when he found out about her infertility.”

Salaudeen (2019) mentions in her online article that one of the women with AIS stated that in South Africa, babies with intersex face the risk of being killed in some communities as they are viewed as bad luck according to traditional beliefs. Furthermore, she states that some families are so conservative that they do not speak of things of a sexual nature. She therefore had no-one to talk to about the concerns and confusions she had regarding her body (Salaudeen, 2019). As seen in the sections above, older medical protocols for the treatment of AIS often entailed that the truth about a patient's variation was kept a secret from them. Some people with AIS have difficulty with trusting others as a result. This can also compromise romantic, familial and friendship relationships. In an online AIS support group (2017), one woman with AIS gives the following advice to parents of children with AIS:

> Don’t hide anything from your child. They are not going to blame or hate you for giving birth to them. They will hate you if you lie to them and they must find out about AIS on their own. Do what you can to help them find out everything about AIS.

Although a diagnosis of AIS can involve various challenges, formal and informal literature such as articles written by Davis *et al.* (2016) and representatives of the AIS support group (2017) and the AIS Support Group Inc. (2019), has shown that some people with AIS experience talking and being open about their variations to be a healing experience. Honesty and openness about their lived experiences have also helped people with AIS to form better relationships with their families and the people around them. One person with AIS shares her experience as it relates to her relationship with her sibling: “These intense feelings bonded my sister and I. Today we are also best friends. I am so blessed to have her as my confidante and sister” (Davis *et al.,* 2016:10). Another example of familial support and how it contributed to a positive lived experience is that of a South African woman with AIS who said the following:

> Luckily, I had a very supportive mother, she protected me from unnecessary surgical interventions that the doctors were advocating for. She also taught me to respect and accept diversity at a young age (Salaudeen, 2019).

An American woman with AIS shared the following with respect to the acceptance of body and self:

> I have come to understand, through my own experience, that being DSD opens a whole new world of possibilities around sexuality. Our anatomies may oblige us to rethink sexuality, to challenge sexist or preconceived ideas about it, and this is a good thing (Davis, 2016:12).

A woman with CAIS states the following in an online AIS DSD support group (2017) post concerning her mental health, romantic relationship, and sex life: “I’ve enjoyed a full, normal, rewarding sex life and now, at 31, I’m going to be married to the love of my life. I’m so glad I am the woman I’ve become.”

The preceding section foregrounds the fact that a diagnosis of AIS has a definite effect on people’s romantic, familial and friendship relationships, both positive and negative. In the next section, there is a discussion on the theories that were used to best support and ground this study.

2.4 THEORETICAL FRAMEWORK

In this section of the study, I present the theoretical framework that forms the foundation of this study. Firstly, theory helps a researcher to contextualize the views, beliefs and attitudes of participants and to form a better understanding. Secondly, theory plays an important role in methodology as it guides the researcher in the formulation of questions, data collection and analysis decisions. Thirdly, in qualitative research, new theories can be formed at the end of the study as qualitative research is associated with inductive research. Lastly, theory acts as a framework that allows the researcher to describe phenomena better. For this study, I made use of the gender structure theory. In the following section, I first discuss the development and academic use of the term gender. With this discussion in mind, I also discuss the gender structure theory and how it applies to this study.

2.4.1 Academic use of term gender

As seen throughout this chapter, the experiences of people with intersex variations are greatly influenced by the fact that they live in a world where both sex and gender contribute to people's identities and realities. Historically, the binary and essentialist views of scientists and doctors determined the differences between the sexes. The distinction between males and females was based on their observable biological differences, like the fact that men had penises and women had breasts and vaginas (Fausto-Sterling, 2000). By the middle of the twentieth century, psychology began to influence the distinction between sex and gender and to contribute to views that gender is socially constructed based on Money's "gender role" theory and Stoller's "gender identity" theory (Cortéz *et al*., 2019; Gillespie, 1969). From the 1970s onwards the term "gender" became increasingly relevant in academia. This term was recognized as significant both as an important topic to be studied, but also as a useful analysis tool in the field of social science and humanities (Bradley, 2013). The academic use of the term "gender" has roots in American and European second-wave feminism, which stemmed from an academic interrogation of women's experiences (or absence thereof). In academic disciplines, the goal was to recover women's stories, experiences, and the roles they played in history, sociology, etc. (Bradley, 2013). This was made possible by using terms like "gender" and "patriarchy" to

explore how the roles and interactions between men and women are fluid and interchangeable rather than fixed.

In this section, I discuss the academic use of the term “gender.” I do this by first providing a defining overview of the concept “gender.” After this conceptualization, I continue to discuss how the concept “gender” was theorised in the world of academia through psychology and feminism.

2.4.1.1 Definitions of gender

In this section, I discuss and define the concept of “gender” and how it is distinguished from “sex.” According to Mama (2009), the concepts “sex” and “gender” are often viewed as referring to the same thing. This is since many languages do not offer clear distinctions between these terms. The English language, however, offers a difference. The concept “sex” refers to a person’s biological traits and capacities, like their internal and external sex organs. “Gender”, on the other hand, refers to what it means to be men and women in terms of the way they express “culturally constructed roles, identities, and symbolic locations within specific geographical, social, and historical contexts” (Mama, 2009:1). Furthermore, gender can be understood as a set of social arrangements and categories to make sense of and divide the world. With these arrangements and categories, there are inequalities between the two genders. These inequalities are derived from the hierarchical societal position of each gender’s roles (Bradley, 2013).

This distinction has gone through important developments over the years. In the following section, I discuss the development of this distinction and some of the criticisms it received.

2.4.1.2 Second-wave feminism and the development of the concept of gender

Meuhlenhard and Peterson (2011) state that some of the earliest distinctions between and uses of the terms sex and gender were in the 1950s by the psychologist John Money and his colleagues, who, as was discussed earlier in this chapter, was influential in the development of the gender identity theory on which intersex protocols from the 1950s depended. According to Cortéz *et al*. (2019:3), Money’s recognized the sex/gender distinction through his perception that people have “subjective identities.” While men and women are biologically different, they also experience differences in the gender-specific

“rules” for behaviour and societal expectations. These may be for instance that women are caretakers and men are providers. To adhere to these expectations and rules, each gender acts in a gender-specific way. Money used the concept of performing a “gender role” to explain this phenomenon (Cortéz *et al*., 2019). This theory, part of a functionalist theoretical perspective dominant in US sociology in the 1940s, maintains that men have instrumental roles that include traits of economic competitors such as aggressiveness, ruthlessness and intellectuality, while women have expressive roles like being caring and nurturing (Parsons & Bales, 1956). According to Cortéz *et al*. (2019) Money’s use and the conceptualization of the term “gender” influenced psychiatrist Robert Stoller in the 1960s. Stoller studied homosexuality, transgender and intersexuality and came up with the concept “gender identity”, which refers to a person’s self-knowledge or belief that they belong to one sex rather than the other. Stoller’s work later influenced the work of feminist scholar Anne Oakley (1972), who famously introduced the distinction between sex and gender into feminism through her work “Sex, Gender and Society” (Bradley, 2013). In this work Oakley (1972) argued that certain socio-cultural aspects linked to each gender may perpetuate gender inequality of women. Oakley and other feminist scholars like Millett (1971), Mitchell (1971), Ortner (1974), and Rubin (1975) showed the link between gender and the inequality of women and the development of the theory of patriarchy, which argues that most social systems are male dominated.

After Oakley introduced the term gender to the world of feminism, the distinction between sex and gender became central to the work of many feminist studies in the 1980s (Bradley, 2013). The distinction aimed to address “the long and very powerful discourse within Northern knowledges which conflates social meaning with the biology of the (individual) body” (Mama, 2009:1). Women’s inequality was justified by pointing to biological differences. In the fourth century BC, philosopher Aristotle argued that men contribute to generation through their semen while women are merely offers a place “where generation can happen” (Mama, 2009:2) Furthermore, the menstrual fluid of women was deemed the weaker version of men’s semen. Second-wave feminists formulated “the distinction between ‘*sex*’ and ‘*gender*’ in order to challenge ideas that located male dominance in biological foundations, and which saw certain sex-roles as inevitable” (Mama, 2009:5). Given the wide variation in “*men’s*” and *“women’s*” behaviours, roles, and power across time and place, the idea of separating “*sex*” from “*gender*” was

proposed in the 1970s as a way to examine societies through a focus on construction. There was a focus on how differences between men and women were socially constructed, with less emphasis on the influence of biology. However, the distinction was coming under increasing criticism. An example of such a work is that of historian Joan Scott (1988:1) in which she argues that "gender is a social category imposed on a sexed body." Other examples of feminists who increasingly contested the distinction between sex and gender are feminist biologists like Lynda Birke (1986), who challenged the naturalist way of thinking in science by arguing that human bodies are not fixed and static but are subject to change through time as the social world changes. Examples of this include that people are exposed to different environmental factors, different diets, and different "trends" that may influence the appearance and function of their bodies (Bradley, 2013). Furthermore, there were feminists who drew on the work of Michel Foucault (1980), who believed that the existence of sexual categories and identities like homosexuality developed due to the stronghold that medicine and psychology had over what was regarded as "normal" and "abnormal/deviant" (Reis, 2009). According to Mottier (2012:28), people who took part in same-sex activities were labelled "homosexuals." According to Foucault (1980), this contributed to the development of homosexuals as a category that is different from heterosexuals. It can thus be argued that the identity of homosexuality was constructed over time.

This constructionist position was pushed even further by the work of French philosopher Jacques Derrida. Some of his main points were that binary thinking is central to western thinking and that all binary categorization is oppressive as it puts limits on what can be said and done (Bradley, 2013). To call someone "man" or "woman" is to compel them to act in a certain way. Furthermore, this does not leave space for groups like transgendered or intersex individuals who do not "fit" into one of these categories (Carroll, 2012). Derrida offered the idea of "deconstruction", which entails the breaking down of binary categories. This philosophical doctrine was very influential in the work of a new generation of feminists. Some of these feminists included Judith Butler (1990) who maintained that the sex/gender distinction in feminist work is limiting to certain groups and that the use of this distinction should therefore be discontinued. In Carroll (2012:6) Butler argues as follows:

> The cultural matrix through which gender identity has become intelligible requires that certain kinds of 'identities' cannot 'exist' – that is, those in which gender does

> not follow from sex and those in which the practices of desire do not 'follow' from either sex or gender.

Butler (1990) furthermore argues that sex/gender should be understood as a way in which people "act out the specific roles attributed to their genders through performativity". For Butler (1990:33), gender can be defined as follows:

> Gender is the repeated stylization of the body, a set of repeated acts within a highly regulatory frame that congeal over time to produce the appearance of substance, of a normal sort of being.

Butler believes the existence and liberation of intersex people, transgender people, non-binary people, and gender non-conforming people challenge the rule of performativity by breaking down the binary thinking (Butler, 1990).

The idea of a radical and complete deconstruction of the sex/gender distinction has, however, been criticized for various reasons. Firstly, it is argued that this level of gender fluidity does not resonate with most people (including most intersex people (ISNA, 2008)), who prefer and accept to live as men and women who have specific gender roles. Secondly, Bradley (2013:23) argues that "the obstinacy and genital difference of bodies and the genital difference is underplayed in this type of theory" as males and females undeniably go through different bodily experiences. Where women menstruate, get pregnant, lactate, and experience menopause, men for instance experience erections, the breaking of voice, the growth of facial hair and muscle (Bradley, 2013). In the context of this study, the bodies of intersex people also influence and determine their experiences in various ways. Their bodies do not behave like that of typical men and women in certain respects and this has a great effect on their experiences and perceptions of themselves. This includes, for example, not getting a period or breasts or experiencing infertility. In their medical article Ngun *et al*. (2010:65) acknowledge the fact that unethical practices of scientists towards minority groups have done considerable damage to people's trust in science. However, they argue that disregarding biological sex differences can be extremely harmful. Ngun *et al*. (2010) reiterate that the different hormones in the bodies of males and females play an important role in their differences. Chromosomes and genes also contribute greatly to these differences as men and women may exhibit different behaviours and be prone to the development of different illnesses and conditions. The importance of bodies should therefore not be downplayed. Thirdly, while it is important to

acknowledge the social construction of gender, it is also necessary to still consider the importance of the sex/gender distinction as not all countries have the same belief systems. According to Bradley (2013:23), there are still areas in the social world where gender awareness and liberation are low, and those countries rely on the gender/sex distinction to explain the construction of differences between men and women.

The above section outlined how gender has been theorised since the second wave of feminism. It discussed how the distinction between sex and gender developed, and how this distinction was increasingly criticised.

2.4.2 The application of gender structure theory

In this study, I draw on Barbara Risman's (2004) gender structure theory to analyse and interpret the findings of this study on the lived experiences of people with AIS. Risman's (2004:430) theory offers a way to organise all the different, "almost limitless" ways in which gender has come to be defined in social science. Firstly, I provide an overview of what gender structure theory entails. Secondly, I provide a brief overview of Davis's (2015) use of this theory in studies on intersex and AIS, and lastly, I discuss the application of this theory to the present study.

American sociologist Barbara Risman (2004:433) argues that gender, in all its complexity, should be understood as a social structure in the social world as it is "deeply embedded as a basis for stratification not just in our personalities, our culture rules or institutions, but in all of these and in a complicated way." It is important to conceptualize the term "structure" to understand the gender structure theory. According to Risman (2004), the word "structure" implies a level of constraint and limitation of certain possibilities. In the context of gender one limitation may be that gender is constricted to include only categories like male and female. Furthermore, this constraint may imply that there are "rules" and "taboos" for each gender. Within a structure, people can, however, act and make certain choices. As part of the structure of gender, this may include how they choose to dress and express themselves in either masculine or feminine ways. According to the structuration theory of Anthony Giddens (1984), there is a constant interplay between the social structure and individuals in this structure as they constantly affect and are affected by one another. West and Zimmerman (1987) state that people actively engage in the act of "doing gender." Through this constant act of "gendering", our day-to-day interaction with

one another contributes to a constant reconstruction and re-understanding of the structure and rules of gender, which is reapplied throughout time.

Risman (2004) believes that there are three dimensions in which gender is structured. These are the institutional, individual, and interactional dimensions. The institutional level of the gender structure refers to how people make sense of their gender through an understanding of various organizational practices and behaviour policies attached to each gender (Davis, 2015). An example may be that official forms only make provision for male and female gender categories or that a person's identification number in South Africa is constituted according to one's body and biological sex (de Wee, 2021), or maternity leave policies at organisations. Another example of gender at an institutional level are the protocols of the medical management of intersex variations which have sought to assign one of two genders to persons with an intersex variation and to make their bodies conform to that decision (discussed in detail earlier in the chapter).

The gender-structured nature of the institutional dimension influences the individual dimension. While the institutional level makes a person's specific gender "official," the individual level entails that a person undergoes development and gain an understanding of themselves as a gendered being. This takes place through the internalization of a male or female gender identity through the exposure to and understanding of its gender-specific personality and characteristics (Davis, 2015).

While sex signifiers like genitalia are often concealed from other people we encounter in the social world, people express and "perform" the gender associated with their biological sex through ways of dressing and acting that are associated with genders. This refers to the interactional level of the gender structure (Davis, 2015). Examples may be that there are different expectations attached to men and women in their roles as mothers and fathers or husbands and wives (Risman, 2004).

From the discussion of the intersex literature in the first part of the chapter, it is, however, clear that it is complicated for people with intersex variations like AIS to navigate life in a complex gendered world. In her study "Contesting Intersex: The Dubious Diagnosis", intersex scholar Georgian Davis (2015:7–8) explains this dilemma as follows:

> Intersex is a problem because it disrupts the traditional order. If our behaviors weren't constrained by gender, if opportunities weren't filtered through gender, and if gender weren't tied to bodies and identities, it is doubtful that intersex would be so problematic throughout the world as it is today.

Davis (2015:9) grounds the analysis of her intersex study on gender structure theory. In Davis's study, she sought to explain how intersex became a DSD. By making use of Risman's gender structure theory she was able to explain how this shift in language has influenced the meaning of intersex at the institutional, individual, and interactional levels.

In this study, I investigated the lived experience of people with AIS in South Africa in three areas specifically. By grounding my analysis in Risman's gender structure theory, I indicate how the three levels of Rismans' theory enabled me to gain a better understanding of these experiences. Furthermore, I consider that South Africa is also a country with a history of apartheid and injustice towards people of colour which resulted in stigmatized treatment of black people and people from lower social classes in the South African healthcare system (Lock Swarr, 2009). While my focus is placed on how the structuring of gender on three different levels have an impact on the lived experiences of people with AIS in South Africa, it is important to consider that ideas of race and class can shape policies, beliefs, and treatment of people on an institutional, individual, and interactional level and subsequently influence the lived experiences of people further.

At an institutional level, I explore how policies and medical practices shaped the experiences of individuals with AIS. As seen earlier in this chapter, the institution of health has played an important role in the experiences of people with intersex variations like AIS through their beliefs that intersex bodies had to be altered to be either male or female. Later in this study (chapter 5) it is seen that gendering on an institutional level played an important role in how the participants were treated in the medical sector. Some participants indicated feeling objectified, experiencing doctors as being insensitive and placing emphasis on the fact that their bodies had to be "corrected."

At the individual level, I explored how the diagnosis and treatment of AIS have shaped the ideas and experiences of the gender of persons with AIS. According to Webb *et al*. (2019), aspects like youthfulness, femininity, and beauty are attached to female body features like breasts, which may reaffirm a person's experience and understanding of their gender. People with AIS may not experience the growth of breasts and can therefore feel

inadequate and inferior if they live as women. In chapter 4 I found that participants did not go through the same gender typical milestones as their female peers and subsequently expressed feelings like shame and inadequacy as women.

At the interactive level, I explored how the diagnosis and treatment of AIS have influenced interactions with family and other relationships, as well as interactions with medical doctors. From birth boys and girls are raised within gender-specific categories and are taught gender-specific roles. In chapter 4 I found that participants' AIS had an impact on their relationships and how they approached relationships as people with variating bodies.

2.5 CONCLUSION

In this chapter, I firstly provided a timeline of the medicalization of intersex variations. This timeline consisted of three eras, being intersex before the 1950s before the John Money era, the era of the medicalization of intersex during the 1950s to the 1980s during the John Money era and, the period from the 1980s until today following the John Money era. This discussion enabled me to indicate how the structure and ideologies of specific societies over the last century have influenced how people with intersex variations were viewed and subsequently treated. Secondly, I provided a detailed overview of the existing literature on the lived experiences of people with AIS worldwide. I discussed these experiences in terms of the authority of the medical fraternity and family/guardians, gendered experiences, and the influences on mental health, relationships, and intimacy. Through this discussion, I illuminated the fact that although people with AIS share an intersex variation, their lived experiences can vary greatly. Lastly, I discussed the theoretical foundations of this study. Here I offered an overview of the development of "gender" in academia and discussed Risman's (2004) gender structure theory. Through this discussion, I was able to provide an understanding of how the idea of gender as a social construct developed and how gender as a social structure dictated various areas of our daily lives. In this last section, I also provided a discussion of how the gender structure theory was applied to the analysis of this study. The next chapter explores the methodology used to conduct this study.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

The medicalization of intersex variations like AIS has greatly affected the lived experiences of people who have this condition. This was evident from the discussion of formal and informal literature on the experiences of people with AIS globally in the previous chapter. However, this study focuses specifically on the lived experiences of people with AIS in South Africa as little is known about the experiences of people with AIS in this context. In this chapter, I thus discuss this research design and methodology that was used in conducting this study.

Before doing research, it is important to understand the concept of a "research paradigm." According to Kivunja and Kuyini (2017:26), a research paradigm can be described as follows:

> A research paradigm inherently reflects the researcher's beliefs about the world that s/he lives in and wants to live in. It constitutes the abstract beliefs and principles that shape how a researcher sees the world, and how s/he interprets and acts within that world.

With its origin in the Greek word for "pattern", it can be argued that the paradigm or world views and beliefs of the researcher are echoed in the different components of the research process (Kivunja & Kuyini, 2017). Rehman and Alharthi (2016:51) state that a research paradigm consists of the researcher's beliefs and theoretical frameworks with respect to ontology, epistemology, methodology, and axiology. Ontology has to do with how reality is viewed. By studying phenomena in the world through a specific lens, a researcher views reality from a specific angle. How the researcher views reality influences epistemology, which has to do with how we gain knowledge and how people understand phenomena observed and experienced in our daily lives (Sousa, 2010). The method a researcher uses to gather knowledge includes how they choose who they want to study, in other words the sample. It also involves how they gather data from their sampling group, and lastly how they analyse and make sense of this data to provide new meaningful knowledge. It is also important to consider the ethical implications of a study, and this refers to axiology (Kivunja & Kuyini, 2017).

As I aimed to investigate the lived experiences of the participants, it was important to make use of a research paradigm that would allow me to gain insight into their lived realities. A qualitative research design was therefore the best suited for this purpose. As opposed to quantitative research, a qualitative research design is not interested in explaining phenomena by quantifying, but rather to describe and understand them. I was best able to get access to the unique beliefs, lived experiences, and worldviews of my participants using a qualitative design (Haradhan, 2018). The philosophical foundations that supported the qualitative research design were a constructivist ontology and an interpretivist epistemology (Pryce *et al*., 2014).

In this chapter I present my research methodology as follows: firstly, I discuss the philosophical foundations for this study in terms of ontology and epistemology. Secondly, I outline the qualitative research design. Thirdly, I discuss the different components of the qualitative research methods I used in this study. These consist of sampling techniques, data collection techniques, and data analysis. Fourthly, I elaborate on the criteria used to evaluate qualitative research with reference to credibility and trustworthiness. Fifthly, I discuss the necessary ethical considerations that I adhered to in this study, and lastly, I reflect on the limitations of the study.

3.2 PHILOSOPHICAL FOUNDATIONS

In doing this research study it was important to consider the underlying philosophical foundations in the form of metatheories. Metatheories, which represent a significant component of any study, refer to ontology (how we perceive reality) and epistemology (different ways in which we form knowledge and accept it as the truth) (Sousa, 2010). Bates (2005) states that metatheories help to guide the researcher's views and thoughts when phenomena are studied in a particular context. In this study, I wanted to provide the participants who live with AIS in the South African context the chance to share their stories in as much detail as possible, and this called for a qualitative research design. As opposed to quantitative research which is often linked to objectivity, measuring, and statistics, qualitative research is linked to subjectivity and in-depth insights on a research topic such as the lived experiences of the people with AIS in South Africa (Streefkerk, 2021). Qualitative researchers view reality from a constructivist ontological point of view so that reality is regarded as something ever-changing and uniquely perceived by the different

members of society. Qualitative researchers also view knowledge from an interpretivist epistemological point of view as it is seen as something that is shaped by people's unique understandings of the world (Schwandt, 1994). In this section, I discuss social constructivism as the ontological stance and secondly, interpretivism as the epistemological stance.

3.2.1 Constructivism as ontological position

According to Gablin (2014), social constructivism is often the point of departure in sociology when looking at how people create a mutual understanding of the world. From this point of view, how people experience reality is influenced by socialisation (Gablin, 2014). This means that people create what we call a reality in terms of synchronised understandings, significances, and meanings that they form out of experiences and daily encounters with the world and other people in the world (Tuli, 2010). Although many aspects of reality are shared, it can be argued that there are as many different realities as there are people in the world. How people experience and share these realities contribute to the notion that reality is ever-changing (Mills *et al*., 2006).

According to Jia (2010), social constructivism has its origins in history, philosophy, and later in psychology. Detel (2015) states that the turn of the twentieth century had a great influence on the growing relevance of social constructivism. This turn was associated with strong criticism of scientific realism and assumptions such as the following:

> Universal rational scientific methods and rules such as that the history of science can be rationally reconstructed as a continuous intellectual enterprise constantly improving our scientific knowledge by applying these methods (Detel, 2015).

As seen in the introduction to this section, the use of qualitative research is relatively young and only gained relevance from the 1970s onwards (Broido & Manning, 2002). This means that proponents of quantitative research, with its positivist ontological basis, view reality is something universal, objective, and unchanged (Ryan, 2018). These rigid and binary views of the world also influenced how gender was seen and subsequently how medical professionals saw fit to deal with intersex variations like AIS. With the shift to qualitative research in the 1970s, the constructivist influence can be detected in the work of medical sociologists interested in investigating the experiences of people who were seen as "medically problematic" (Preves, 2001). For many years before this, the medical

protocols of intersex treatment remained unquestioned and unchallenged, and therefore what was known about intersex mostly came from medicine or academia (Karkazis, 2008). As nondisclosure was regarded as part of the medical protocol in the treatment of intersex variations like AIS, it contributed to the fact that the concept of intersex was met with stigma, secrecy, shame, or curiosity. The lived experiences of people with intersex variations like AIS, and subsequently a part of the reality about AIS, remained unknown. With the growing relevance of qualitative research methods that employ constructivist and interpretivist foundations, it became possible to acknowledge and incorporate the lived experiences of numerous stigmatised and minority groups, like people with intersex variations, into what we now know as reality.

According to Gablin (2014), a social constructivist position has five main features. The first of these is that it stands opposed to positivism (Gablin, 2014). According to Samy and Robertson (2017), positivists argue that the activities and interpretations of people in the social world have no impact on any of the phenomena in the world. Constructivists, however, believe that the world exists based on how people make sense of it through interpretations and experiences (Samy & Robertson, 2017). The second feature of a constructivist position has to do with challenging the status quo of how the world is seen. Often this status quo means that certain groups have power over other groups (Gablin, 2014). This links closely with postmodernism and poststructuralism, which developed as a criticism of the fixed nature of modernism and structuralism where there was no space for so-called “grey areas” like people who are born with atypical bodies (Maese, 2017). Thirdly, Gablin (2014) argues that the way in which we understand the world is a product of how people have interacted with each other throughout history. References to the historical timeline of the medicalization of intersex variations in Chapter 2, reveals that each era influenced the next with regard to how intersex variations were perceived and understood in the world. The fourth feature involves the goal of the constructivist position. While the goal of quantitative research from a positivist perspective is to explain certain phenomena and produce fixed and factual knowledge of the world, qualitative research and constructivism aim to rather explore, understand, and observe existing phenomena in the world (Gablin, 2014). The final feature of social constructivism entails a redefinition of concepts like the mind, self, and emotion as social processes rather than strictly authentic and individual.

In the next section, I discuss interpretivism as the epistemological perspective that follows the persuasion that reality is constructed and therefore the assumption that we construct and understand knowledge through interpretation by assigning meaning.

3.2.2 Interpretivism as epistemological position

Since this study departs from a constructivist ontological position, it is important to discuss the complimenting epistemological perspective known as interpretivism. Interpretivism stems from the idea that human/social sciences and physical science are vastly different and must therefore be studied separately and using different methods (Pham, 2018). From a positivist epistemological point of view, one must be able to prove reality by measuring it or by providing some sort of evidence of the existence of specific phenomena (Pham, 2018). Interpretivism, however, differs from positivism as it assumes that people create and understand reality through the interpretations and meaning they form as they interact with the world. Like the shift to social constructivism, Dean (2018) states that the shift towards an interpretivist way of thinking has been characterised by a move away from unethical and objective research towards an approach that emphasises how meaning and subsequently knowledge is formed. This shift can also be observed throughout the history of the medicalisation of intersex variations. Unethical and invasive treatment protocols remained unchanged for 40 years after the 1950s when Money introduced these protocols (Karkazis, 2008), but from the 1990s people began to challenge these protocols. Through the emergence of the internet, intersex people started to find out more about their own experiences and gather knowledge to which they never before had access. They could also share their experiences and knowledge about their variations with each other via support groups (Zieselman, 2020).

While people with intersex variations like AIS were able to find out more about their own variations, the rest of the social world still has a lot to learn. People of minority groups like those with AIS are often stigmatised and their voices excluded. This is problematic for various reasons. It can contribute to the furthering of stigmas, othering, curiosity, fetishization and sensationalisation of intersex conditions. If the only knowledge about intersex variations is in the form of medical journals or an overemphasis on gender issues by social science, it leaves few options other than to objectify these groups and alienate them even further. Furthermore, if these groups do not have a voice, they have no way of

“introducing” themselves to the rest of the world as “normal” people who just happen to have slightly different bodies (MacKenzie *et al*., 2009). While there are people in society who are willing to help the cause of intersex people, they might, however, be a bit “clumsy” in identifying areas where people with intersex variations like AIS truly require help. On FRIDA’s (2021) website Intersex South Africa’s (ISSA) state some of their main goals. These include ending unnecessary invasive surgery on intersex children, spreading knowledge, and ending discrimination and violence against intersex people. In doing this study on the lived experiences of people with AIS in South Africa, I aim to help my participants represent other South Africans with AIS and act as a voice that will contribute to insightful and helpful knowledge of AIS.

Ryan (2018) argues that culture and historical setting has an influence on the lived experiences of people and therefore influence how they gather knowledge and what understanding they have of the world. As seen in the literature review, the medicalisation of intersex variations like AIS, went through various stages. Although the changes in the medical protocol have, to some extent, remained the same, there have also been changes such as a growing emphasis on informed consent and psychological assistance to patients and their parents (Kemp, 2013). This means that people of different age groups may have vastly different lived experiences and knowledge due to their interpretations of their lived realities. South Africa is also a culturally diverse country. People of different ethnic and cultural groups may therefore also provide vastly different accounts of their lived experiences. Ryan (2018) also states that an interpretive researcher influences the new knowledge that is produced in a study since the researcher’s values, norms and beliefs have an influence on the methodology in terms of the selection of the sample group, the data collection and analysis, and the interpretation process.

From the discussion on the ontological and epistemological positions of this study, it follows that the choice of a qualitative research design complements a constructivist and interpretivist position the best. Understanding is the goal of the study and the personal role of the researcher, and the construction of new knowledge are important (Jackson *et al*., 2007). In the following section, I discuss my use of a qualitative research design for this study.

3.3 QUALITATIVE RESEARCH DESIGN

According to Akhtar (2016:86-87), a research design can be seen as the blueprint or "master plan" that a researcher uses to approach the research problem and answer the research question in a study. This plan considers which methods would be best suited for collecting the necessary data for analysis and the subsequent the production of new meaningful information. The problem that has to be addressed in this study is that little is known about the lived experiences of people with AIS in South Africa. It was therefore important that I select a non-invasive research design that would allow me to gather as much and as detailed data as possible from the participants about their own experiences growing up and living with AIS. The most suitable research design for this study was a qualitative research design. Other studies on intersex variations like the master's thesis of Van Jaarsveld (2018) on lived experiences of people with Turner's syndrome and the PhD study of Davis (2015) on AIS also made use of qualitative methods to gather data for their studies.

Research that is embedded in interpretivist and constructivist paradigms mainly resonates with qualitative research methods (Babbie & Mouton, 2001). As seen in the above discussion, interpretivists want to gain an understanding of how knowledge is constructed through the lived experiences and interpretations of the people in the social world. By applying qualitative research methods, interpretivists can gather rich, descriptive data that will enable them to provide *rich reports* (Thanh & Thanh, 2015:25). Thanh and Thanh (2015) further argue that interpretivists want to explore reality as it exists through the eyes of multiple people and qualitative research methods make this possible. The proponents of the interpretivist epistemology, emphasise the relationship between the participant and the researcher. Through in-depth interviews, new realities are constructed as the researchers potentially transform their interpretations of the participants' lived experiences into new knowledge (Goldkuhl, 2012).

Creswell and Creswell (2017) state that a qualitative approach is best to explore and understand a phenomenon when previous research on the topic is limited or the sample understudied, a thought that is closely related to this study. This type of research is particularly useful when the important themes are yet unknown, the topic is new, the subject has not been explored in a group or existing theories do not apply to the targeted

group. A qualitative approach was therefore suitable because of the limited South African sociological research on people with AIS. It was also suitable as the existing research on AIS in South Africa has mostly been medical. It is written from the perspective of medical professionals and excludes the views of people with AIS.

A qualitative approach also allows flexibility in the research process (Kumar, 2014), intending to explore the inherent diversity associated with the lived experiences of persons with AIS. In using this approach, the primary objective was to gain insight into the feelings, views, and lived experiences of the participants to construct a conceptual framework of the topic as an inductive contribution of the study. Although the sample size in a qualitative approach may be relatively small, it does provide valuable insights and an understanding of the participants' lived experiences (Maree, 2007). Since little is known about the lived experiences of people with AIS in South Africa, there is a great need to understand their lived experiences in more depth as opposed to making generalisations about these narratives.

The characteristics of qualitative research, as described by Creswell and Creswell (2017), align with the research questions and objectives of this study. Data collection could take place in the participants' natural environment, and I could collect data through direct contact with the participants. Participants could share their personal views and lived experiences freely, after which the information obtained was coded and arranged inductively according to the patterns and themes relevant to the study (Maree, 2007). A qualitative research approach furthermore gave me the opportunity to uncover the underlying themes that informed the meaning participants attach to their life situations and issues of interest to the study.

Informed by the characteristics and proponents of my qualitative research design, I made use of a methodology that complements this research design. In the next section, I offer a detailed account of the methodology I used for this study.

3.4 RESEARCH METHODOLOGY

According to Igwenagu (2016), the methodology of a study includes the overarching design, approach, and strategy for conducting the study. The methodology influences the researcher's choice of research methods for use in the data gathering process (Rehman &

Alharthi, 2016). The research methods of a study entail the choice of sampling, data collection methods, and data analysis. This section outlines these methodological.

3.4.1 Sampling

According to Lopez and Whitehead (2013), sampling enables the researcher to choose a section of the general population that will best represent a specific group that is being studied. Before one can decide on the type of sampling to use, it is important to understand the population that will be studied.

The population that was used for this study is people with AIS in South Africa. The sampling method that was chosen was a non-probability sampling, meaning that participants are selected according to the subjective judgement of the researcher. The reason for this choice was that the specific nature of the research topic ruled out the use of random sampling. There are only a small number of people in the entire South African population who have an intersex variation and even fewer who have AIS. There is no way of identifying the entire population of people with AIS as no national register is kept. Some people who have AIS may not have been formally diagnosed and may, therefore, be unaware that the diagnosis applies to them. As the selection was not random and the number of potential participants was limited, the type of non-probability-based sampling that was used for this study was purposive judgemental sampling. This type of sampling is rooted in the participants' knowledge about the topic researched. The non-negotiable sampling criteria for this study was that all the participants had to be people who had been medically diagnosed with AIS. Furthermore, all participants had to be older than 18 as children were excluded from this study. Potential participants who had symptoms of severe depression were excluded from the study unless they were under the care of a psychologist. This is discussed in more detail under ethical considerations in this chapter. The aim was further to include as many different AIS lived experiences as possible. I therefore attempted to include participants who varied in race, sexual orientation, and age. As there is only a small number of potential participants, this criterion was regarded as more flexible, meaning that I was able to gain insight into the lived experiences of participants from different contexts.

To gain access to potential participants, I approached three groups for assistance with identifying and recruiting potential participants: the first was a support group for AIS, the

second was the organisation Intersex South Africa and the third was Rare Diseases South Africa. I emailed a summary of the study to conveners or contact persons of these intersex platforms and asked whether they would be willing to post the information on their social media platforms or forward it to their members. I used these conveners as gatekeepers and only once the participants had received the details of the study, such as the informed consent forms, specific information in the study, and the interview guide and had agreed to participate voluntarily, I made direct contact with them. After this, an interview between each participant and myself was scheduled.

The contact details of the convenor of the support group for AIS was found online and she was contacted for assistance. The support group is no longer formally active, but the convenor was still informally in contact with some of the participants and she agreed to forward details of the study to them and, if someone indicated that they were willing to participate, to provide me with their contact details, which she did. I then contacted the small number of potential participants, most of whom agreed to be interviewed. There were one or two participants who responded to initial emails and said they would consider participating but did not respond to follow-up emails. At least one participant who had been referred to us through the support group did not meet the criteria of having a formal AIS diagnosis but had another intersex variation and had to be excluded from this study.

Intersex South Africa responded to initial emails, but not to a number of additional requests for assistance with this project. Rare Diseases South Africa was contacted with information about this study.[16] They forwarded the details of one person, who agreed to be interviewed. It was challenging to find enough participants merely through the probability-based sampling method of purposive judgemental sampling. This led to the decision to use

[16] ISSA refers to the Intersex South Africa. The main goal of this society is as follows: “The eradication of non-consensual, unnecessary genital “correction” surgery of all intersex people upon being born (ISNA, 2019).”

Rare Diseases South Africa is another organization with the mission of “bridging the gap to improved quality of life for those impacted by rare diseases and congenital disorders through advocacy and empowerment (Rare Diseases South Africa, 2021).”

a second type of sampling, namely snowball sampling. Snowball sampling entails that the researcher relies on existing research subjects for referrals to other possible willing subjects. This type of sampling is mainly used in studies where the population can be, in the words of Katz (2006:4), seen as a hidden population to which researchers do not have easy access, as is the case with people with AIS. One of the participants was recruited via snowball sampling. Some participants suggested other participants who were already participating in the study, and one participant referred us to someone who has an intersex variation, but not an AIS diagnosis.

Five participants were ultimately interviewed. Although it would have been more ideal to get closer to ten participants, five was considered the minimum number that would be sufficient to gather enough rich data to do an analysis. The following table present the participants' self-identified biographical information:

Table 3-1: Biographical information of participants

Name	**Age**	**Diagnosis**	**Race**	**Gender**	**Sexual orientation**	**Relationship status**
Leigh-Ann	29	CAIS	Black	Female	Straight	Single
Thandi	34	CIAS	Black	Female	Queer	Single
Sameera	43	PAIS	Coloured	Female	Straight	Married
Amanda	44	PAIS	White	Female	Straight	Married
Ronel	47	CAIS	White	Female	Straight	Married

It is significant to mention the specific biographical information in this table as these categories play an important role in understanding the lived experiences of participants as people with AIS. The treatment that older participants have received can for instance differ

from that of younger participants as treatment protocols have changed over time. This may influence the lived experiences of participants. Race could also influence the lived experiences of participants in terms of the type of intersex care that has been available to different people, in particular in South Africa with its history of apartheid. Black participants might also have additional experiences of racism and discrimination in health care settings. Gender is another important aspect to consider in the lived experiences of participants as the lived realities of men and women differ greatly as men and women are brought up to act out different gender roles and adhere to different gendered expectations. The sexual orientation of participants might also influence their lived experiences as the expectations for different sexual orientations differ greatly. Furthermore, the ways in which people of different sexual orientations are treated and subsequently how they perceive themselves within a heteronormative society also differ significantly. In this study one of the avenues of exploration was how AIS has influenced relationships, therefore the relationship status of participants is an important indicator of their lived experiences and how AIS have affected this aspect of their lives.

The section below offers an overview of the data collection techniques used during this study.

3.4.2 Data collection techniques

I made use of a life history method in this study. Life history methods follow the principles of qualitative data collection, and as the term suggests, entails participants telling their life stories. This was done by making use of an in-depth, online, face-to-face, or written interview with each participant. The interviews aimed to get each participant to tell the story of their life in their own words (Ssali et al., 2015).

To give some structure to the interviews, an interview guide with potential themes and questions was sent to participants beforehand. I also kept it at hand during the interview (see Appendix B). This ensured that similar broad topics and questions were introduced to each participant, but it allowed enough flexibility so that each participant could determine the direction of the interview. The interview guide served as a means to provide the participants with a sense of predictability with respect to the topics that would be raised in the interview and allowed them the chance to consider what they wanted and were willing to discuss and which questions they would rather avoid. It also aimed to reassure

participants that there no inappropriate questions would be included (e.g. direct questions about surgeries or appearance) and provided them with the opportunity to raise concerns about any of the questions. The interview guide was therefore in a sense sent as part of the informed consent process. The interview guide included questions about their early childhood, lived experiences of medical care throughout their lives, as well as the influence that an AIS diagnosis has had on their familial, friendship, and romantic relationships during different stages of their lives. Yes or no questions were avoided during the interview since the aim was to gather rich and descriptive data rather than short answers. Once I was put into contact with the participants, I sent them the interview guide along with a short background of the study and the informed consent form. All the participants received the interview guide positively and expressed the view that they appreciated the chance to see what the interview would be about beforehand.

Interviews took place between November 2020 and October 2021. The COVID-19 pandemic broke out during this time and lockdown restrictions were implemented in South Africa in March 2020. This affected the ability to conduct face-to-face interviews. Participants were, therefore, given the option to conduct interviews via an online platform (such as Zoom), or if this was difficult, to provide a written account in response to the interview guide. Three of the participants agreed to online interviews and these were conducted via the online platform Zoom. These interviews lasted for approximately one hour to an hour and a half.

A fourth participant indicated that they do not have a phone or other technology to conduct an online interview and that they prefer a face-to-face meeting. This interview took place in a quiet corner of the outdoor area of a restaurant to adhere to COVID-19 restrictions and to ensure privacy.

A fifth participant declined to be interviewed face-to-face or via an online platform and preferred to participate by writing down the answers to the questions on the interview guide. In this case the interview questions were sent together with the informed consent form and short background and the participant was told that they could answer the questions in as much detail as they preferred in their own time and at their convenience.

Interviews were conducted in the preferred languages of the participants resulting in two English interviews, one interview conducted in both English and Afrikaans, one Afrikaans

interview and an account of a participant that was written in Afrikaans. The language in which the interviews were conducted did not result in any significant language nuances that could be identified and did not seem to play a significant role in the way in which participants expressed themselves. Each interview started with a discussion of the main point of importance, which was the participant's diagnosis with AIS. This better contextualized the rest of their life story. This was followed by a chronological discussion, starting with their early childhood, and then proceeding to later years and their present life. Throughout these interviews, I regularly asked the participants whether they were alright to proceed with the interviews to ensure that they did not become drained. These participants also agreed to be available for follow-up interviews if necessary. The transcribed interviews were sent to all of the participants for member-checking, and they were asked to clarify certain points or to add anything they felt had been left out during the initial discussion. Follow-up and clarifying questions were sent with the transcribed interviews.

Gathering information about someone's life history allowed me to understand the transformation of the participants because of certain events, lived experiences, and phenomena in their lives. These lived experiences or phenomena have, throughout the years, led to choices that formed who and where they were in their lives at the time of the interview (Singh et al., 2019). Life history methods are especially useful in research on the lives of minority groups. For example, in the wake of feminist studies, life history methods came to be an especially useful and effective way of, in Kouritzin's (2000:2) words, writing/righting what is known about women and their histories as stigmatized and often inaccurate accounts existed of their lived experiences, as is the case with other oppressed groups. As this study aimed to investigate the lived experiences of a minority group – people with AIS in South Africa – life history methods were well suited. Since what is known about people with AIS and any other intersex variations was often written from the perspectives of outsiders such as medical professionals, there are inaccurate representations of people with intersex variations. This further stigmatises them as a collective group. An example of this is the award-winning book "Middle Sex" written by Jeffrey Eugenides (2002). This book received criticism from members of intersex communities. According to Intersex Initiative (Koyama, 2007), the main point of criticism was that Eugenides did not meet with any intersex people while he was writing the book. Furthermore, he directed questions about intersex variations to the public via media

interviews and public readings. The problem with this is that the public mostly consists of people with no lived experiences and insight into what it is like to have intersex variations. The whole book is therefore built on unreliable insights into intersex experiences. Another example is the book “Between XX and XY,” written by Gerald N. Callahan (2009), which also garnered criticism for reasons such as being very sensationalist and being written from an outsider’s perspective. In contrast, the recently published book “XOXY”, written by Kimberley Zieselman (2020) who herself has an intersex variation, is considered a good example of content that gives her life history and that is written from an insider’s perspective. Through this book, other people with intersex variations can relate to her lived experiences and it can teach gender-typical readers about the true lived experiences of those who are living with an intersex variation. This is seen in the reviews of intersex scholars and intersex activists like Georgian Davis, Elizabeth Reis and Sherri Groveman Morris who praised the book for its rawness and ability to capture the real lived experiences of someone who has AIS (InterAct, 2020). In this way, it breaks the silence and stigmatization around intersex variations. Making use of the life history approach in the investigation of the lived experiences of people with AIS in South Africa was therefore important as it enabled me to foreground the lived experiences of the participants. The Darlington Statement, a joint statement by the intersex community organisations of Australia and New Zealand, emphasises the importance of the formation of allies and providing education regarding intersex variations (Intersex Australia, 2017). According to the statement, it is also crucial to keep to the “Nothing about us, without us” notion. This means that intersex issues should not be used as a means to an end without the informed consent and personal input of intersex people. Furthermore, what is known about intersex variations should come from people who experience it first-hand. In a recent Twitter thread, an intersex researcher, Anick (2021), provided some critique of how gender-typical people attempt be “inclusive” of intersex on surveys. Some of his criticism includes that the option to choose between men, women, “intersex’ or “binary” immediately contributes to the othering of intersex people. Furthermore, he states that people should be mindful that the language and terms used to refer to intersex variations are not too academic or medicalised, etc. Examples like Anick’s twitter thread shows the importance of the voices of intersex people in redeeming them as a minority group and fighting for the correct representation of them.

According to Kouritzin (2000:2), the application of life-history methods gives researchers the ability to do the following:

> Listen beyond…hearing beyond the words of a person and living oneself as a researcher into the story of the participant's life in terms of their understanding and experience thereof.

Gathering in-depth and rich data is therefore pivotal to allow participants as much space and room as possible to tell their own stories. With in-depth research the possibility exists that multiple interviews have to be conducted with some of the participants to gather rich data (Singh et al., 2019). The first interviews produced rich data and participants were contacted with a few additional questions to either clarify or to elaborate if they wished to do so. These questions were sent via e-mail and were answered in a written manner and returned to me.

Data collection was followed by data analysis. The next section elaborates on the data analysis procedures.

3.4.3 Data analysis

In keeping with the preceding discussion of the qualitative data collection procedures, the detailed narratives of participants required transcription and in-depth thematic and narrative analysis. This, according to Blair (2015), is initiated using content analysis by creating codes. Elliot (2018) explains the act of coding as "how researchers break down their data to make something new".

After I transcribed the interviews, I first colour-coded the data into the different question themes, namely diagnosis, childhood, adolescence, relationships with friends, family, and romantic partners, mental health, and relationships with the medical establishment. Secondly, I used open coding, also known as first-level coding, to create certain themes from the raw data and roughly categorized and organized the data of the different interviews (William & Moser, 2019). During open coding, I compared these indicator concepts to material found in the literature. The open coding process involved reading and re-reading transcribed interviews to search for themed patterns (Williams & Moser, 2019).

Second, I used axial coding. According to Allen (2017), axial coding is a data analysis technique that is used in qualitative research to put corresponding data together to form

certain themed categories and subcategories from all the data collected. The first step was to “indicate concepts.” Some of the concepts I found through my coding process were, for example, “stigmas of an atypical body,” with themes such as “not getting a period” or “infertility”. The second concept I found was “the mental and emotional effects of having an atypical body,” and examples of themes that were identified include “fears of intimacy and dating” and “self-blame for failed relationships”. Axial coding was the last phase and the refinement of the coding process. This was possible through the selection of the main theme and linkage to other selectively coded themes. The purpose of selective coding was to create a theory that would contribute to new knowledge about AIS.

Although the analysis and interpretation of data were in the hands of myself as the researcher, it was important to represent the lived experiences of the participants as accurately as possible. To ensure that research is done in a manner that accurately depicts a certain reality, it is important to make use of criteria to evaluate the research done. In the following section, I discuss some of the criteria that are used to evaluate qualitative research, and which were applied to this study.

3.5. CRITERIA FOR EVALUATING QUALITATIVE RESEARCH

Gunawan (2015:4) states that trustworthiness can be seen as “a matter of persuasion whereby the scientist is viewed as having made those practices visible and therefore auditable”. According to Shenton (2004) and Gunawan (2015), naturalists often question the trustworthiness of qualitative research as the validity of results cannot be evaluated using the same methods that are applied in quantitative research. It is, however, possible to address the issue of trustworthiness in qualitative research by using applicable measures. Some of these measures are discussed below.

3.5.1 Credibility

One of the most essential of the measures to ensure trustworthiness is credibility, or the attempt to ensure that the study accurately tests or measures what it set out to test (Shenton, 2004). Some of the suggested ways in which a researcher can strengthen the credibility of a study are to use research methods that are suited to a particular study, a well-established familiarity with the social group that will be studied, regular debriefing sessions between the researcher and study leaders, etc. (Shenton, 2004).

As noted above, the present study adopted qualitative research methods to gain an in-depth understanding of the lived experiences of people with AIS. The chosen methods aimed to give participants as much control over the interview as possible by providing them with the interview guide prior to the interview and by allowing them to lead the interview and to discuss only the parts of their story they were comfortable with. This avoided a situation where participants were put in a position where they had to lie or be vague about a topic to avoid speaking about it and was a way of helping to encouraging honesty among participants. Participants were also reassured of the confidentiality and anonymity of data to make them feel comfortable enough to freely and honestly discuss any topic they wished.

By doing extensive research on the existing literature on intersex variations like AIS, I grew in familiarity with the population under studied, which contributes to the credibility of the study. I consulted both academic, activist, and other literature to broaden my knowledge. I acknowledge that as someone who does not have an AIS diagnosis, I will never fully understand what it means to live with AIS. I also had regular contact with supervisors for debriefing sessions. As one of my supervisors also conducts research on AIS, we were able to discuss the applicability of the ideas, concepts, and resources we found. During these sessions she was also able to guide me to remain focused on the topic and main objectives of the study.

3.5.2 Trustworthiness

Another way of ensuring trustworthiness in qualitative research is by ensuring confirmability. In quantitative research this has to do with the objectivity of the study. In qualitative research, this is challenging to achieve. It is, however, not impossible. Shenton (2004:72) states the following:

> Here steps must be taken to help ensure as far as possible that the work's findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher.

To this end, I made use of life history methods where the participants had control over their interviews and told the stories of their lived experiences on their terms. I made use of prompting questions where necessary, but otherwise aimed to play a non-intrusive role.

Transcribed interviews were also sent to participants to confirm that it is a true reflection of their experiences as discussed during the interviews.

While it is important to evaluate qualitative research to ensure validity and research of a high quality, it is also especially important to include the ethical considerations or axiology of a qualitative study where a researcher interacts with other people. This is to protect both the researcher and the participants. In the next section, I discuss some of these important ethical considerations during this study.

3.6 ETHICAL CONSIDERATIONS

As this study aimed to investigate the lived experiences of people with AIS in South Africa, I interviewed participants who have a health-related issue in the form of AIS. What is known about people with intersex variations like AIS is that in many cases (but not necessarily all), they do not find out the full truth about their diagnosis until they are much older (Donan & Yanay, 2016). Medical protocols dating from the 1950s advised medical practitioners to not be fully transparent with people with AIS. The view was that knowing about one's condition might cause anxiety or lead to gender confusion. People with AIS often only found out the truth about their diagnosis later in life, which ironically, often led to anxiety or feelings of anger towards medical doctors or parents for having lied to them (Feder *et al*., 2016). These medical protocols have only started changing over the last two decades. A South African medical article by Kemp (2013) shows that intersex treatment protocols have been adapted to now include full disclosure and psychological counselling for patients who are old enough. This was evident in my study where four of the participants aged 33, 34, 44 and 47 had been subjected to half-truths and lies from health care professionals and only found out the truth about their variations later in their lives. One of the younger participants, aged 29, received her diagnosis with full disclosure and honesty from her doctor.

Although the study carried the possibility that the participants who had fallen victim to secrecy surrounding their variation would be vulnerable subjects, doing this research was important for several reasons. The first is that apart from medical studies done by doctors, little is known about the experiences of people with AIS in South Africa. Medical studies usually do not incorporate the experiences, opinions, and voices of people who live with an intersex variation like AIS into their findings. According to Suen (2015), it is essential to

provide research evidence in areas where studies about certain phenomena are lacking. During this study, some of the participants felt emotional and vulnerable as they discussed certain topics and revisited certain experiences like failed relationships, difficult teenage and school years, and infertility. However, as examples from other studies show, despite feelings of vulnerability, participants often find great value in participating in studies that foreground their experiences (Noland, 2012). This was clear from how freely, openly and in detail all the participants share their life stories during the interviews. No participant stopped the interview or protested any of the prompts or questions that were asked. Noland's study found that participants, even those who had been subjected to rape and abuse, were willing to take part in studies on the topic of sex (Noland, 2012). Participants found great value in participating in these studies rather than experiencing them as harmful, even though sex is regarded as a very sensitive topic. In the context of my study, at least two of the participants are publicly open about their AIS and hope to combat secrecy, shame, and stigma surrounding intersex variations like AIS by disclosing and explaining their intersex status to people who are curious or ignorant, and by contributing to a research project such as this one.

According to Aluwihare-Samaranayake (2012:65), a qualitative researcher aims to do the following:

> Capture the voices of participants and represent them and their experiences in as true a form as possible, study persons in their natural environment, study persons by directly interacting with them, understand the participant's social world through the participants' voices and lenses and using the participants' words to tell stories.

I interacted closely with the research participants to enable them to tell their life stories and relate their experiences living with AIS through life history research methods. According to Arifin (2018), the application of ethics principles is especially important in qualitative studies that employ in-depth data collection measures, including in-depth face-to-face interviews. I had to act ethically in this study as the topic of discussion leaned towards sensitivity. Furthermore, as discussed in the section on data collection, qualitative research may encounter a problem of potential power dynamics and imbalances. I thus had to pay careful attention to various ethics considerations while doing the research. According to Aluwihare-Samaranayake (2012:65), ethics entails that a researcher strives to always do good and avoid doing any type of harm to their participants, whether it is

mentally, physically, or psychologically. Anwar (2015:23) adds to the definition of ethics by stating that a researcher should not “breach confidentiality” or “distort data.” I, therefore, did not discuss the content of interviews with anyone and always attempted to stay true to the real narratives of the participants while writing up findings and doing analysis. Research ethics is a relatively new field, with the Nuremberg Code as formulated in 1947 being the first to protest unethical research, in that case the various unethical human experiments that took place under Nazi control in World War Two. The Nuremberg Code aimed to provide a set of guidelines that could be used internationally when doing research or experiments that involve people. These guidelines include voluntary consent, informed consent, right to withdraw, avoidance of harm and suffering, duty, and the responsibility of the researcher to the participant (Anwar, 2015). For this study, it was important to follow the contemporary codes of practice and ethics guidelines and to make sure I had the necessary expertise, skills and sensitivity to conduct the research.

The next section focuses on some of the specific ethics principles that became relevant during this study. These include the following: a discussion of informed consent and voluntary participation; confidentiality, anonymity, and privacy; and that no physical, mental, or emotional harm should come to participants (Arifin, 2018).

3.6.1 Informed consent and voluntary participation

Informed consent and voluntary participation play a significant role in assuring the standards of ethics of a study and avoiding possible deception of participants. Marshall *et al*. (2006:1989) state the following:

> Informed consent represents a key ethical concern in clinical and community-based research. Voluntary informed consent is universally accepted as a prevarication for scientific research involving human beings.

Deception can happen when a researcher is not honest about the intentions of and methods used in conducting research. It is therefore important that participants are informed about all aspects of a study before they participate. I closely adhered to this principle in the study to safeguard the participants and myself. Since most of the participants had been lied to or deceived about their AIS at certain stages of their lives, I felt that it was especially important to be open and honest with them and to provide them with a complete picture and all the information of what this study would entail before they

agreed to participate. Informed consent is an ongoing process over the course of the research, which means that participants permit to voluntarily participate in a study only after they fully understand the research and risks related to that specific research (Tulyakul & Meepring, 2020). Voluntary participation means that the participants should be willing to take part in the research (Marshall *et al*., 2006). The process of obtaining informed consent included the provision of an information sheet to participants before conducting the interviews (See Appendix A). The information sheet informed participants of their rights, the study's purpose, the procedures of the study, and the risks and benefits of the study. As stated previously, I also provided each participant with the interview guide with a short background to the study and examples of the topics that would be discussed (See Appendix B). I reassured them that I would not be asking or discussing any invasive content. This also allowed them the chance to prepare for the interview and to think about the aspects of their lives that they were willing to discuss during the interview. Giving them the opportunity to read through this informative sheet on their own time, gave the participants time to respond to me via email concerning any questions and problems. Participants could indicate whether they were willing to participate in the study or not. In the informed consent form I also recommended that if they were under the care of a psychologist, they discuss their participation in this study with their psychologist beforehand. This was put in place to help participants decide whether it would be helpful or harmful for them to participate in the study. If their psychologist believed that the participant would not be affected negatively by the study in any way, they could proceed. None of the participants, however, indicated that they suffered from severe depression at the time of the interview. Before the interview started, I asked the participants again if they agree to participate and whether they understood what was expected of them. All the participants agreed and stated that they felt comfortable participating in the study.

3.6.2 Confidentiality, Anonymity, and Privacy

The second set of ethics considerations include confidentiality, anonymity, and privacy. These aspects deal with the protection of the participants' identities. Fouka and Mantzorou (2011:6) explain that confidentiality entails that "individuals are free to give and withhold as much information as they wish to the person they choose". According to Surmiak (2018), attention to confidentiality is especially important in studies that involve vulnerable participants. When sensitive information is exposed, it may harm participants from

stigmatised groups or participants who are dependent on certain people or organizations (Surmiak, 2018). Wiles *et al*. (2006) state that confidentiality in research implies that information that is retrieved through interviews is not repeated outside of the interview without the permission of participants. I thus did not discuss the content and data that had been obtained from interviews with anyone outside the study. Due to the lockdown regulations adopted in South Africa to curb the spread of COVID-19, I worked from home and also conducted two of the interviews from home via Zoom. I conducted these interviews at times when no one else was at home to ensure confidentiality. I conducted the third interview in my office on campus behind a locked door and with no one else in the office.

Another ethics principle that I considered and applied was anonymity. Anonymity implies that the identity and names of participants remain undisclosed. Although I knew the true identities of the participants, I used pseudonyms which I selected in the research report to protect the identities of the participants. As part of this specific set of ethics considerations, I also had to consider the privacy of the participants. Levine (1976, cited in Fouka & Montzorou, 2011:6) defines privacy in social research as follows:

> Privacy is the freedom an individual has to determine the time, extent, and general circumstances under which private information will be shared with or withheld from others.

3.6.3 No harm done to participants

The third ethics principle is that no harm should be done to the participants. This implies that no physical, emotional, or psychological harm should be done to participants during interviews. Babbie and Mouton (2001) warn that although harm is often unintended in qualitative interviews, questions and discussions may be very personal and some of the participants may therefore feel exposed, insecure, embarrassed, and uncomfortable answering certain questions. In this study, however, a life-history research design was used. This enabled the participants to offer the starting point of their narrative accounts and to determine the course of the interview. It allowed them to only discuss topics and disclose information with which they were comfortable. Although none of the participants at any time indicated that they were uncomfortable, I tried to gather from their body language and facial expressions whether they were uncomfortable discussing certain topics. Two of the participants mentioned that thinking about certain experiences made them “tear up”

and therefore I did not push them to elaborate on these experiences any more than what they volunteered on their own. In the informed consent form, I indicated that a psychologist would be available should participants feel the need to contact a professional. The psychologist volunteered to help participants in distress by means of a telephonic or online consultation free of charge if any participant felt a need to debrief or deal with emotional distress. As agreed with the psychologist, Dr Naidoo, the first consultation would be paid for by the research supervisor. Should the participant need additional counselling after this session, the psychologist committed to ensure that such counselling would be organized. However, none of the participants opted to use these counselling options. As three of the interviews took place on the online platform Zoom, I recognized that exposure to a computer screen can be tiring and strenuous for one's eyes. I regularly asked participants who I interviewed through Zoom if they were alright to ensure that the duration of the interviews did not exhaust them. I also made sure that the participant who I interviewed in person was comfortable by regularly asking if she was all right to continue with the interview.

Ethics principles should not only apply to the participants in a study, but also the analysis and reporting of the study. Babbie and Mouton (2001) state that it is important to be honest when reporting your results and to be open about the limitations of the research methods or the findings. Some of the limitations with respect to this study are discussed in the next section.

3.7 LIMITATIONS

While doing this study, I recognised the fact that the sample was small even for a qualitative study. This means that this study is not generalisable with respect to the experiences of people with AIS in South Africa. Some of the factors that contributed to the inability to generalize the findings include the fact that I made use of a qualitative research design where the aim is not to generalize. Furthermore, I required a specific population and therefore I could not make use of random sampling. Due to the limitation in my sample size and selection I did not have access to certain groups or individuals, and this limited the data I could analyse. As seen in the discussion of sampling methods, South Africa is a country of great diversity where economic vulnerability is a concern that may have compromised the opportunity for certain individuals with AIS to participate in this study.

Not all viable candidates have access to necessary technology like cell phones, tablets, laptops, and an adequate internet connection for them to receive the invitation email and to later participate in online or telephonic interviews. It may also not have been possible for them to either host me at their homes for a face-to-face interview or for them to travel to a destination where this interview could take place.

Furthermore, not all people who had been identified agreed to participate in this study. There were cases where emails were sent out and gatekeepers did not reply. There were also cases where I was put into contact with participants and upon emailing them, they did not return the email. This could have been for various personal reasons. These people's lived experiences were therefore excluded from this study, and it was therefore not possible for me to capture all the different and unique lived experiences of people with AIS in South Africa.

Due to personal preference, convenience, and COVID-19 restrictions, three of the interviews took place via the online platform Zoom. While this was a convenient way of conducting the interviews, at times the internet connections and technical aspects of Zoom made the interviewing process a bit challenging due to buffering, lagging, and delayed feedback. However, this did not affect the quality of the interviews significantly and I was able to gather data of a high quality. The impersonal nature of an online interview also made it awkward at times to conduct such a personal interview over an online platform instead of in a direct face-to-face manner. Where a direct face-to-face interview would allow me to pick up on the body language of a participant, an interview over Zoom did not allow me much insight into the body language of a participant other than what I was able to observe from facial expressions, hand gestures and upper body language. According to Garner (2012), one of the downfalls of online interviewing is that not all participants or researchers are comfortable with being on camera and they may struggle to speak freely and to engage with the interview, while it might be different in a face-to-face interview. This did not pose a great challenge, and after the initial awkwardness of meeting a stranger and all the introductions, we were able to have interviews that were data-rich and high in quality.

The last limitation I experienced as the researcher was my own initial ignorance on the topic, as I am not someone who has an intersex variation like AIS. I felt that I had to be

especially careful in analysing the data accurately to represent the lived experiences of the participants as South Africans with AIS. As someone who does not have an intersex variation, I remembered that life history research methods entail that the participants tell their own stories, and they therefore lead the interview to a great extent. This allowed me to fall back on some of the qualities of qualitative research and to be open to understanding the experiences of these participants. I learned to rely on what participants said rather than to explain it from my interpretations and from theories about their experiences (Maree, 2007).

3.8 CONCLUSION

In this chapter, I discussed the methodology I used to investigate the lived experiences of people with AIS in South Africa. A constructivist ontological position and an interpretivist epistemological position underpinned this research project. Furthermore, I discussed why the use of a qualitative approach was the most suitable for this study. This was followed by a discussion of the methodology in terms of the sampling procedures, data collection methods, and analysis process. Finally, I concluded the chapter with a discussion of the various ethics considerations I had to bear in mind and some of the limitations of the study.

CHAPTER 4: FINDINGS AND ANALYSIS: PART 1

4.1 INTRODUCTION

In Chapter 3 I outlined the methods that were used for this study. With the use of these methods and from my interviews with five participants, I gathered rich data that I analysed and from which I was able to reach insightful findings. One of the main objectives of this study was to explore how the medicalization of AIS has affected the lives of people with AIS in South Africa. In this section, I address two of the subsections of this objective. First, I discuss and analyse the findings that relate to how the diagnosis and treatment of AIS have shaped participants' ideas and experiences of gender. Secondly, I discuss and analyse the findings that relate to how the diagnosis and treatment of AIS have influenced the familial and other relationships of the participants

4.2 DEALING WITH AN ATYPICAL BODY: PUBERTY MILESTONES AND GENDERED IDENTITIES

In this section, I make use of Risman's (2004) gender structure theory to explore and analyse how the awareness of bodily difference, diagnosis, and treatment of AIS has shaped the gendered ideas and experiences of persons with AIS at an individual level. The individual level of Risman's theory refers to how individuals develop and understand themselves as gendered beings. This takes place through the internalization of a male or female gender identity through the exposure to and understanding of gender-specific personality and characteristics (Davis, 2015).

As feminists have been arguing, bodies and how they function are important parts of gendered identities. A crucial time for gender formation is puberty when bodies go through certain changes. Even though these changes are often a source of great agony for young men and women, they can find comfort knowing that most of their peers are going through similar uncomfortable experiences. Furthermore, these experiences indicate that their bodies are doing "what they should be doing" and therefore signify "normality." For example, in a study among young South African students, Padmanabhununni and Fennie (2017) found that the attitudes around menstruation were largely positive as students viewed menstruation as "a natural event that can be anticipated and predicted."

However, because their bodies are not sensitive to androgen hormones, people with AIS do not go through bodily changes like menstruation, the growth of body and pubic hair, and problems with sweat, oil, and acne like other teenagers. Therefore, they may struggle to relate to their peers and feel "isolated" (Davis *et al.,* 2016). I discuss participants' experiences in the next section.

4.2.1 Not getting a period

In this study Leigh-Ann and Sameera stated that the main reason for going to the doctor, eventually leading to an AIS diagnosis, was the fact that they still had not started their periods late in their teens or early adulthood. For many people with AIS, in particular CAIS who are born with female phenotypical bodies, the absence of menstruation is often the main cause for concern and eventual medical inquiry (Davies *et al*., 2016). Thandi and Ronel received little explanation for why they had not started menstruating. Since Amanda was raised as a boy, menstruation as a puberty milestone did not apply to her life as an adolescent or young adult.

By observing how their peers who had started to menstruate were treated, Leigh-Ann and Sameera became aware of the importance of menstruation and its link to womanhood from a young age. Leigh-Ann (2021) stated that she "waited anxiously for her time to come", while Sameera (2021) remembered "the fuss" people made over her friend who started to menstruate and told her "she is a woman now." Mondragon and Txertudi (2019) state that period positivity has been incorporated into education, healthcare practices, media, and families. This strengthens people's beliefs that periods are a strong sign of womanhood in terms of fertility and reproductive ability.

Since menstruation is a milestone for women, Leigh-Ann and Sameera recalled that their friends and family would ask them whether they had started their periods yet. This indicates that on an interactional level of gender structuring, their friends and family also had certain gendered expectations of their development as women. In response to this question, they would "fake it" or "tell a white lie." Davis *et al.* (2016) offers supporting accounts of people with AIS faking their periods. Sameera (2021) shared her experience as follows:

> I just remember waiting and waiting and waiting and I think when I was in Grade 8 or Standard 6, I really started feeling inadequate or like starting to hide it from other people.

As menstruation is seen as a natural and normal process for women, the absence of periods indicates that something is not quite right, and this means that you are not entirely a "normal woman." Like the other participants, Thandi (2020) did not get her period and recalled being seen as "the girl with developmental issues" as she experienced impaired bodily growth and did not grow in length. She had limited breast development and did not start to menstruate. Like other intersex people, this made her feel that she could not relate to her sisters and female peers who menstruated (Davis *et al.,* 2016).

Both Thandi and Leigh-Ann have people in their families who they suspect have AIS. While there are many of these family members who never admitted it, Thandi and Leigh-Ann could tell from their own experiences and behaviours as people who are not menstruating in a world of menstruating women, that their family members also did not get their periods. Although there is nobody other than Sameera that has AIS in her family, she stated that although nobody talks about it, they are all watching her pre-teen niece in anticipation for signs that her period has started. This silent feeling of anticipation and anxiety manifests as a fear of deviance and hope for typicality.

4.2.2 Breasts growing and not growing

Like menstruation, the growth of breasts in most cultures signifies womanhood, motherhood, vitality, and sexual readiness. This development is therefore greatly anticipated in young women. Webb *et al*. (2019) state that during puberty breast growth or the lack of breast growth is the most visible sign of bodily change (or the lack thereof) in a woman.

Three of the participants, Thandi, Leigh-Ann and Ronel, have CAIS and had little to no breast development. The experience of not developing breasts was particularly traumatizing and difficult for Sameera, who has PAIS. She shared her experience as follows:

> For me the breast part was the biggest deal. I was so ashamed. I did not undress myself in front of – I still do not undress myself in front of people. It is something that I cannot do until this day. To be honest, I am even ashamed to get undressed in

> front of my husband. I feel horrible about it. Even when I look at myself in the mirror, I always feel like that. Yes, it is a reminder for me (Sameera, 2021).[17]

Van de Grift and Kreukels (2019) state that people with AIS who have smaller breasts may experience a poor body image, low self-esteem, and a sense of being different. As a result of her breasts not growing, Sameera started to wear loose-fitting clothes in an attempt to hide it.

While breasts are linked to motherhood and nursing in a non-sexual way, it is also closely linked to sexuality, especially heterosexuality (Ward *et al*., 2006). The media portrayal and sexualization of breasts convey a message about the role of breasts in a woman's ability or inability to be regarded as sexy or beautiful (Ward *et al*., 2006). In their British study on men's preference for women's waist-to-hip ratio, breast size, and ethnic group in Britain and South Africa, Swami *et al*. (2009) argue that there were differences in preferences between these cultures. South African men found black women with a high waist-to-hip ratio and large breasts attractive while they found white women with a high waist-to-hip ratio with small breasts attractive. In the British setting, the opposite was found (Swami *et al*., 2009). Webb *et al*. (2019) state that since breasts develop during adolescence, they have an aspect of youthfulness attached to them, which is often regarded as "desirable and ideal." Sameera experienced the fact that her breasts did not develop as a key reason for one of her relationships not working out. She felt that she was undesirable for her boyfriend and that it is still a source of feelings of inferiority as a woman for her. She said: "In that relationship, I actually felt that he did not want me because of my breasts. That is how I felt that I was not good enough. I always feel that (Sameera, 2021)."[18]

---

[17] "Die bors gedeelte was vir my die grootste ding gewees. Ek was so skaam gewees. Ek het my nie uitgetrek voor – ek trek my nou nog nie uit voor mense nie. Dit is iets wat ek tot vandag toe nie kan doen nie. Om eerlik te wees, ek is even skaam om uit te trek voor my man. Ek voel horrible daaroor. Even as ek 'n dag myself kyk in die spieël dan voel ek altyd so, ja, dis 'n reminder vir my (Sameera, 2021)."

[18] "Ek het eintlik gevoel in daardie verhouding hy wil nie vir my hê nie oor my borste. Dis hoe ek voel, ek was nie goed genoeg gewees nie. Ek het altyd daardie gevoel (Sameera, 2021)."

The centrality of breasts in women's body images was also demonstrated in a South African study on cancer perceptions in KwaZulu Natal (Zwane, 2021). In the study, one of the participants stated, "our beauty is in our breasts." In this study, Zwane (2021) found that participants associated disease-free breasts with beauty and attractiveness. In their Brazilian study Almeida *et al*. (2015) found that women who undergo mastectomies often express feelings of shame when losing their breasts, since breasts are linked to their body image as women and subsequently their self-esteem. In their Canadian study, Webb *et al*. (2019) provide the account of poet Audre Lorde who had to undergo a mastectomy after being diagnosed with breast cancer. After her surgery, she was told that if she wore a breast prosthesis nobody would even know she only had one breast. Lorde, however, felt that the only concern for doctors in telling her this was to keep other people comfortable by "normalizing" her body (Webb *et al*., 2019). This reminds one of how doctors often want to "fix" and "normalize" atypical bodies, but also of the gendered expectations of bodies and their centrality to ideas of femininity and masculinity.

Amanda had full breast development by the age of 11. According to the AIS Australia Support Group Inc. (2019), it can sometimes happen that people with PAIS develop traits of the opposite gender to that which they were assigned, and this can lead to great confusion and shame in the person. Amanda recalled her experience as follows:

> When I was in Standard 3, I think it is Grade 5 today, my breasts began to develop and it was terrible to do physical exercise at school with the boys because you have boobs and I do not mean bee-stings, you have BOOBS and now you have to swim with them and do physical exercises and get undressed among the boys and all those things. For me, it was the most terrible experience (Amanda, 2021).[19]

While Amanda has always identified more with a female gender identity, she has PAIS and was raised as a boy and lived a part of her life as a man. She therefore had to adhere to

[19] "Toe ek in Standard 3 was, ek dink dit is vandag Graad 5, toe het my bors al begin ontwikkel en dit was vir my veskriklik gewees om L.O. te doen saam met die seuns, want jy het boobs en ek meen nie bystekies nie, jy het BOOBS en nou moet jy saam met hulle daar swem en L.O. doen en uittrek en tussen die seuns en al daardie goed. Dit was vir my die verskriklikste ervaring (Amanda, 2021)."

some of the social norms and expectations of being a man. As Webb *et al*. (2019) explain, breasts are often highly sexualized, and Amanda experienced shame as a boy having breasts and eventually rather took the punishment for “forgetting her sports clothes at home” for physical exercise periods at school rather than to participate with the boys. In his study on the stigma of gynecomastia, Huber (2012) argues that there is a sense of reward and easing of the mind in being considered “normal” and that people strive towards normality.

4.2.3 Infertility

Throughout a person’s life, their gender is constructed through their exposure to the different gender roles of men and women (Giddens, 1984). During the process of gendering, young women see that women have children, and they internalize this phenomenon as part of their roles as women (West & Zimmerman, 1987). Fertility is therefore linked to womanhood. Greil *et al*. (2011) state that like other binary categories, health and disease are socially constructed. The opposite of fertility, which is regarded as normal and healthy, is thus infertility, which is linked to atypicality. According to Bista (2015), infertility in women, especially in developing countries like South Africa, is something that often leads to great shame, hardship, and stigmatization due to traditional beliefs of bad omens and curses. Since women with AIS do not have a uterus or ovaries, they are infertile.

Three of the participants, Thandi, Sameera, and Ronel, found out about their infertility when they were teenagers. The other two participants, Leigh-Ann and Amanda, found out when they were young adults.

When Thandi and Sameera got the news of their infertility at the respective ages of 13 and 19, it did not bother them too much. Thandi (2020) said “I think at that age it was a relief because I was 13. It was like ‘okay cool, no kids, great!’” Sameera (2021) also remembered “not being much fazed” by this knowledge. However, their infertility affected them later in their lives. Thandi stated that she attempted to convince herself over the years that she does not want children and that it was not meant to be. She has, however, reached a point in her life where she now wants to have children and said that she may investigate avenues like adoption. Sameera stated that during her twenties, she found distraction by going out with her friends and becoming invested in her career.

Sameera's infertility did not bother her too much on a personal level. However, it had an impact on her socially. She shared her experience as follows:

> I remember often when people asked me when we're going to reach babies, I did not feel good about it. Then I would tell people we do not want to have children, we are too busy, you know. There was always an excuse (Sameera, 2021). [20]

According to the Romanian study of Tripathy *et al*. (2020), infertile women may find ways to cope with their infertility with self-assurance and active avoidance coping. Tripathy *et al*. (2020) further report feelings of hopelessness and worthlessness in infertile women. Bista (2015) states that in developing countries infertile women often have lower social status. This may lead to lying and keeping secrets about their infertility. Sameera experienced this and shared the following narrative:

> For the first four years of our marriage, his (my husband's) people did not even know that I could not have children. I began to build up a complex, not for myself, but I began to feel bad for him. I began to feel like I was doing him wrong (Sameera, 2021). [21]

Sameera and her husband got divorced and she recalled that before the divorce she told him to find himself a woman who could give him children. Sameera's reaction reflects the view of infertile women in Bista's (2015) study who felt that their infertility compromised their romantic relationships. Some participants also feared divorce, and like Sameera, some suggested to their husbands that they should remarry or have a second wife.

For Leigh-Ann, Ronel, and Amanda, the news that they could not have children was hard to process when they found out about it. When the doctor told Leigh-Ann that she did not

---

[20] "Maar ek onthou baie as mense my gevra het wanneer gaan julle nou babatjies haal, het ek nie lekker gevoel daaroor nie. Dan het ek nou maar altyd vir die mense gesê ons wil nie kinders hê nie, ons is te besig, you know. Daar was altyd 'n verskoning by gewees (Sameera, 2021)."

[21]"Vir die eerste vier jaar van ons huwelik het sy mense nie eers geweet ek kan nie kinders kry nie. Ek het meer begin 'n kompleks opbou nie vir myself nie, maar ek het begin sleg voel vir hom. Ek het beginne voel ek doen hom 'n onreg aan (Sameera, 2021)."

have a uterus or ovaries she remembered feeling a sense of shock and denial. She stated that as a woman you have a plan to start a family in the back of your mind. She shared her experience as follows:

> At the time I was about 21 and I was dating someone, and it felt pretty serious, so my whole plan was that by 23 we would be married, by 25 we will have our kids and by 20 we will have this and that, and I think that presented a different, different life plan (Leigh-Ann, 2021).

Like Thandi, Leigh-Ann went through a process of coming to terms with her infertility. She describes it as follows: “I think it is this always constant evolution of what that means for my life (Leigh-Ann, 2021).” Leigh-Ann recalled believing in miracle conceptions and later considering adoption. She has dated men who already have children as she felt less pressure on her to have children of her own. She also went through a phase where she did not want children and subsequently sought to date people who also did not want children. She also stated that in the back of her mind she thought that her relationships at the time did not work out because she got the news that she was infertile. According to Bista (2015), the news of infertility harmed the self-esteem of all the participants in his study, leaving them with worries about their future lives. Tripathy *et al*. (2020) state that infertile women often feel isolated from other women and may experience feelings of loneliness and social deprivation.

According to Gurevich (2020), people can develop feelings of worthlessness and shame as a result of their infertility. Other feelings of depression and anxiety, guilt, and isolation are also associated with infertility. These feelings indicate a sense of difference and deviation from what is seen as typically associated with women and almost considered the standard (Risman, 2004). Although Ronel has accepted her infertility now that she is older, she mentioned that it was a sore point for her for a large part of her life as she badly wanted to have children. She bluntly said the following about her infertility: “I can’t have kids. I feel inferior to other women (Ronel, 2021).”

Amanda expressed that it was very tough for her to know that she could not have children. As a child, she and her friends would play and pretend to be pregnant and all the “normal games” that children play. Through social interaction with men and women in her life, Amanda learned the rules and expectations, but also the milestones of womanhood (Davis, 2015). She said that when she reached the age where she knew most women

have babies, knowing she could not have children was very painful for her. She often wondered what her children would have looked like and if they would have had her “tip-tilted nose” (“*wipneusie*”). Both Amanda and Leigh-Ann mentioned that their infertility forms part of what they experience as some of the worst aspects of having AIS.

4.2.4 A different body

While fertility, reproduction, and motherhood are closely linked to the importance of being a woman, reproduction is not always the end goal of sexual interactions. Over the years, sex for the sake of sexual pleasure has gained acceptance and has become widely encouraged and normalized (Farvid, 2015). Throughout the history of the medicalization of intersex as discussed in Chapter 2, doctors regarded the possibility of heterosexual sex as important in their treatment protocols (Reis, 2009). This places great emphasis on the appearance and functionality of a person’s reproductive organs (Shick *et al*., 2010). All of the participants had genital reconstructive surgeries to “normalize” the function and appearance of their reproductive organs. In all of the cases, this has had an impact on their perceptions of themselves as women.

Sameera had genital reconstructive surgery as a baby and does not remember this procedure. Thandi’s gonads were removed during her teens, and this affected her self-image greatly. She stated the following:

> And I’m like, cause now I’m starting to realize that I’m scared of dating. I don’t want to show these scars to people. I’m not going to ever be able to do that without an explanation (Sameera, 2021).

Thandi’s comment implies that there is a certain norm of what a body should look like and she was afraid that she might have to explain that her body was atypical (Davis, 2015).

The scientific foundation of medicine contributes to the fact that people value the opinions and judgments of doctors (Davies, 2015). The Intersex Society of North America (ISNA) (2008) states that most intersex people prefer to live with either a male or female gender identity. Furthermore, women are raised to believe that their appearance is essential to their sexuality and in their perceptions of themselves (Schick *et al*., 2010). This explains why an intersex woman in Amato’s (2016) study in the U.S. stated that some intersex people get genital reconstructive surgeries due to a belief that their bodies are abnormal.

Intersex women trust surgeons to construct “normal vaginas” for them to positively contribute to their wellbeing and relationships.

Ronel had a vaginoplasty and recounted that doctors used a part of her colon to build her vagina. During that procedure, there was a complication, and as a result, she feels that her new vagina does not have an appealing appearance. In a psychological study Schick *et al*. (2010) state that genital dissatisfaction results in higher self-consciousness and anxiety. This may result in sexual devaluation, which can have a significant impact on a person’s sexual experience. Like with Ronel, doctors used a part of Amanda’s colon to build her a vagina. As a result of the surgery, Amanda’s constructed vagina has scar tissue that does not allow her vagina to stretch. She can therefore not have penetrative sex and she has to deal with the feeling that she is missing out on intimate experiences. Although Amanda always identified as a woman, she was convinced that vaginoplasty will only add to this feeling of femininity, but she now deeply regrets this surgery. Both Amanda and Ronel are also concerned about unpleasant vaginal odours and Ronel wonders whether her orgasms are the same as other women’s, but added that she won’t know because “I can’t discuss orgasms with other women because I am different (Ronel, 2021)”. According to Tamar-Mattis (2014), scarring and incontinence are some of the common risks in genital reconstructive surgeries in adults with intersex variations. In her study on 57 adult intersex patients who had genital surgery, she found that problems like dissatisfaction with functional results, clitoral arousal, overall sex life, sexual anxieties, sexual desire, and painful intercourse were common.

In the next section, I provide an account of how AIS has influenced relationships and the social aspects of participants’ lives by looking at some of the shared themes that stood out in the interviews of all the participants.

4.3 RELATIONSHIPS AND THE SOCIAL ASPECTS

In this section, I use the gender structure theory to explore and analyse how the diagnosis and treatment of AIS have influenced interactions with family and other relationships. The interactional level of gender refers to how people “perform” the genders associated with their biological sexes by acting in the ways expected of their genders. They learn these gender roles through interactions with other people in the world (Davis, 2015).

4.3.1 Rejection and difficult relationships with parents

Four of the participants in this study indicated that their AIS and its medicalised process had a negative impact on their relationships with at least one of their parents. Through difficult interactions with their parents, participants formed certain perceptions of themselves as people with atypical bodies.

According to Digitale (2008), new parents can find it difficult when doctors reveal uncertainties about their new baby's sex. From a binary perspective, finding out that their baby's body is atypical is not exactly something that "books prepare them for". There are various platforms like Intersex Human Rights Australia and IGLYO, OII Europe & EPA and the British DSD Families that offer advice and guidance for parents on how to support their child with an intersex variation. There is, however, often no psychological help available that specializes in helping the parents of intersex children (Feder, 2009). There are only a few support group platforms like that of the UCSF medical centre in California (Allday, 2011) to help parents cope with their child's diagnosis.

All the participants in this study indicated that their parents never received psychological counselling after they found out that their children had atypical bodies. Due to confusion and a lack of psychological support, parents put their trust in medical professionals to make a call about their child's body (Conn *et al*., 2005). This may lead to a wrong gender assignment like in the case of Amanda, or the belief that it would be in the best interest of the child to keep the truth about the child's variation a secret or to lie about it to the child and other people like in the case of the other four participants (Conn *et al*., 2005). This often results in strenuous relationships between parents and their children.

Sameera and Amanda were born with atypical bodies and although doctors recommended treatment plans, surgeries and offered gender assignment, their parents were not given a diagnosis. According to Feder (2009), doctors may keep some of the information from parents as it may interfere with the successful rearing of the child in his or her assigned gender. This statement emphasizes the medical importance of rearing a child in a particular gender and reaffirms the old idea of doctors that a person living in the wrong gender is unsettling (Reis, 2009) and that a person must fit into one of the gender binary categories.

Ronel, who has CAIS, was also diagnosed as a child. Her parents knew what signs of AIS to look out for since her older sister also has AIS. As opposed to the parents of the other two participants, her parents were given a diagnosis. However, although her parents knew early on that she had AIS, they were not open about her diagnosis and to this day Ronel's mom refuses to talk about it. As children and teenagers, Ronel, Thandi and Sameera experienced that their parents lied or hid some of the truths about their medical and surgical procedures from them. This often results in confusion and feelings of violation in people with intersex variations (Feder, 2009).

When Sameera was a child, her mother told her that she would tell her why she was in the hospital as a child when she was older. However, this never happened. She believes her parents were ashamed of her condition and therefore never knew how to tell her the truth. Sameera was born in the 1970s. During this time, Money's intersex treatment protocols, of which non-disclosure of an intersex diagnosis was a part, were in full use (Reis, 2009). By emphasizing the urgency of secrecy, parents receive and internalize the message that they must be ashamed of their child's variation (Karkazis, 2008).

When Thandi's gonads dropped at the age of 13, her mother insisted that they should not tell anybody and that she was going to do something to fix it. Not even her father was told. Thandi's father still does not know about her AIS as it would seemingly cause a feud between her parents and her father would likely blame her mother for Thandi's condition. Thandi says that AIS is carried on the maternal gene and that when something is wrong with the baby in her culture, the mother of the child is to blame. The South African study of Behrens (2020) found that in some South African cultures, intersex babies have been subject to infanticide as they were seen as a bad omen. In these cases, the family members would kill the child and tell the mother that the child was stillborn. This also hints at the stigma that exists in the face of a body that is not "normal."

During her teens, Thandi attempted to talk to her mother about her variation. She even attempted to connect with her mother through their mutual experiences of menopause since Thandi's body went through menopause when she was put on hormone replacement therapy after her surgery. This conversation was, however, "shut down so quickly (Thandi, 2020)" since it is regarded as taboo to talk about things of a sexual nature in her cultural context.

Oketchi's (2018) Nigerian study shows that some African cultures view sexuality as something that is extremely sacred and by discussing it or speaking about it in public, this sacredness is compromised. This, however, leads to a lack of the necessary sexual education among these groups. Thandi shared the following about her mother's reaction when she thought that Thandi was dating:

> She kind of like, was shouting at me and telling me all these things about HIV and when I turned around and said 'yeah, but how do you expect me to have sex when I'm intersex and we have never discussed all of this', she got quiet and that was the end of the conversation (Thandi, 2020).

Ronel had a similar experience. Being curious as a teenager, she tried to insert a tampon, but when her mother found out, she was very angry and scolded her, but without discussing the situation or her AIS with her. Even though her older sister and two of her other sisters' daughters have AIS, it was and still is regarded as taboo to ask questions and talk about her variation in her family. Despite knowing that something was wrong with her body, Ronel was only told that she and her eldest sister "are the same." As a result of secrecy and non-disclosure, Ronel experienced anger towards her mother throughout her life. She stated the following:

> My mom still till today don't even want me to talk about it. And I have told her straight the more you keep it a secret the more people will have no idea we are normal humans with just a stupid insensitivity syndrome (Ronel, 2021).

She also stated that although many of the female members of her family have AIS, nobody talks about it. Conservatism also contributes to secrecy and shame. Families may not want to discuss the biological atypicality of their children due to the fear of confusing others (Donan & Yanay, 2016).

Sameera was very understanding of her parents' choice in her surgery as a child and said that she would not have wanted to grow up with a body that had an atypical appearance. While she never blamed or had conflict with her mother, she also experienced being lied to by her parents as a teenager. She shared this experience as follows:

> I think from the age of 13 the expectancy was that I was supposed to have my period and they were like 'no, no wait, wait, it will happen', so they kind of lied to me for a number of years (Sameera, 2021).

Since the gender binary divide posits that there is a correlation between one's biological sex and gender identity, the atypical bodies of Thandi, Ronel and Sameera posed a threat to what society regarded as "normal" with respect to a female body (Ambrosino, 2017). This induced their parents' need for secrecy.

After Leigh-Ann received her AIS diagnosis as a young adult, her mother urged her to keep her variation a secret and, like Thandi, not to tell her stepfather. A few months after her diagnosis, she experienced an emotional breakdown and shared this experience as follows:

> I was also quite upset with my mom at the time because she just said that let's not tell anyone. Let's keep this a secret and yeah, I think I was also upset, but I could not really talk to anybody and…she wasn't really talking to me as well (Leigh-Ann, 2021).

All she wanted was for her mother to accept her as she was. Leigh-Ann believes that part of her mother's reaction has to do with her mother experiencing great guilt and that she has not quite accepted her diagnosis yet. Her mother would for example make statements that she cannot wait for Leigh-Ann to have children while she knows that Leigh-Ann is infertile. Leigh-Ann and her mother also have different ideas about how she should deal with her AIS. When Leigh-Ann "came out" as having AIS on social media, this, according to her mother, hurt the family. This reaction by her mother again implies that having an AIS diagnosis is something to be ashamed of and that should be hidden from other people.

Amanda also received her official AIS diagnosis in her early adulthood. Amanda stated that her father initially struggled to accept her diagnosis and that it is sometimes still difficult for him to make peace with it. According to Amanda, her father accepted it, but when he wants to hurt her, he would make unwelcome comments that refers to her AIS.

4.3.2 Missing out

As discussed earlier with regard to puberty milestones, participants in this study experienced feelings of missing out. This also applies to other parts of their lives. While some of the participants directly stated that they felt that they had been robbed of certain experiences, others indicated these feelings more subtly and indirectly.

Although Sameera does not remember much of her childhood, she knows that she was in the hospital for numerous months as an infant and said that her mother told her that they did not know her as a baby. In an American study done by Franck (2015), it was found that while parents are encouraged to be involved in their child's hospital care, this is often challenging. This is caused by factors like transport problems, food, a place to sleep, care of other children, and issues with taking leave from work. Sameera's life was different from that of other babies who could live with their parents after they were born. She therefore "missed out" on this aspect of her life.

Amanda also experienced a sense of missing out as a child. According to a Romanian study by Ovidiu *et al*. (2020), it is still recommended that the gender assignment of a person with PAIS born with an atypical body should be done as soon as possible by considering genital appearance. However, this can lead to the wrong gender assignment and can result in the gender dysphoria that Amanda experienced growing up (Danon & Yanay, 2016). Through social interaction, children learn and express the gendered roles of men and women through play (West & Zimmerman, 1987). While Amanda felt like a girl, she was raised as a boy and stated that she could never play games like house-house or get a little kiss from a boy like her girlfriends did during childhood. During the interview, she expressed feeling robbed growing up as a boy. She stated that if she was raised as a girl, she would have been able to participate in sports and that she might have had the chance to perform well academically, but that her being raised as a boy caused her to "take a huge knock (Amanda, 2021)".

Like Amanda, Thandi also stopped participating in sports. She shared her experience as follows:

> I immediately stopped taking sports. I was really good at running and you know, cricket and things, so I was told I should stop playing sport. I should focus on other things like reading and, you know, debating and anything that will not involve me taking off my clothes in public (Thandi, 2020).

Throughout her teenage years, Thandi was not allowed to have sleepovers with her friends. She stated that she often had to come home only to sit in front of the television. According to Davis and Preves (2019), it is common for children and teenagers with AIS to miss out on important social and gender-shaping experiences due to surgery or the fear of exposing their bodies.

Sameera, Ronel, and Amanda, had feelings of missing out with respect to the romance and intimacy aspects of their lives. According to Kinsman (2014), the secrecy and shame associated with intersex variations like AIS can result in the fact that “the path to romantic connection with another human can feel isolated and impossible.” By living and interacting in a gendered world, the participants became aware of certain expectations and behaviours that were custom to courtship (Risman, 2004). Sameera stated that as a teenager all her friends were getting boyfriends but since she was very ashamed, “those things were not for her (Sameera, 2021)". Amanda never had relationships during her school years and that she envied her cousins who had boyfriends or girlfriends at family events.

4.3.3 Social withdrawal and pushing people away

Feeling like you are different from other people can be an alienating and painful experience. Since the world is structured in a gendered manner, men and women can relate to and construct their identities by observing other men and women (Risman, 2004). While, through the internet, intersex people have access to other intersex people, they still live in a gendered world (Karkazis, 2008). In some cases, people find comfort in withdrawing from social situations and may gain a sense of control in the fact that they are the instigators of alienation rather than being in the position where others reject them. Two of the participants, Sameera and Ronel, stated that their AIS has led them to withdraw from certain social situations throughout their lives.

As a teenager, Sameera was very shy and introverted. She kept herself away from friends outside of her family and often declined invitations. In a study by Simons *et al.* (2020), some intersex participants indicated social withdrawal since they felt that they could not explain their experiences to others. Furthermore, they felt that their gender-typical peers had stigmatized and pre-conceived ideas and expectations of their behaviour as people with atypical bodies. Sameera became more extroverted and social during her twenties but she struggled with depression throughout her twenties. She stated that she felt insecure and inadequate. According to Abraham (2020), it is common for people with underlying anxiety to react by withdrawing and isolating themselves. Sameera became very defensive and mentioned that she developed the attitude that she does not need a man and began to push her husband away since she believed that she was bad for him. When she was

32, she went through her divorce and lost her job and subsequently experienced, in her words, a “midlife crisis (Sameera, 2021).” This has impacted her greatly. Sameera shared the following in this regard:

> I kind of began to go into a bubble, into a bubble in which I almost still am. I am so introverted for the last few years. I do not even worry about friends anymore, I just go to work. It is all I do. I have thrown myself into my work (Sameera, 2021).[22]

At the time of the interview, she felt that she did not have the mental or physical capacity for anything other than her work and said that she does not even have the energy for her husband and family in the evenings after work.

Ronel also experienced social withdrawal, but by pushing people away. According to Raypole (2021), people push others away for various reasons, which may include a fear of intimacy, attachment issues, low self-esteem or low self-confidence, and trouble with trusting others. For many people with intersex variations, these experiences are common. Ronel stated that throughout her life all her friends kept asking her when she was going to have children. When they kept on pushing on that topic, Ronel started to push them away.

4.3.4 Fears and insecurities about intimacy and dating

According to Franck (2018), romantic relationships are strongly influenced by gender. Gender roles also contribute to what men and women expect and view as the characteristics of a suitable partner. Having atypical bodies, people with intersex variations like AIS can feel that they do not fit into these expectations and subsequently experience fear of intimacy and dating.

For two of the participants, their fears about dating and intimacy resulted in relationship avoidance for some parts of their lives. In Zeeman and Aranda’s (2020) American study, intersex people reported challenges with romantic and intimate relationships that often

[22] “Ek het half-en-half in ‘n bubble beginne gaan... In ‘n bubble waarin ek amper half nogsteeds is. Ek is so introverted die afgelope paar jaar. Ek worry nie eers oor vriende meer nie, ek gaan werk net, dis al wat ek doen. Ek het my ingegooi in my werk in (Sameera, 2021).”

resulted in complete avoidance. The reasons for this avoidance included sexual anxiety and attempts to protect themselves against negative reactions of partners on realizing that their bodies are different. As a teenager, Sameera held back a lot when it came to romantic relationships. She stated that men also did not seem to be very interested in her and she jokingly said that she thinks it is “because she did not give off enough pheromones (Sameera, 2021).” Sameera remembered that she always prayed that she would meet someone who would accept her as she is.

In Franck’s (2018) American study on intersex and intimacy, there were participants who expressed that intimate experiences with their partners left them feeling sexually inadequate. This was also the case for participants in this study. For Thandi one of the main reasons why she sought out medical help on her own when she was older, was because she feared dating and hoped that doctors could provide her with answers about her scars. When she dated someone, she felt uncomfortable being intimate with the person as she did not know what to expect. Maddie Rose (2020), the intersex writer for Teen Vogue, echoed Thandi’s fears by stating that she often “cuts hookups off short” since she fears that the partner would find out about her body. She also does not always know how to explain “how sexual pleasuring worked” for her body.

Leigh-Ann became intimate with someone for the first time when she was 19 and remembered telling her friends that it felt as if “he was hitting a wall (Leigh-Ann, 2021).” She remembered that after she found out about her diagnosis, she became very self-conscious, especially regarding intimacy with a romantic or sexual partner. She described this feeling as follows: “So, you kind of become like, in the back of your mind you always say like, oh does he know I’m different? Can he feel that I am different? So there is always that (Leigh-Ann, 2021).”

Although Sameera knew she could not have children, doctors told her after her surgery that she could have sex if she wanted to. Sameera was intimate with someone for the first time when she was 27 and recalled her experience as follows:

> It was also a very scary exercise for me because it was almost like I had to go find out if I can have sex. When I actually met someone who I felt comfortable with, it was very clinical. I had to go see if I can have sex type of thing (Sameera, 2021).

Franck (2018) states that when the partners of intersex people find out the truth about their variation it often leads to reactions like confusion, misunderstanding, discomfort, and repulsion. Due to feelings of vulnerability with respect to intimacy and dating, three of the participants indicated that they approach relationships with great caution and often try to evaluate their longevity beforehand. Thandi stated that a romantic relationship means 100% honesty about many things. For Thandi, considering a romantic relationship means that she must evaluate whether the person is going to stay or run and if she is willing to lose the person at a particular point in the relationship. She stated that the topic of having children is common when dating men. If the person wants children, she already knows "this is not going anywhere (Thandi, 2020)". Thandi described her approach to relationships as follows:

> I drag people out a lot and then just do what the young people are doing now – ghost them. Just disappear when things get extremely serious. When I see that this is going to lead to anything serious, I run, so, for a few months it's just, they don't know any difference and when it becomes intimate, I run (Thandi, 2020).

Leigh-Ann also approached her relationships by pre-interpreting the relationship to see if it had potential or not. Leigh-Ann related that if she felt that the relationship could work, she was upfront about her variation, but otherwise, she would not disclose that she has AIS.

4.3.5 Self-blame for failed relationships

While failed relationships are a common part of life for most people, people with AIS often experience this phenomenon as particularly painful. Since the participants indicated that they had certain fears and insecurities about intimacy and dating, all participants experienced self-blame after rejection from potential romantic partners, went through breakups, or experienced a divorce.

Levels of self-esteem can greatly affect the success of various aspects of a person's life like romantic relationships (Erol & Orth, 2016). Sameera's shyness and the fact that Amanda grew up feeling like she lived as the wrong gender led to them not having romances as teenagers. Both participants expressed that they struggled with knowing how to approach relationships later in their lives.

Feelings of insecurity can also end relationships (Lemay & Clark, 2008). Furthermore, there are often correlations between people who have problems with their body image and

failing relationships (Mcnamara, 2016). Participants in this study also blamed themselves for their failed relationships because of their poor body image and feelings of inadequacy as women. Sameera, for example, stated that when in her twenties, a man she knew was not interested in a relationship, and she experienced great pain and sadness for years to come. She believed that he was not interested in her since her breasts did not develop and that she was therefore "not good enough". Thandi said that when a relationship ended or someone cheated on her, she would believe that it was due to her not being good or feminine enough for the person.

Ronel and Sameera went through divorces, which they also attribute to their feelings of inferiority and guilt because of their infertility. Sameera shared her experience as follows:

> We definitely had problems but not from his side. More from my side. I was so that I never really opened up for him. I don't know. Somehow, I always thought that our marriage would not last long, I would not forever, I hid it behind a facade of "I don't need a man, I don't need you" and I treated him like that and for many years I was like that, that I do not need you, I do not need you (Sameera, 2021).[23]

Leigh-Ann, Sameera, and Ronel attributed their failed relationships to the fact that they cannot have children. In a study on 47 500 Danish women, a failure to conceive made women three times more likely to have divorces or end relationships (Firth, 2014). Leigh-Ann recounted that different romantic partners had different reactions to finding out about her AIS. While some accepted her for who she was, others "pulled the disappearing act (Leigh-Ann, 2021)." When one of Leigh-Ann's earlier relationships ended she felt that it was because she could not have children, even though her boyfriend at the time provided different reasons for the relationship not working out. According to Gurevich (2020), it is common for infertile people to fear that their partners would leave them. Furthermore, self-

[23] "Ons het defnitief probleme gehad, maar nie van sy kant af nie. Meer van my kant af. Self was ek so dat ek ook nie regtig oopgemaak het vir hom nie. Ek weet nie, somehow het ek net altyd gedink ons huwelik sou nie lank hou nie, ek sal nie vir ewig... Ag ek het dit weggesteek agter 'n brawade van 'I don't need a man, I don't need you' en ek het vir hom so behandel en vir baie jare was ek so gewees van 'ek het nie jou nodig nie, ek het nie jou nodig nie (Sameera, 2021).'"

blame for infertility can be used as a way to reduce the pain and loss felt by a romantic partner or loved one (Gurevich, 2020). After Sameera and her husband got married, she began to form a complex that she is not good enough for him as she could not have children and allowed him to have a “normal family.” Ronel’s experiences of infertility also exacerbated her feelings of inferiority as a woman, which contributed to conflict with her husband.

4.3.6 Fears and regrets about others finding out

While coming out as having intersex can be a freeing experience and an opportunity to combat stigma, many intersex people experience anxiety about the idea that someone might find out about their variation. Charbonnier and Graziani (2016) state that people from stigmatized groups experience “minority stress”, which is associated with feeling discriminated against and being rejected. The act of “coming out” can add to this minority stress. In this study, three of the participants shared narratives in which they spoke about these fears and regrets about coming out.

Thandi knows many intersex people who regret coming out. She provided an example of a person who wanted to keep their intersex variation silent at all costs since the person grew up in a village and was brought up as male. This person believed that if someone thought that he was something other than a boy, it would cause outrage and can potentially lead to his death (Salaudeen, 2019). According to Charbonnier and Graziani (2016), the discrimination and “phobia” faced by people who have different bodies stem from the emphasis of society on binary differences in sex and gender. These result in gender inequalities, sexism, stigmatization, and judgement. Not all types of intersex are noticeable at birth, intersex people may go unnoticed until later in their lives, but still experience fears because of knowing how their difference may be perceived by their communities.

According to Charbonnier and Graziani (2016), the stress of coming out lies in the fact that people must face their differentness within themselves, but also in revealing it to others. When Leigh-Ann found out about her AIS she initially felt very self-conscious that people would know. She shared an experience as follows:

> I felt like such a fraud, and I felt like people could see, and initially, I would say it is like some sort of shame or feeling like it is a secret or feeling like you are about to be found out that does have a huge impact (Leigh-Ann, 2021).

Leigh-Ann participated in a national beauty contest and expressed that one of her biggest fears during this time was that it would become publicly known that she has AIS. Since she was in the public eye at that stage, she feared that journalists would sensationalize her AIS and that they would “paint a different picture if that is not actually the case (Leigh-Ann, 2021)”. According to Uzuegbuman (2013), anything involving sex and violence interest people and gain media coverage. Leigh-Ann, therefore, felt scared that someone else would control her narrative.

In the context of their work, Thandi and Sameera experienced some regret after coming out as having AIS. While Thandi came out via social media by making use of her YouTube channel, she stated that when her video went viral, she “freaked out.” She did not realize that so many people would view it. One of the fears and later regrets that she experienced was that people at her work would find out that she has an intersex variation. She stated that when her boss congratulated her on her interview, she felt like she wanted to resign. She now tries to not discuss her intersex with her colleagues at work. She stated the following:

> I think I don’t want the pity from my colleagues and with people I kind of like, the idea that they might just leave. So, I tend to just sort of like sitting in it for a little bit about whether or not I am going to tell them (Thandi, 2020).

When a person is being pitied it makes them feel as if they are struggling or in a bad situation. This can translate them being seen as “different” from other people. According to Florian *et al*. (2000), a person who is pitied is often viewed as inferior to those around them. Being pitied isolates a person as those who pity them may have compassion with their situation but find comfort in the fact that they do not “share in the sufferers' predicament.” As people with AIS have different bodies from those around them, pity may be a common reaction that is often combined with sensationalism, curiosity, and stigma, which ultimately dehumanizes and objectifies the person. It may also be as a result of ignorance about what such a variation entail. Due to secrecy, stigmatization, and shame, little is known about intersex people, and this contributes to confusion and othering in the eyes of others (Carpenter, 2018).

Sameera is only open about having AIS with her family and close friends and does not disclose her intersex to strangers. According to Sameera, she was once open about her intersex more publicly, but she regretted it later. Sameera previously did some work for

ISSA and stated that she felt a strong urge at the time to “come out” as having AIS. She told her boss at the time that she has AIS and although she believes that it was not the reason for the problems she experienced in her work, a part of her feels that “things became sour “after the people from her work became aware of her intersex variation.” She stated that a small part of her feels exposed. This also relates to the argument of Florain *et al.* (2000) that pity is used to observe the “sufferer” from a safe distance due to a fear of becoming involved in the problems that a person faces.

4.3.7 People’s rejection and insensitive comments

Due to the secrecy, shame, and stigma surrounding intersex variations and the fact that little information is available about them, people with AIS often encounter insensitivity (whether it is deliberate or due to ignorance) and rejection. Thandi shared a narrative of insensitive comments made by people in her life. Ronel and Amanda also indicated that they experienced rejection from extended family members.

As seen in the previous discussion, pity enables people to gesture care, but it is strongly linked to the widening of the space between what is considered as functional and normal and what is considered as disrupted, damaged and abnormal (Florian *et al*., 2000). Kimberley Zieselman (2020), intersex author of the book XOXY, stated that she had close friendships with her girlfriends, but after her surgery when she was told that she had a “hysterectomy”, she became aware of the great distance and awkwardness that formed between her and her friends as a result of pity. Due to other people’s dilemmas, people can become ignorant and insensitive to the experiences of those who are in a different situation than them. For Thandi, the worst part of having AIS is listening to the people’s insensitive dialogue. Some of these dialogues may have been known while others may not have been. She shared the following experiences:

> And everyone always goes “You’re so lucky!” which is not a very nice thing to hear. It is as if, if people hear that I don’t get my period and they say, “Oh my word, you are so lucky.” Yeah, I guess, but I don’t think so. I would have loved to also get my period, you know. So, I’m much bothered by it (Thandi, 2020).

Another example was when one of her good friends said that he would not marry someone if that person were not pregnant with his child already, because he wants to make sure that the woman can have a child. According to Thandi she “lost it”. For her, it is “those little

nibbles” that make it hard to have AIS (Thandi, 2020). This demonstrates how gender and gendered expectations are ubiquitous in every interaction.

4.4 CONCLUSION

In this chapter, I provided a discussion on how the stigmas of having an atypical body affected participants' gendered experiences on an individual level. I also discussed how it affected the social aspects of their lives like their relationships with their family and romantic partners on an interactional level. In Chapter 5, I continue to discuss and analyse the findings on participants’ experiences with the medical institution and how they came to terms with their AIS diagnosis.

CHAPTER 5: FINDINGS AND ANALYSIS: PART 2

5.1 INTRODUCTION

In Chapter 4 I argued that the gender-structured nature of the world has influenced perceptions of what a typical male and female body should look like. I focused on how the gender structuring at the individual and institutional levels contributed to how people with AIS view themselves as women with atypical bodies in a gendered society. I also discussed how their AIS diagnosis has influenced their relationships with other people who have certain gendered expectations. Following on Chapter 4, this chapter focuses on interactions with medical professionals and experiences of their healthcare, as well as the factors that helped them come to terms with an AIS diagnosis

5.2 HOW DOES MEDICAL INTERVENTION MITIGATE AND PERPETUATE STIGMA INVOLVING PEOPLE WITH ANDROGEN INSENSITIVITY SYNDROME (AIS)

The literature review revealed that an important factor in perpetuating stigma and "othering" of people with intersex variations like AIS has been that these conditions have been medicalized and have come under the authority of medicine in the modern era. At the core of this medicalization has been ideologies of sex, gender and sexuality (Karkazis, cited in Davies, 2015). It is, however, important to note that individuals with intersex variations still require medical care – some conditions are life-threatening and require immediate medical intervention, while others, including AIS, requiring help with decisions around gonad removal, genital surgeries and managing hormonal treatment. It is, therefore, the type of care and intervention and the quality of care that people receive that is at the heart of the criticism of the medicalization of AIS and other intersex variations.

Most of the participants in this study experienced some of the widely known concerns that have been characteristic of the medical treatment of intersex, like the withholding of information, deception, undergoing surgeries without full consent, and feeling objectified by medical practioners. Participants, however, also reported positive experiences and interactions with doctors, indicative of some progress in the medical management of AIS. In this section I discuss these experiences and how interactions with medical professionals have contributed to perpetuating the stigma and difficulties of having an AIS diagnosis, but

in some instances also helped participants to understand and live with their variation and to access good quality medical care.

5.2.1 Difficult experiences: harmful medical practices

According to Risman (2004), gender can be seen as a social structure in society due to its constraining qualities. These include the rules and expectations attached to what it means to be a man or a woman in terms of one's bodily function and appearance and how one should act. These constraining ideologies and expectations influence the various social institutions in society, including medical institutions. In the case of intersex, the atypical bodies of intersex people challenge these gendered expectations, and medical protocols at institutional levels and interactions with healthcare workers at the interactional level often respond by trying to 'fix' intersex individuals' bodies and gendered behaviour by focusing on making individuals conform as closely as possible to the sex, gender and sexuality expectations of being male or female. The message that healthcare institutions and its members convey about intersex variations both construct and reconstruct how the rest of the social world view this variation. This message is, however, often one of othering and stigma.

In this section I discuss participants' negative experiences with healthcare professionals and provide an analysis of the ways in which these interactions have created stigma with respect to having an atypical body that doesn't conform to gendered expectations about biological sex.

5.2.1.1 Secrecy, half-truths, and deception

As seen from earlier intersex management protocols, secrecy and so-called goodhearted deception were viewed as a way of protecting participants against the truth of their variation (Conn *et al*., 2005). The fear was that the truth could lead to gender confusion and dysphoria in individuals (Danon & Yanay, 2016), which demonstrates how gendered expectations of bodies and identities were written into treatment protocols at medical institutions. However, by keeping the truth from patients, doctors conveyed a message that atypical bodies have to secretly be fixed so that the patient can live a normal life as either a man or a woman. This secrecy and lies often result in medical procedures being done

without the full understanding and consent of individuals, leaving them feeling violated, confused, and ashamed (Carpenter, 2015).

The bodies of Sameera and Amanda were deemed atypical at birth and Ronel's parents, as a result of her older sister having AIS, were aware that she might have the same variation. These three participants were, therefore, referred for medical treatment when they were infants. They therefore only have partial memories of their interactions with medical professionals and the treatment they received. The recollections of their parents and family members have helped them make sense of their early medical experiences. Amanda, for example, remembers that she was afraid of the doctor as a child. She had to get testosterone injections around the age of three to promote the masculine development of her body since the internist told her mother that she was a boy. Amanda remembered these procedures as follows:

> Oh, I was very afraid of the doctor but after I got the injection on my bum, I got a sweet. He would say "come here and stand here with me and I will give you a sweet" and then I knew it was going to burn (Amanda, 2021).[24]

Ronel also still has memories of her visits to the doctor as a young child: "I remember all of them. Even waking up in theatre, I think I was about 4 or 5 when this happened (Ronel, 2021)." Sameera had to rely on the memories of her sister about the time she was an infant in hospital. Her sister told her that she was in a ward with a boy who had breasts and that her family did not understand "what that was about (Sameera, 2021)." Sameera later felt that because she was in a ward with another person with an atypical body, she was thrown into a category of abnormality and weirdness.

Thandi went to a doctor for AIS-related concerns the first time at the age of 13 when she was a teenager. She remembers secrecy surrounding these consultations and as a result being very confused about what was going on and about what was going to happen.

---

[24]:"O, nee, ek was baie bang vir die dokter, maar nadat ek die inspuiting gekry het op die boud dan kry ek 'n sweetie. Dan sê hy vir my kom staan hier by oom, ek gaan vir jou 'n sweetie gee, dan weet ek, kyk, dit gaan brand (Amanda, 2021). "

Thandi (2021) remembers being “kicked out of the room” during one of these first consultations when the doctor insisted on speaking with her mother alone.

Sameera also experienced secrecy and half-truths from doctors. She remembered that when she went to the doctor at the age of 22 for some health matter, the doctor “immediately became very interested in her (Sameera, 2021)” and offered her testing without disclosing what the tests were for. The doctor spoke to a professor and on the same day, Sameera was called to come for a CT scan. Sameera recalled feeling surprised as she could not afford the scan at that time since she did not have a medical aid. However, the doctor offered to pay for the scan to have the opportunity to do tests on Sameera.

Ronel had a surgery to remove her gonads when she was 13 and proceeded to have vaginal reconstructive surgery for the elongation of her vagina when she was 14 or 15. She was not given a full explanation and understanding of the surgery and its implications, even though she was already at an age where she could give medical assent. For her gonadectomy her parents told her that she had to have a hernia repaired, but it was not explained that gonads would be removed. For her vaginal elongation surgery she was told that she was born without a womb and that doctors had to make her vagina a bit longer to enable her to “be normal one day (Ronel, 2021).” She was not told the full truth about her surgery. She believed her parents had her best interest at heart and therefore trusted them. She stated the following:

> I trusted it, my parents. I accepted it. It was no problem because you trust your parents. You trust your parents with your life so you accept it (Ronel, 2021).[25]

Thandi also underwent surgery at the age of 13 without being giving full information about the procedure. This was six months after she was taken to the doctor because her gonads descended. This followed the consultation where she was told to leave the room so that the doctor could speak to her parents, who were told that her womb might be cancerous. The surgery was to remove her internal gonads, but she was told that the surgery was “for

[25] “Ek het dit, vertrou my ouers. Ek aanvaar dit. Dit is no problem, want jy vertrou jou ouers. Jy vertrou jou ouers met jou hele lewe, so jy aanvaar dit (Ronel, 2021).”

the cancer". Although internal gonads do carry a risk of becoming cancerous for individuals with AIS (Hughes *et al*., 2012), this risk is often overstated by clinicians and offered as justification for the surgery without telling their patients or their parents that it is internal gonads that are being removed (Zieselman, 2020). Numerous accounts of intersex people, like that of Zieselman (2017) and Davis *et al*. (2016), give examples of how doctors have been deceptive about the nature of individuals' internal sex organs. This is also often done without fully explaining the implications of removing the gonads (e.g., life-long HRT is needed to prevent osteopeorosis). Thandi, for example, did not receive HRT after her gonadectomy and therefore didn't grow taller. Sameera wasn't prepared for the emotional changes that can accompany taking HRT. The option of not removing the gonads and just monitoring it for potential cancerous growth are seemingly never discussed. At the core of these practices of for instance emphasizing a cancer diagnosis rather than explaining an AIS diagnosis to an individual, is again fuelled by gendered norms about bodies and doctors seeing an atypical body that doesn't neatly fit into a binary category as something that needs to be hidden and fixed, not fully understood and accepted. This is reinforced by a number of other medical practices.

Thandi's surgery was marked by a fear of cancer and feelings of confusion, but also memories of objectification and violation. Prior to the surgery she had to endure being examined by what appears to have been a number of medical students who accompanied the specialist, reinforcing feelings of being different and of being a fascinating object to study. She remembers:

> I was there for like four days and I think at the time [Hospital A] was a teaching hospital, something like that. I think I just remember one morning a bunch of, I think it was students, but it was a lot of people with like notepads and I was covered in sheets, so they were just like touching and writing down and there was a lot of fascination and they left. After that there were two doctors, they had a conversation. A day later I had little scars and the cancer was supposedly gone (Thandi, 2020).

Ronel also clearly remembers feeling objectified and embarrassed by being a medical object of interest:

> For me, the worst was when the professors and doctors had me lying naked on the bed and the students would stand around me and I will be pricked and poked and pointed at, it was a bit embarrassing. Got worse as I got older (Ronel, 2021).

She further remembers “the closed curtains” and “doctors examining my private areas, it was not easy, sometimes I had to get naked, sometimes twice for different doctors (Ronel, 2021.”

Amanda also recalls intense embarrassment that caused her to burst into tears as she was examined by medical students prior to surgery in her twenties:

> Later on I am crying so much that I ask [professor A] if the men could go out and that I do not have a problem with the women students there, but then he said no, they must learn and gain experience and whatever (Amanda, 2021). [26]

The experiences of these participants confirm the experiences of intersex people globally: that doctors are very curious and even fascinated by the bodies of individuals with intersex variations, even to the point of going out of their way to examine them and to use them as case studies to educate medical students. This, however, results in the objectification, further stigmatization, and insensitive treatment of intersex individuals, which is a global problem. In an online interview, the intersex filmmaker, River Gallo, spoke about how the medical community objectify intersex people in America:

> The amount of times that we’re told to like strip down to be examined, to have medical students look at us…every intersex person has stories where their bodies were objectified by the medical community.

These experiences also extended to interactions with other medical professionals. Thandi spoke of an incident where she went for an ultrasound to confirm that she did not have ovaries or a womb. The radiographer did an ultrasound and went outside to speak to the doctors. Thandi remembered that the doctors looked fascinated and invited more doctors into the consultation room until it was very crowded. She recalled feeling very embarrassed and that at that moment she “wished that they would find a womb” and tell her that “they have made a mistake (Thandi, 2020)”. This reaction of Thandi demonstrates the clear social expectations that bodies should fit into a neat binary category (e.g., women

[26] “Ek huil naderhand so ek vra vir professor A kan die mans nie net uitgaan nie, ek het nie ‘n probleem as die vroue studente daar is nie, maar toe sê hy nee, hulle moet leer, hulle moet ondervinding opdoen en wat ookal (Amanda, 2021).”

having a womb and ovaries), and that when that is not the case, it calls for medical scrutiny and intervention. She recalled this moment as follows:

> The next thing she (the radiographer) said to me was “how does it make you feel knowing that you will never have children?” and I was like [thinking], that is not an appropriate way of telling someone that they will never have children. Like, I might have come here knowingly, but maybe I did not want to hear that, you know (Thandi, 2020).

While medical doctors and healthcare professionals’ first responsibility may be to save lives and provide necessary healthcare, Grissinger (2017) believes there are various areas that need improvement in the medical sector. The training of medical staff in the field of professional etiquette and code of conduct is essential in one of these areas (Safdar & Safdar, 2019). Like Thandi, Leigh-Ann also encountered an incident that involved unprofessional remarks by medical staff. She noticed that medical personnel who are inadequately trained tended to be inconsiderate, rude, and insensitive and that it caused her discomfort when she had to interact with them. Leigh-Ann provides an example of this as follows:

> I mean, I remember when I went in for my surgery to have my gonads removed, the nursing assistant, the staff nurse, she, so my doctor had written, and she did not know what it means. I was being admitted into, it was the gynaecology ward, and there was another woman and there were other people in the room and then she asked me, which was a bit rude, and then she asked me “What is this?” And I explained it to her, I mean regrettably so, in front of other people and then she did the whole pity, like “Oh my gosh, I am so sorry, like, you are so young (Leigh-Ann, 2021)”.

The nurse’s ignorance about AIS and her reaction communicated to Leigh-Ann that bodies that are different should be pitied, fuelling the stigma for a sex development variation such as AIS. Thandi was also responsible for educating a nurse, further contributing to intersex people’s resentment and resistance to visiting health facilities (Zieselman, 2017).

Amanda stated that she bitterly regrets getting the vaginoplasty surgery done as she had complications and do not have a functional vagina after the surgery. Amanda attempted to get medical help from various doctors after the unsuccessful surgery, but they met her with dismissive and insensitive remarks. Ronel also remembered doctors as being cold and stated the following about the surgeon who did her vaginal elongation surgery: “I ran into him in social life, but even then they look at you as specimen A or B (Ronel, 2021).”

These experiences of insensitivity, fascination with intersex variations or poor knowledge resulted in some participants experiencing it as particularly inconvenient to consult a new doctor. Thandi dislikes going to see a new doctor and said that every time a new doctor meets her, she must “deal with issues (Thandi, 2020)”. This has reached a point where she does not want to go to doctors who are not her day-to-day physicians. For example, she might go to a doctor for the flu but would then routinely be asked if she is taking any medication and when she states that she is on Premarin, which is a menopause medication, doctors become very curious. She must then explain her whole situation. According to Thandi, throughout her life she has been met with different reactions like awe, curiosity, and pity from health professionals.

Like Thandi, Leigh-Ann stated that whenever she went to a new doctor for something like the flu, they asked her when she last had her period. According to Leigh-Ann this is a very awkward question, and she is often met with very surprised reactions from doctors. In an online interview with Maria Cohut (2020) of Medical News Today, Aleksandar Berezkin from Russia who has an intersex variation, stated that since much of the focus is placed on “fixing” intersex children, adult intersex patients find it challenging to find doctors who can help them ethically and respectfully.

Leigh-Ann added that during attempts to access life insurance, there are always phone calls from nurses to discuss new policies and she would be asked if she is on chronic medication. In this context, she would always have to explain why she had undergone certain surgical procedures and when she would mention that she had had a gonadectomy, people would respond by saying that they thought that she was a female. While there is a distinction between sex and gender, society is structured in a gendered manner to expect that if you have a female gender identity and present yourself in a feminine way in how you dress and behave, that would imply that your body is also biologically female (Davis, 2015; Mama, 2009; Risman, 2004).

This discussion shows that the participants have had various negative experiences with healthcare professionals. I also indicated how doctors and healthcare professionals contribute to the stigmatization of intersex variations through secrecy, fascination, and insensitivity. However, the accounts of the participants also revealed that some of them had positive experiences with doctors and that they experienced these doctors input as

extremely helpful in their AIS journey. The next section elaborates more on these experiences.

5.2.2 Positive experiences of medicalization and affirming interactions with healthworkers

From the 1990s onwards the healthcare system began to face great criticism for the treatment protocols and management of intersex variations (Karkazis, 2008). In the early 2000s, some healthcare practitioners also began to voice their agreement with the view that intersex patients themselves should have a say in their treatment (Leidolf *et al*., 2008). It is clear from participants' negative experiences with healthcare professionals that the medical care available in South Africa to people with intersex variations like AIS can still greatly improve, as is the case in other parts of the world (Davies, 2015; Salaudeen, 2019; Pikoli, 2021). In some instances, however, participants, experienced the medicalization of their variation as positive as they were able to put a name to their experiences. Participants also reported some encouraging experiences where medical professionals went out of their way to break down stigmas, to be understanding and supportive, and to help them feel comfortable and accepting of themselves.

5.2.2.1 Getting a diagnosis

For some of the participants, receiving a diagnosis of AIS from their doctor was a positive experience that brought relief and enabled them to put a name to the differences they had experienced with respect to their development. This was true in the cases of Thandi and Amanda. According to Thomas (2017), it is common for people who have been misdiagnosed, undiagnosed, and who were confused about the symptoms or bodily phenomena they had experienced to feel a sense of great relief when they finally receive a diagnosis. This is also the case for some people born with intersex variations (Davis *et al*., 2016). Thandi explained her feelings after receiving the diagnosis:

> I think my diagnosis kind of brought some form of relief to know that at least there is some form of name for whatever it is that is going on with my body. So, I was not distraught by the diagnosis. I was kind of like very relieved. It was a huge sigh of relief to say, okay at least now we know what it is and now we can move on. There is nothing that sucks like not knowing what is going on with your body and you cannot relate to anyone else (Thandi, 2020).

Amanda, after being misdiagnosed as transgender for years, believes that after she received her diagnosis her life started to move in the right direction. She mentioned that she was extremely relieved after receiving her diagnosis as it provided her with answers, and she felt that she could finally be who she always was and did not have to pretend to be a man anymore. Amanda found it easy to accept her diagnosis and stated that she did not feel much different to before as she always acted and lived as a woman (even when she was raised as a boy). About receiving a diagnosis, she said:

> How can I explain this? The pieces that were left out from my childhood and teenage years were filled. Almost like a colouring book. That is how I feel about it (Amanda, 2021). [27]

These experiences confirm why people with intersex variations have repeatedly called for honesty and transparency about their variations, globally and in South Africa (Zieselman, 2020; Salaudeen, 2019; Davies *et al*., 2016). It is evidence that, contrary to fears behind medical protocols in the past that patients would experience confusion and gender dysphoria, the full truth brought clarity and relief for participants.

5.2.2.2 Positive interactions with healthcare workers

(a) Medical doctors and specialists

A further encouraging finding from the interviews were reports of positive and affirming interactions with healthcare workers. This was the case for almost all of the participants, despite them having had negative experiences with doctors. Thandi and Amanda both spoke very highly of their interactions with endocrinologists who treated them with honesty, compassion, and sensitivity. According to Stone (2019), any instance where a patient must go to the doctor can be a stressful experience filled with anxiety, worry, fear, and apprehension. This is also the case for people with intersex variations, who often dread visits to specialists (Davies *et al*., 2016). There are many benefits for the patient when a healthcare professional shows empathy. It builds a patient's trust and calms their

[27] "Hoe kan ek sê? Die stukke wat weggelaat is in my kinderlewe en my tienerjare is toe ingevul. Amper soos 'n inkleurboek. Dit is hoe ek voel daaroor (Amanda, 2021). "

anxieties, which can often have a positive effect on the outcome of the person's health issues (Stone, 2019). This is also a recommendation in Frader *et al.,* (2004) on how to reform intersex medical care.

Thandi stated that her endocrinologist was the first doctor who took proper time to consult with her. She took her into her office and consulted with her for three hours. After this long consultation where she took time to explain Thandi's AIS variation to her and to answer all her questions, she asked Thandi's permission to physically examine her. She told Thandi that she could say no if she did not feel comfortable with undressing and being examined. This small act of asking her consent before examining her, made a great difference to Thandi's experience. By asking for consent before examining her, the doctor communicated respect towards Thandi. It was a moment of humanity and made Thandi feel that she has authority and autonomy over her body, not the medical practitioner. Thandi recalled that she cried hearing this as she had so many experiences where she was told to take off her clothes for a physical examination. The encounter left her feeling that "not all doctors were savages (Thandi, 2020)" and that some try their best to have compassion with what a patient is going through. In the early 2000s there were some medical practitioners who started adding their voices by saying that intersex patients themselves should have a say in their treatment (Leidolf *et al*., 2008). In general, according to Searfoss (2020), it is common for doctors, especially doctors who did their medical training before the turn of the century, to assume that the examination of patients implies informed consent to touch them. As discussed earlier in the chapter, participants had particularly negative associations with physical examinations and often left them feeling violated and exposed, which is common experience for people with intersex variations (Danon & Yanay, 2016). A doctor asking for permission to physically examine Thandi therefore had a particularly powerful impact.

Thandi also believes that her lengthy consultation session with her endocrinologist acted as a therapy session. She shared her experience as follows:

> We got to talk a little bit and she was very much interested in everything about me and I think after leaving that office, I was mostly like very, I felt very good about that consultation. I think that was the first time where I was like, maybe I should talk to someone (Thandi, 2020).

This is evidence that just by talking to someone who shows compassion, a person can experience a sense of relief from their burden (Condrell, 2011). By allocating adequate time for the consultation, she communicated to Thandi that she had her best interest at heart and that she should have full information about her AIS variation. She created a space to fully and discuss the diagnosis and treatment options with her in an unrushed manner.

Amanda also felt that her endocrinologist was the best doctor she ever had and she refers to her as having been a “people’s person (Amanda, 2021).” After being misdiagnosed for years, this specialist took the time to run proper diagnostic tests, which picked up her androgen insensitivity and helped explained her feelings of being assigned and raised as the wrong sex. She also took the time to explain this to Amanda, to discuss treatment options and to answer any questions that she had. Amanda said the following about the doctor: “She saved my life. If it wasn’t for her, I don’t know where I would have been (Amanda, 2021)”.[28]

Leigh-Ann also had a positive experience with her general practitioner (GP), who was honest and disclosed the full details of her variation with her. She said that something that helped put her at ease when she was diagnosed with AIS was that her doctor was very honest with her during the process. By being honest and open with patients, despite possible harsh realities, doctors show respect for patients and regard them as people who can make their own decisions. In this way, they are not merely objectified or seen as having something that should be “fixed”, they are given the authority and agency to make informed decisions for themselves, which is what intersex people have been calling for (Leidolf *et al*., 2008). Leigh-Ann stated that her doctor told her that her case was very rare and that the last time he saw something like it was when he was in medical school, and he was already an old man at the time of her diagnosis. He told her that he was not going to pretend that he knows everything or that he is the expert. This general practitioner is still Leigh-Ann’s treating doctor and she stated that she is very happy with the medical care she receives from him.

---

[28] “Sy het my lewe gered. Was dit nie vir haar nie dan weet ek nie waar ek sou gewees het nie (Amanda, 2021)“.

(b) Psychologists

Psychologists are seen as key members of the multi-disciplinary team that have to help individuals with intersex variations and their parents make treatment decisions (Kemp, 2013; Frader *et al.,* 2004) None of the participants or their parents, however, were referred to psychologists after receiving an intersex diagnosis to support them in making decisions. Almost all of the participants, with the exception of Amanda, sought out psychological help on their own later in their lives. All of them reported that they benefited from psychotherapy and that it helped them to differing degrees to come to terms with their AIS diagnosis and dealing with the stigmas attached to it.

Thandi went to see a psychologist a few years after she got her diagnosis. The reason for delaying it that long was that she wanted to protect herself and did not want to "bump into the psychologist at the mall while picking up oranges (Thandi, 2020)". Thandi was also brought up with the belief that it was taboo to seek psychological help and this also contributed to her putting it off for a long time. It was only after her interview with a television channel about having AIS that Thandi chose to consult a psychologist. This was because she went public and talked about having AIS. Her manager at work unexpectedly congratulated her on the television interview, which made her feel anxious and overwhelmed. She realized that she wanted to feel "100% comfortable" with herself now that she and her AIS diagnosis was in the public eye and she decided to seek out the help of a psychologist in pursuit of this goal. She described her relationship with her psychologist, whom she still consults, as follows:

> Another thing that made me like talking to her about it was that it was the first time that I was just being honest and not speaking outside of myself and not just giving information out, but like speaking about me and my experiences and what I go through on a daily basis. So, we just continued until now (Thandi, 2020).

Thandi recounts that throughout her life she thought that she must be gay, although she knew that she was not, and her psychologist helped her deal with this confusion. This anxiety is as a result of gendered expectations of sex, gender and sexuality, and as people with intersex variations like AIS do not neatly fit into one of the two sex categories, their sexual orientation might be confusing to them and cause distress (Carpenter, 2020).

Leigh-Ann experienced “an emotional breakdown” after learning about her diagnosis due to an “emotional build-up of things that I was not talking about or really processed (Leigh-Ann, 2021)” and she was taken to hospital. The doctor who consulted with her at the hospital referred her to a psychologist and she had one session with her. Although Leigh-Ann felt that this initial session did not really help her or make a difference, it was the starting point for her and she sought other psychological help. She started seeing the psychologist on her campus on a more regular basis. She stated that it was a big help in terms of processing her diagnosis, working through the problems she had with her mother, and processing how an AIS diagnosis had affected her.

Ronel was supported by both a psychologist and psychiatrist. She experienced anger towards her mother in particular. As a result of the shame she experienced throughout her life about having AIS and being different, she struggled to control her anger. She developed bipolarity, which sent her into a downward spiral as she felt that she “had ruined everyone’s life”. However, she ultimately got psychological and psychiatric help:

> And both sat with me and say “Right, fine, we will work through this. We are going to help you. You are going to love yourself after this.” And both went and researched AIS. I mean, for them to be able to do that and for them to work through it to be able to help me, meant a lot to me because nobody has ever done it and has said “Right, fine, we go research to find out what makes you unhappy.” That helped me a lot (Ronel, 2021).[29]

Sameera decided to seek psychological help six years after her diagnosis as she struggled with depression. However, she described her relationship with psychologists as complex as she found it difficult to express herself to the psychologist. At one point, she stopped going to see psychologists because she felt that she was trying too hard to explain her situation to them. She did find great value in the fact that her psychologist told her the name of her variation as it enabled her to find out more about AIS.

---

[29] Die sielkundige en die psigiater. En al twee sit met my en sê right fine, ons gaan hierdeur werk. Ons gaan jou help. En jy gaan jouself liefhê hierna. En hulle al twee het gegaan research doen oor AIS. Ek meen, vir hulle om dit te kon doen en vir hulle om deur dit te gaan werk om my te kon help, het vir my baie beteken. Want niemand het dit nog ooit gedoen en gesê okay, right, fine, we’ll go do research to find out what makes you unhappy. Dit het my baie gehelp (Ronel, 2021).

In this section I discussed how gender norms and expectations of what a “normal” body should look like contributed to the quality of the medical care the participants received. In some of the cases participants had had negative experiences which furthered their feelings of alienation and shame. In other cases, they were treated with respect and humanity, which boosted their body image and self-esteem. In the next section, I discuss other ways in which participants came to terms with an AIS diagnosis and coped with some of the stigmas that were discussed throughout this chapter.

5.3 COMING TO TERMS WITH AIS

5.3.1 Support from family members, friends, and romantic partners

According to a Korean study by Park and Park (2014), when a member of the family experiences stigma as a result of a condition or mental illness, it often affects the whole family. This can have negative consequences for the family structure, but can also strengthen family relationships. Three of the participants found support in their family members. Amanda stated that her greatest source of support for her AIS lies in her family and extended family. Her brother and her mother in particular are her biggest pillars of strength. She also said that her brother’s children and her extended family always accepted her and that she never experienced rejection from her family. In Amanda’s family, there is no secrecy about her variation and this has enabled a very open relationship between her and her family members.

While Thandi experienced secrecy from her mother regarding her AIS, she bonded with her mother’s cousins, who also has AIS. She recounted that this cousin helped her significant as she considered certain treatment options. She is also very close to her sisters. She openly talks to them about having AIS as it is a possibility that one of them may carry the AIS gene and one day give birth to a baby that has AIS. In her Australian study on the supportive family members with intersex, Jones *et al*. (2016) found that sisters were generally the most supportive of a family member’s intersex variation out of all the family members. While Jones *et al’s.* (2016) study indicated that fathers and brothers often have negative reactions to an intersex family member, Leigh-Ann experienced her relationship with her stepfather as especially supportive. She shared her experience as follows:

> I always felt guilty for keeping a secret away from him, so then eventually one day I could not take it anymore, so I did tell my dad and I think for him more than even like being angry or being upset for why I took so long to tell him, he was just very supportive, and I remember him actually asking me so do you feel like you are a boy or a girl? And I said I am a girl and then he said you will always be my baby girl and it was just that acceptance. So, for me, that was just like one of the better things that have happened (Leigh-Ann, 2021).

Leigh-Ann is also close with her mother's side of the family as her maternal grandmother raised her.

According to the study of Jones *et al*. (2016), intersex people often feel more comfortable talking to their close friends than to family members about matters related to their intersex. Participants in this study also found support in their friendships. Thandi stated that her AIS does not come up in conversations at all anymore. When she meets someone new and they find out about her AIS they are very interested and ask a lot of questions, but after a while, it dies out. For Thandi, her AIS is not her identifier in her friend group, and she believes that it is something that her friends know in the back of their minds and move on.

When Leigh-Ann told her close friend from university that she had AIS, her friend started to cry and this made her tear up as well. For Leigh-Ann the disclosure of her AIS to her friend strengthened their friendship. Upon hearing that Leigh-Ann has intersex, another friend volunteered to one day be a surrogate for Leigh-Ann. Although Sameera did not have many friends during her school years, she made close friends who support her after finishing school.

Throughout Amanda's school years she had a close friend who she described as her identical twin. Although she had a difficult time growing up, she was never mocked or rejected by her peers and felt accepted. This helped her cope with having an atypical body and with identifying as a girl while she was raised as a boy. According to Vannatta *et al*. (2009), peer acceptance is essential during school and can be linked to a person's social competence later in their life.

Support and acceptance from partners also helped participants to cope with AIS. Amanda stated that her husband is a source of great support for her. Sameera used to pray to meet someone who would love and accept her as she is and even though she and her husband

went through a divorce, they got back together as she believes that he always accepted her as she was and never gave up on her, an answer to her prayer.

5.3.2 Gathering information

By being subject to secrecy, lies, shame, and non-consensual medical procedures, people with intersex variations often lose their power and agency over their bodies (Carpenter, 2015). In an effort to empower themselves the participants in this study “took control” using various avenues, which I discuss in this section.

Two of the participants took control by searching for answers. Thandi suspected that her doctor was lying to her about her variation when she was a teenager. She went to look for answers when she was 25. The emergence of the internet in the 1990s played an important role in the lives of people with intersex variations like AIS. By means of the internet, they were able to do their research on their variations and gain answers where they could not necessarily find it from doctors (Zieselman, 2020). After doing her research on the internet and forming an idea of “the problem”, she decided to, without telling anyone, go and see an endocrinologist at one of the public tertiary hospitals. After they ran tests, the endocrinologist speculated that Thandi’s scars may have been from the removal of her gonads when she was 13. After Sameera found out the name of her variation, she was also able to research her variation and it brought her closure and acceptance.

5.3.2.1 Coming out and being visible

The AIS Support Group Inc (2019) has shown that some people with AIS find talking and being open about their variations to be a healing experience. Honesty and openness about their lived experiences have also helped people with AIS to form better relationships with their families and the people around them. Three of the participants in particular spoke of the value and importance of being open about their AIS. Amanda is completely open about her AIS and was interviewed about her life as someone with AIS for a well-known South African magazine. She also made the fact that she has AIS visible on her social media. She said that she sometimes wonders if a stranger would be able to tell that she is “different” and stated that if someone would perhaps walk up to her and ask her curious questions, she would be completely open and honest with them and explain to them that she has AIS and what it entails. She believes that being open about her AIS helps to

challenge stigmas and to help combat the secrecy and shame that is often associated with having AIS.

According to Donahue (2019), being “out” as a member of the LGBTQI+ community enables a person to be themselves. The experience can be very empowering. Furthermore, it can enable a person to help others who are in similar situations to them (Hemmingway, 2017). Like Amanda, Ronel believes that being open about her AIS helps to break down the stigmas of having an atypical body. Throughout her life, she experienced great shame and anger because AIS, which was so common in her family, was kept a secret. She stated the following: “And I have told her straight, the more you keep it a secret the more people will have no idea we are normal humans with just a stupid insensitivity syndrome (Ronel, 2021).” She said that when she tells people that she has AIS she is often met with reactions like “Oh my gosh, she has two genders! (Ronel, 2021)” Reactions like this from people indicate that people have certain gendered expectations and if someone’s body deviates from these expectations, it can lead to reactions like surprise, curiosity etc. This, however, does not stop her from being open about her AIS.

Thandi also believes that she can help people with AIS by being open about her variation. She stated that she likes to share her lived experiences with people and tell them how she navigated some of the stigmas and how she dealt with some aspects of having AIS.

5.3.3 Connecting with an intersex community

As discussed in the previous section, the emergence of the internet in the 1990s allowed intersex people to do research and find answers (Zieselman, 2020; Karkazis, 2008; Davis, 2015). The internet, however, also enabled the formation of online support groups and movements like the Intersex Society of North America (ISNA). This enabled intersex people to meet people with similar variations and to share their stories, experiences, advice, and knowledge, all of which contributed to the development of “the intersex narrative” (Kerry, 2011). Most of the participants spoke about how intersex support groups and contact with other people with AIS had helped them greatly during certain times of their lives.

Sameera and Thandi found great value in being part of intersex support groups and even became actively involved in South African intersex organizations for some time. For many

years people with AIS were made to believe that their variations are extremely rare and that they are the only ones who have it (Zieselman, 2020). This contributed to feelings of great alienation and stigmatization for this group of people. Sameera found great value in having access to other people with AIS. She described her experience as follows:

> For me remembering that I was not the only person that had this condition and there's a whole world out there where people have the same issues or similar issues as mine, I think there was a sense of normality after that, knowing that I was not the only person. And then there were people that I could speak with. And I think in that stage of my life I was 28 years old. And I think I grew a lot after that. There came a huge sense of acceptance (Sameera, 2021).

For a while, Sameera worked alongside Sally Gross for a few years.[30] When she experienced challenges in her personal life as a result of her divorce, depression and the loss of her job, she had to step back from being part of the organization.

Thandi wanted to be part of an intersex organization. After some meetings with a member of an online intersex organization, she was put into contact with other intersex people in Johannesburg with whom she helped to form an organization called Intersex South Africa. It was based on the foundations of what the late Sally Cross had started. Due to a busy schedule, Thandi had to also temporarily step back from this organization, but she stated that she plans on joining them again later. According to Cull and Simmonds (2010), intersex support groups can provide information, but also emotional support to intersex individuals. For Thandi, it is nice to have intersex friends as they have connections on social media. Although she is not as active in the organization anymore, she stated that whenever she has a question or difficulty with her AIS, she talks to her intersex friends. She mentioned, for example, that she just recently spoke to them about her fears about being intimate with someone she has started to see since she has "never dated a guy in like ever (Thandi, 2020)." She finds comfort in the fact that she can be friends with them because they all have an intersex variation and can relate to her experiences.

[30] Sally Gross was an important figure in South African activism. According to Isaacson (2014), Gross's was an intersex activist, an anti-Apartheid activist and a Palestinian activist. She was instrumental in starting an intersex movement in South Africa.

Amanda also found that being part of an intersex organization gave her a sense of purpose through the fact that she could help and support other intersex people. She is involved in an international group called Androgen Insensitivity Syndrome AIS – CAIS - PAIS. Amanda takes pride from the fact that she can provide people with advice by relating her own lived experience. She stated that her group recently spoke to a young woman with PAIS from Israel who was rejected by her family and according to Amanda she feels grateful that she can talk to this girl and tell her that everything will work out for the best.

Leigh-Ann also found value in intersex organizations shortly after her diagnosis. She reached out to someone from Intersex South Africa, who put her into contact with numerous other intersex people from South Africa. Through this she became part of Intersex South Africa. Leigh-Ann felt that being part of a support group is crucial and beneficial for someone who has just found out about their diagnosis as it puts the person at ease in the sense that they are not alone.

5.3.4 Acceptance

I end this section with a discussion of how people with AIS have accepted and embraced the positive aspects of their atypical bodies.

As people with AIS have bodies that vary from the norm, they often face stigma in the form of secrecy, shame, discrimination, and judgment. While this stigma has negative effects on the lives of all the participants, there were some of the participants who were able to cope with these stigmas through acceptance over time and by embracing their bodies and seeing the positive aspects of living with AIS. I discuss these experiences in this section.

Two of the participants found that they were able to accept certain aspects of their lives with AIS like infertility and missing out on certain experiences over time. Sameera stated that it was helpful to find out about her diagnosis when she was an adult. She said the following:

> At the age I found out I think I was an adult and I was able to understand the situation and back in the 70’s, I mean it made sense that they did not know much of it during those times (Sameera, 2021).

She also shared that the acceptance of her intersex came with age for her. She stated that she never allowed herself to grieve the fact that she could not have children and at the age of 44 she has fully accepted the fact that she would not have children of her own. She has the chance to experience being a parent since her sister's youngest daughter lives with her.

Sameera tells anyone who is going through the emotional roller coaster of having AIS that it gets better. She says that her life as someone with AIS has not been easy, but that she no longer remembers the pain as it used to be – it has faded.

Throughout her interview, Amanda emphasized that there were many things that saddened her in her life, but that she had to accept it as she cannot turn back the clock. One of the greatest sources of grief for Amanda was the fact that she could not have children of her own. She stated that after she turned forty, she began to accept it. She shared the following experience:

> It's only now in my 40s that I begin to accept it. The Lord has a purpose with my life and there are a lot of children who do not have parents to who I can give my love and who I can love, but unfortunately, it was not meant for me (Amanda, 2021).

Participants also found acceptance in embracing the positive aspects of their unique bodies. Thandi stated that there are a few benefits to having AIS. She shared her experience as follows:

> I think there are a few things that are fun about being AIS, for example I never get to shave, which is cool. And I guess the part where I basically don't have any odor because I don't have any sweat glands, so that is nice. I don't spend much on perfume, roll-ons, and that kind of stuff, so that is pretty cool. But I think what I like the most is the gorgeous skin because I have never had a pimple ever, so when people are struggling with their skin problems, I can't relate. I have never had that (Thandi, 2020).

Leigh-Ann and Amanda also shared that they do not struggle with skin problems, do not sweat, or have body odor, and that their hair does not get greasy.

Amanda stated that she is grateful for the fact that having AIS taught her not to be judgmental towards other people and to treat other people with compassion and acceptance.

5.4 CONCLUSION

In this chapter, I addressed the research objective to explore the possible ways in which interactions with medical professionals have helped or hindered living with AIS. There were negative experiences like secrecy, deception and half-truths that contributed to and strengthened stigmas associated with atypical bodies. There were, however, also positive experiences, like empathy, compassion and sensitivity from doctors, medical professionals, and psychologists, which contributed to the breaking down of stigmas. Secondly, I provided a discussion and analysis of the various ways in which the participants came to terms with their AIS. The next chapter presents the conclusion of this study and offers recommendations for future studies.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

This last chapter offers concluding remarks in the form of an overview of each chapter. This is done by first discussing how I addressed each of the specific research objectives. Secondly, I give a summary of the findings, and lastly, I provide recommendations for future studies.

6.2 CONCLUDING REMARKS: SUMMARY OF CHAPTERS AND FINDINGS

The general aim of this study was to investigate the lived experiences of people with AIS in South Africa. Several specific objectives were also formulated and were addressed in the respective chapters of the dissertation. Chapter 2 addressed the objective of exploring what the literature and theory states about the lived experiences of people with AIS. Chapter 3 addressed the objective of identifying and employing a relevant research design and methodology for the study. Chapter 4 addressed the first two sub-objectives of the specific research objective aimed at exploring how the medicalization of AIS has affected the lives of people with AIS in South Africa. The first sub-objective was to explore how the diagnosis and treatment of AIS have shaped ideas and experiences persons with AIS with respect to gender. The second was to explore how the diagnosis and treatment of AIS influenced family and other relationships. Chapter 5 addressed the third sub-objective of the specific research objective, which aimed to explore how the medicalization of AIS has affected the lives of people with AIS in South Africa. This third sub-objective aimed to explore how people with AIS experience their interactions with health care professionals. In this discussion, I provide an overview of the most important points addressed in each chapter. I then discuss the implications of the findings of this study and recommendations for study.

In Chapter 1, I introduced the study and provided some of the motivations and reasons that make it important to conduct this study. This was done by first providing a contextual discussion of what AIS is. With this discussion in mind, I followed by explicating how the world of medicine has gained control over “the issue” of intersex bodies. It became evident that the atypicality of intersex bodies poses a threat to the gender norm. This has led to medical management and treatment protocols that were aimed at normalizing and fixing

these bodies to enable intersex people to live as “normal” men and women. These protocols were, however, often invasive and lies and secrecy about the variation were seen as justified, which produced and perpetuated the stigma and shame that affected individuals experienced. This affected the lived experiences of people with intersex variations like AIS in various ways. As a result of the secrecy and shame around intersex variations, I found that little is known globally about the lived experiences of people with intersex variations and that even less is known about the lived experiences of people with AIS specifically and within the context of South Africa.

In keeping with addressing the first specific research objective of this study, which was to explore what the literature and theory state about the lived experiences of people with AIS, Chapter 2 provided the literature review and gender structure theoretical position that was used to ground the study. This chapter consisted of two sections, of which the first consisted of the literature review and the second of the theoretical discussion.

In the literature review, I first offered a historical timeline of the medicalization of intersex from the early 1900s up until current times. This timeline shows that three eras stood out. The first era before the 1950s was marked by the search for “true sex” through physicians’ belief that hidden within each person with a sex variation was the sex that they were destined to be born into. They saw it as the responsibility of physicians to “interpret patients’ lives and decide on a treatment” (Reis, 2009:90). The second era from the 1950s to the 1980s focused on the influences of the psychologist John Money and his contributions in shaping the treatment protocols for people with intersex variations. This era was associated with the notion of “best sex.” This referred to the sex that would be the most suited in terms of the person’s genital appearance and whether this appearance resembled a male or female body better. The last era, from the 1980s onwards, discussed the role of activism in the de-medicalization of intersex variations. This entailed directly challenging the intersex treatment protocols of the John Money era, re-evaluating the necessity of intersex reconstructive surgeries, and combatting the secrecy, shame, and stigma that has surrounded sex variations over the last century. This review of literature provided an overview of how the views, attitudes and behaviours around intersex variations have developed in the world of medicine and how this influenced people’s perceptions of intersex.

I furthermore discussed the literature on the lived experiences of people with the specific sex development variation of AIS across the world. This made clear that the medicalization of intersex has affected people with AIS's experiences in various ways. People with AIS people globally have experienced that doctors and their parents had authority over their bodies. Furthermore, growing up and living with AIS has affected their experiences of living in a gendered world in various ways. It was also seen that AIS has affected their various relationships and their mental health.

In the second part of Chapter 2, I discussed the underlying theoretical framework of this study, which was gender structure theory. I started the theoretical discussion by discussing how the understanding of the concept "gender" developed and gained different meanings because of the way in which it was used in academia in fields like psychology and feminist studies. It also discussed how the distinction between sex and gender developed. This distinction was increasingly criticized by feminist scholars for its contributions to male dominance and non-inclusion of certain groups like queer, transgender, and intersex people.

This discussion became the motivation behind the use of the gender structure theory. I selected this theory as it provided me with the necessary means to analyse the lived experiences of people with AIS in South Africa, not just at an individual, interactional, or institutional level, but at all of these levels. This theory argues that gender is a social structure, which like other social structures have certain constraining qualities and rules. It was seen that gender structuring takes place on three societal dimensions, namely the institutional, individual, and interactive dimensions, and that people's experiences and perceptions of reality are greatly influenced by deep-rooted gendered expectations that exist at all three of these levels. This theory enabled me to analyse how these gendered expectations influenced the lived experiences of the participants as people with atypical bodies in a highly gendered world.

Chapter 3 discussed the research design and methodology. My discussion of gender as a social construct and use of the gender structure theory informed the philosophical foundations of this study. I thus made use of a constructivist ontological position based on which I argued that people's perceptions of a gendered reality are socially constructed and that this has contributed to the lived experiences of people with AIS in various ways. I also

made use of an interpretivist epistemological position based on which I argued that people's understanding of the social world is shaped by their interpretations of it. Since little is known about AIS beyond the stigmas, secrecy and shame, a lack of new knowledge and understanding of it through the narratives of people with AIS themselves can perpetuate these stigmas. The use of the gender structure theory also informed the research methods and design for this study. In Chapter 3, I discussed the most relevant research methodology to investigate the lived experiences of people with AIS in South Africa. Since gender structure theory posits that gendering is a complex process that takes place at three levels, it was important to do an in-depth study to get rich data on how this multi-layered gender structuring affected the lived experiences of the participants. In this study I therefore made use of a qualitative research design and qualitative research methods. Feminist and queer research often make use of a qualitative research design (Westmarland, 2011). The sampling methods that were used were purposive sampling and snowball methods. I conducted in-depth online, face-to-face and written interviews with five people over the age of 18 who had been medically diagnosed with AIS. I made use of life history methods to collect data and used an interview guide to structure the interview. After the transcription of interviews, I made use of thematic analysis to organize the data into codes and themes. I also discussed the ethics that were considered during this research and outlined some of the methodological limitations of this study.

The specific research objective of Chapters 4 and 5 was to explore how the medicalization of AIS has affected the lives of people with AIS in South Africa. This objective consisted of three parts. The first was to explore how the diagnosis and treatment of AIS shaped persons with AIS' experiences of gender. The second was to explore how the diagnosis and treatment of AIS influenced family and other relationships. The last of these was to explore how people with AIS experience their interactions with health care professionals and whether it helped or hindered living with AIS. I made use of Risman's (2004) gendered structure theory to form a main argument to address these objectives. The main argument for this study was that gender is ubiquitous and that the gendered nature of society at the individual, interactional and institutional levels influence the medicalization of AIS and individuals' experiences of it. From the analysis of the findings in Chapters 4 and 5, I was able to draw various conclusions.

In the first part of Chapter 4, I found that for participants with AIS, gender at an individual level, meaning how they construct their identities as women, was shaped by binary expectations of the body. Not having all the biological traits typical of women, plus some biological traits that are typical of men, affected their perceptions of themselves as women in various ways. In this study, participants indicated that they were painfully aware of the link between "normal" female pubertal changes like menstruation and the growth of breasts to womanhood. This caused a crisis for some of the participants as they battled feelings of being 'less of a woman' because their bodies didn't achieve these milestones. This pressure that bodies should conform to certain expectations was also reinforced at an interactional level with friends and family constantly enquiring whether they had started their period, when they were planning to have children, or reacting with confusion about "you have two genders" when learning of their intersex variation. These interactions show how these fixed expectations about bodies and how they should behave have been internalized and are constantly communicated in everyday interactions. Not meeting pubertal milestones stirred worry that something was not right with their bodies. Having a different body that didn't behave in the expected manner for one's gender made participants doubt their femininity and fed into feelings of shame, isolation, inadequacy, and inferiority and a need to hide their difference.

There was also an important link between pubertal changes and fertility. In participants' narratives, they reported feeling a sense of loss for not being able to have children and feeling inferior as women. They also experienced guilt for not being able to give their partners children. These experiences demonstrate that being able to conceive and produce children is an important expectation of both men and women. When a body goes through all the changes "that it should", it implies good reproductive health and that a person would be able to have children. For women, fertility and motherhood are strongly linked to what society regards as a "normal" and expected achievement for women. When people meet these gendered expectations, they are rewarded with for example positive affirmation for reaching certain gendered goals. If they don't meet these gendered expectations, they may experience negative sanctioning like disapproval, criticism and embarrassment.

These gendered expectations of bodies also affected participants' intimate or romantic relationships. Since there is great emphasis on sex for the act of reproduction, but also

pleasure, an important function of both male and female bodies is to experience “normal” sex. This implies that a person’s sex organs should have a certain appearance and function and that any deviation in the appearance or function should be corrected to enable a person to have “normal” sex. Participants had reconstructive surgeries to match their bodies with their gender identities as women, but also to enable them to have “normal sex”. Despite surgical procedures, some participants are not able to have what they understood as “normal” sex and they experienced a sense of missing out and regret having surgery as a result. This shows that there is an emphasis on the importance of sexual experiences, but also a specific gendered ideal of what sexual experiences should entail and how each person should contribute to or benefit from these experiences. Participants’ experiences also further bring into focus the complications often experienced from surgery and call into question the so-called successes of these surgeries (Reis, 2009).

Participants expressed that their relationships with their parents were at times difficult. As parents usually have a binary expectation of a new baby’s sex, there is little to no preparation in place for when a baby is born with an atypical body. As a result of this, parents tend to depend on the advice of doctors to make difficult decisions about a newborn’s body and their sex and gender assignment. This also seemed to be the case from what participants were told by their parents.

Furthermore, finding out that your child who you raised within a certain gendered identity has traits of the opposite sex, caused extreme reactions. This also stems from a gendered expectation connected to a person’s body. The parents of participants did not receive psychological counselling after finding out about their children’s AIS. As such, many of them seem not to have been in a position to come to terms with their child’s variation and find a healthy and constructive way to move forward. Participants have indicated that their parents kept the truth about their AIS and the reasons behind certain surgical procedures from them, only providing them with limited explanations and unwilling to speak or discuss the topic of their child’s AIS. This shows that there are still protocols that at least until recently convinced parents not to disclose the truth about their child’s AIS to them.

Some participants also indicated that after learning of their diagnosis, there were negative consequences when they tried to be open and honest about their variations, especially for

their relationships with their family members in cases where it was considered a taboo topic. Some experienced rejection from family members. This shows that there is still much shame and stigma connected to an AIS diagnosis and that it can be strenuous on important social relationships and interactions.

The findings from this study also show how important relatability is to social interaction as it affirms one's position in the world (Gergen, 2013). Participants indicated that they experienced a sense of missing out. Through interactions, children learn certain roles and expectations of men and women, and if they are restricted to certain social interactions, they form the perception that they are different from their peers. Furthermore, since participants did not go through the same bodily development as their friends, they could not relate to certain experiences. Participants also reported that they were not allowed to take part in certain activities in which their peers engaged for fear that someone would notice the atypicality of their bodies. Some participants never experienced romantic relationships as they grew up as they became aware of certain gendered expectations of romantic relationships. This shows that "normality" is still highly valued as part of a person's ability to fit into societal context. Participants indicated that they felt inadequate and insecure and that they reacted to social interactions by either withdrawing or pushing people away. As a result of feeling different, participants found comfort and control in removing themselves from social situations rather than being rejected. This indicates that the gendered nature of society leaves people with AIS often feeling alienated and out of place.

This study indicated that people with AIS experience fears and insecurities surrounding dating, romantic relationships, and intimate experiences. This shows that they were socialized to know that there are certain characteristics in terms of a person's appearance and gendered behaviour that people look for in a romantic partner. Participants expressed that they have avoided relationships, experienced fears, and had insecurities about intimacy. Some feared being honest and feared being rejected by romantic partners. These fears resulted in very cautious approaches towards relationships. Participants have also indicated self-blame when their relationships failed. Some reasons for this were feelings of inadequacy as a woman and the inability to conceive. This shows that the world still holds the view that a person's body must either have male or female characteristics and that certain attributes for each sex are regarded as expected, ideal, favourable, or

essential in relationships. This contributes to a belief that if people do not meet these expectations and if they do not fall within a binary gender group, they are not “relationship material.”

Some participants in this study indicated fear and a sense of regret in coming out as having AIS. Reasons for this included violence against intersex people, sensationalism, pity and effects on certain relationships. Participants also reported that they have experienced insensitivity and rejection in some of their social interactions. This indicates that many people are not yet open to or understanding bodies and identities that are different from binary gendered categories.

The findings in Chapter 5 suggest the following:

The medical experiences of people with AIS were central to their overall experiences. Patients and families still rely on doctors to make sense of an AIS diagnosis and to help them make decisions regarding their treatment and surgical procedures. The authority of doctors is, therefore, still valued and trusted and doctors still have great power over how intersex variations are viewed and understood in the world today. Healthcare remains one of the most powerful institutions in the lives of people with AIS in South Africa.

In the past, doctors viewed AIS and other intersex variations as something that required emergency medical attention. This was certainly the experience of participants in this study. None of the participants or their parents were seemingly given the option of not having surgery and to live their lives with their bodies unaltered. This shows that medicine still strives to “fix” intersex people to make them normal men and women. Participants also indicated that as children they underwent certain medical procedures and surgeries without their understanding or consent. Participants have reported that treatments like hormone replacement therapy (HRT) and surgery had affected their lives. If participants were aware of their procedures, they could have asked questions and may have been better equipped to make informed decisions on some of these treatment options.

Participants indicated that secrecy and half-truths are still common in the treatment of AIS. This communicates the idea that there is a certain norm and whatever opposes this norm should be kept hidden until it complies with the norm. In this study, it became evident that this had effects on their relationships with their families and how participants viewed

themselves. I also found that healthcare professionals came across as unprofessional in their bedside manner and general interaction with people with AIS. Doctors often treated participants in ways that displayed a lack of appropriate training in working with intersex patients. This was visible from doctors' fascination, the rude and insensitive comments of medical staff and how some doctors turned regular doctors' visits for common health problems like the flu into AIS-related visits.

Participants, however, also indicated that there are signs of positive change in how the institution of health approaches intersex treatment. Some doctors communicated respect and dignity to participants by being honest and transparent and by admitting that they do not have all the answers. Some explained everything and made sure that their patients understand their variations through detailed and thorough consultation sessions. During consultation sessions, some doctors also showed compassion by listening and emotionally supporting patients who receive their diagnosis. There were even examples of doctors who had asked permission to examine the patient and asked whether the patient felt comfortable with certain aspects of procedures. This indicates that some medical practitioners uphold the principle that every person should have bodily autonomy and that consent to examinations and procedures are not implied.

While South African medical doctors like Kemp (2013) state that psychological care and counselling after a diagnosis is part of the treatment plan, none of the participants were referred to psychologists after their diagnosis. This indicates an area where South African intersex protocols and policies can still improve. Participants who sought out psychological help themselves found great value in speaking to psychologists.

Other factors that helped participants come to terms with having AIS were the support of friends, family, and romantic partners, and even colleagues at work. This demonstrates that people can be accepting, supportive and willing to learn more about intersex variations and the experiences of those who have it. This may also indicate that there is a growing understanding of diversity within sex, gender and sexuality categories in some contexts, which contributes to more open-mindedness and acceptance of misunderstood or stigmatized groups.

The study also found that the availability of the internet and AIS-specific support groups like the South African AIS support group (SAAIS) and general South African intersex

support groups like ISSA were valuable for participants. It has given them the tools and confidence to search for answers themselves and to stand up for their rights, insist on knowing the truth and resist unfair and unethical treatment.

Local and international intersex and AIS support groups like (Intersex Society of North America) ISNA and the AIS DSD Support Group for Women and Families makes important intersex and AIS information available to people with AIS, their parents, friends, family members and romantic partners. This creates awareness of intersex variations like AIS and helps people to understand what the variation means and what the implications are. It helps individuals understand what others with intersex variations like AIS have experienced and how to combat stigma and discrimination. Being part of intersex support groups enables individuals to learn from others with intersex variations like AIS. It also enables individuals to influence the meaning of intersex and it creates a sense of belonging.

Through the narratives of participants, I found that some people find it important to be open about their AIS. They see it as an opportunity to teach people with both typical and atypical bodies that it is okay to be intersex and not something to be ashamed of. Making AIS more visible can help to prevent the unnecessary surgeries that are done to conceal the truth about intersex. It also helps people with intersex variations to accept themselves and help others to accept themselves and challenges the binary gender structure. There are people with AIS who manage to find happiness and acceptance of their lives with AIS and who embrace the difference of their bodies

With these concluding views in mind, I provide some recommendations for future studies.

6.3 RECOMMENDATIONS FOR FUTURE STUDIES

An important focus for future research should be intersex in general as people with intersex variations globally and in South Africa still face great stigmatization. While it would be ideal for intersex people to be open about their variations, South African intersex activist Nthabiseng Mokoena (2015) have reported that their media visibility and openness about their intersex have shown them that people who are open about their intersex still face stigmatization, threats of violence and are met with curiosity over their genital appearance and gender identity. This reaction from the public indicates that there is a

general lack of intersex information available and that it is important to contribute to knowledge on intersex. More studies on the umbrella term “intersex” can help to combat misinformation. It is, for example, common to confuse intersex with transgender issues. However, it is important to distinguish between these groups as their experiences and lived realities are vastly different and by viewing them as the same, people of both groups are stigmatized (Intersex Society of North America, 2008).

More research is also needed on the specific types of intersex variations as intersex is a broad term, but individuals with different variations can have vastly different experiences and needs. The aim of this study was to contribute to an understanding of AIS as an intersex variation. Another South African example is the master’s dissertation at Wits University by Nadine van Jaarsveld’s (2018) on the lived realities of women with Turner’s syndrome. Additional studies on specific types of intersex variation will further contribute to the knowledge on intersex.

Participants emphasized the need for sensitivity and understanding in their medical treatment, for better information and the agency to give consent for surgeries. Future studies could, therefore, also focus on the training of general practitioners (GPS) and general healthcare workers with respect to intersex matters.

Participants indicated that psychological care is an important and beneficial aspect of their treatment. It can therefore be beneficial to explore whether there are any specific intersex treatment protocols in the field of psychology in South Africa. Participants also indicated that their parents did not receive psychological counselling after finding out about their children’s diagnosis. It is therefore important to investigate ways in which parents specifically could be supported in making the best choices for their children with AIS.

While people want to be supportive of intersex people, they may not know how to help in truly helpful and meaningful ways. Therefore, it may be beneficial to study ways in which people without intersex variations can be allies to people with intersex variations.

Currently there is little funding for intersex research. South African intersex organizations also struggle to flourish after the death of the iconic South African intersex activist Sally Gross. Mokoena (2015) states that most of the activist work for intersex rights are done by non-government organizations (NGOs) and that these organizations are greatly reliant on

international donations. Furthermore, activism is a time demanding activity that does not pay enough to cover living costs. For this reason, there are only a few people who are actively involved in keeping South African intersex organizations alive. While intersex falls within the LGBTQI community, InterAct (2021) states that a mere 1% of LGBTQI funding goes to all intersex advocacy organizations combined. This indicates that intersex-related concerns do not receive nearly enough attention. Participants have indicated that being part of South African intersex organizations have been beneficial to them. Since it is seen as a very helpful platform for coming to terms with AIS, it is important to investigate ways in which South African intersex organizations can be supported and developed to address some of the reasons why they are not flourishing.

6.4 CONCLUSION

This study aimed to do a sociological investigation of the lived experiences of people with AIS in South Africa. I was interested in how the medicalization of AIS had influenced participants' ideas and experiences of gender, how it influenced their different personal relationships and how it affected their relationships and experiences with healthcare professionals. The participants revealed from their experiences that gendered expectations of the development, functioning and appearance of a female body did affect how they perceived themselves as women at an individual level. These gendered assumptions of bodies also influenced interactions with friends, family and medical professionals. What is more, these assumptions were at the centre of medical protocols to which participants had been subjected and that advocated silence and keeping the truth from individuals, as well as subjecting participants to surgeries without full consent and an understanding of the implications of these surgeries for their lives.

LIST OF SOURCES

Abraham, M. 2020. *Social withdrawal - anxiety causes & solutions.* https://www.calmclinic.com/anxiety/symptoms/social-withdrawal Date of access: 6 Nov. 2021.

AIS Support Group Australia Inc.. 2019. *Intersex peer support Australia.* http://www.aissga.org.au/ Date of access: 28 Feb. 2020 .

Akhtar, M. I., 2016. Research Design. Research in Social Science. Interdisciplinary Perspectives, Volume 68.

Allday, E. 2011. *UCSF's support group for parents of intersex kids.* https://www.sfgate.com/health/article/UCSF-s-support-group-for-parents-of-intersex-kids-2372303.php Date of access: 4 Dec. 2021 .

Allen, M. 2017. *The Sage encyclopedia of communication research methods*. SAGE publications.

Almeida, T.G. Comassetto, E. Alves, K. D.M.C. Dos Santos, A. A.P., 2015. Experiences of young women with breast cancer and mastectomized. Escola Anna Nery Revista De Enfermagem, 19(3):432–438.

Aluwihare-Samaranayake, D. 2012. Ethics in qualitative research: a view of the participants' and researchers' world from a critical standpoint. *International Journal of Qualitative Methods*, 11(2):64–81.

Amanda. 2021. Interview 4. [Personal Interview]. 20 Sept., Potchefstroom.

Ambrosino, B. 2017. *The invention of 'heterosexuality'*. https://www.bbc.com/future/article/20170315-the-invention-of-heterosexuality Date of access: 21 July 2021 .

Anick. (Give the Twitter@). 2021, 10 Nov.)Give title of tweet. https://twitter.com/intersexaf/status/1458475820243095568?s=24 Date of access: xxx

Anwar, M. 2015. What does it mean to be ethical in research? what should it mean? *Jurnal Bisnis & Manajemen*, 16(1):22–28.

Arifin, S.R.B.M. 2018. Ethical considerations in qualitative study. *International Journal of Care Scholars*, 1(2):30–33.

Babbie, E.R. & Mouton, J. 2001. *The practice of social research*. 2nd ed. Oxford University Press.

Batch, J.A., Evans, B.A.J., Hughes, I.A. & Patterson, M.N. 1993. Mutations of the androgen receptor gene identified in perineal hypospadias. *J Med Genet*, 30:198–201.

Bates, M.J. 2005. *An Introduction to Metatheories: Theories and Models*. pp. 1-19.

Batista, R. Costa, E.M.F. Rodrigues, A.D. Gomes, N.L. Faria, J.A. Nishi, M.Y. Arnhold, I.J.P. Domenice, S. De Mendonca B.B., 2018. Androgen insensitivity syndrome: a review. *Arch Endocrinol,* 62(2):227–235.

Behrens, K.G. 2020. A principled ethical approach to intersex pediatric surgeries. *BMC Med Ethics*, 21(108):1–9.

Bennecke, E. Köhler, B. Röhle, R, Thyen, U. Gehrmann, K. Lee, P. Nordenström, A. Cohen-Kettenis, P. Bouvattier, C. Wiesemann, C., 2020. Disorder or difference of sex development? Views of affected individuals on DSD terminology. *The Journal of Sex Research ,* 58(4):1-10.

Birke, L. I. A., 1987. Beyond nature versus nurture: Process and biology in the development of gender. *Women's Studies International Forum,* 10(6), pp. 555-570.

Bista, B. 2015. Lived experience of infertility among community dwelling infertile women. *Journal of Nobel Medical College*, 4(1):46–56.

Blackstone, A. 2003. Gender roles and society. In *Human Ecology: An Encyclopedia of Children, Families, Communities, and Environments*, Publisher. pp. 335338.

Blair, E. 2015. A reflexive exploration of two qualitative data coding techniques. *Journal of Methods and Measurements in the Social Sciences,* 6(1):14–29.

Bradley, H. 2013. *Gender.* Polity Press.

Broido, E.M. & Manning, K. 2002. Philosophical foundations and current theoretical perspectives in qualitative research. *Journal of College Student Development,* 43(3):434–445.

Bullough, V.L. 2003. The contributions of John Money: A personal view. *The Journal of Sex Research*, 40(3):230–236.

Butler, J. 1990. *Gender trouble: feminism and the subversions of identity*. Routledge.

Calafell, B. & Nakayama, T.K. 2016. Queer theory. in KB Jensen & R Craig (eds), *International Encyclopedia of Communication Theory and Philosophy*. John Wiley and Sons, pp. 1-5.

Callahan, G. 2009. *Between XX and XY: Intersexuality and the myth of two sexes*. 1st ed. Chicago Review Press.

Carroll, R., 2021. Introduction: femini (Tulyakul & Meepring, 2020) (Anon., n.d.) (Rose, 2020) (InterConnect, 2021) (FRIDA, 2021)m, queer theory and heterosexuality. In: Rereading Heterosexuality. Edinburgh: Edinburgh University Press, pp. 1-21.

Carpenter, M., 2013. *Clinicians acknowledge lack of justification for surgeries on intersex infants in Australia.* [Online]
Available at: https://ihra.org.au/22925/clinicians-acknowledge-lack-of-justification-for-infant-surgeries/
[Accessed 3 October 2020].

Carpenter, M. 2015. The human rights of intersex people: addressing harmful practices and rhetoric of change. *An International Journal on Sexual and Reproductive Health and Rights*, 24(47): 74–84.

Carpenter, M. 2018. The ‘normalisation’ of intersex bodies and ‘othering’ of intersex identities. in JM Scherpe, A Dutta & T Helms (eds), *The legal status of intersex persons*. Intersentia, pp. 445–514.

Carpenter, M. 2020. Intersex human rights, sexual orientation, gender identity, sex characteristics and the Yogyakarta Principles plus 10. *Culture Health and Sexuality*, 23(2):1–18.

Carroll, R. 2012. *Rereading heterosexuality*. Edinburgh University Press.

Charbonnier, E. & Graziani, P. 2016. The stress associated with the coming out process in the young adult population. *Journal of Gay and Lesbian Mental Health,* 20(4):1–17.

Clarecais, 2021. *Differently normal.* https://differently-normal.com/2021/10/25/the-invention-of-intersex Date of access: 3 Nov. 2021.

Cohut, M. 2020. The intersex gap in research and healthcare. https://www.medicalnewstoday.com/articles/the-intersex-gap-in-research-and-healthcare Date of access: 15 Nov. 2021.

Colisson, C. 2018. *'The I in LGBTI stands for invisible, ignored'.* https://mg.co.za/article/2018-01-10-00-the-i-in-lgbti-stands-for-invisible-ignored/ Date of access: 25 Sept. 2020 .

Condrell, K.N. 2011. The benefits of talking are not apparent to many people. http://www.valueoptions.com/solutions/2011/11-November/story5.htm Date of access: 16 Nov. 2021.

Conn, J., Gilliam, L. & Conway, G. 2005. Revealing the diagnosis of androgen insensitivity syndrome in adulthood. *Ethics in Practice*, 331(7517):628–630.

Conrad, P. 2003. Medicalization and social control. *Annual Review of Sociology*, 18(1):209–232.

Cortez, M. Gaudenzi, P. & Maksud, I. 2019. Gender: pathways and dialogues between feminist and biomedical studies from the 1950s to 1970s. *Physis: Revista de Saúde Coletiva,* 29(1):1–20.

Creswell, J.W. & Creswell, J.D. 2017. *Research design: qualitative, quantitative, and mixed methods approaches.* 5th ed. SAGE Publications.

Cull, M.L. & Simmonds, M. 2010. Importance of support groups for intersex (disorders of sex development) patients, families and the medical profession. *Sex Dev*, 4(4-5):310–312.

Danon, L.M. & Yanay, N. 2016. Intersexuality: on secret bodies and secrecy. *Studies in Gender and Sexuality,* 17(1):57–72.

Davey, R.A. & Grossman, M. 2016. Androgen receptor structure, function and biology: from bench to bedside. *The Clinical Biochemist Reviews*, 37(1):3–15.

Davis, G. & Preves, S. 2019. *Reflecting on intersex. The Kaleidoscope of Gender: Prisms, Patterns, and Possibilities*. Sage Publications.

Davis, G. 2015. *Contesting intersex: the dubious diagnosis*New York University Press.

Davis, G., Feder, E.K., Liao, L. & Baratz, A.B. 2016. *Normalizing intersex*. VOICES: Personal Stories from the Pages of NIB (Narrative Inquiry in Bioethics). John Hopkins University Press.

De la Harpe, M.M. 1959. Die estrogeenproduserende testessindroom. *S.A. Tydskrif vir Geneeskunde*, pp. 751–754.

De Paula, A.A.O.R. & Viera, M.M.R. 2015. Intersexuality: a clinical singularity. *Rev. Bioét,* 23(1):69–78.

de Wee, N., 2021. *Department of Home Affairs proposes new ID system for LGBTQI+ persons.* [Online]
Available at: https://www.thesouthafrican.com/lifestyle/lgbtqia/breaking-department-of-home-affairs-new-id-system-lgbtqi-sihle-mthiyane-gender-marker/
[Accessed 25 November 2021].

Dean, B.A. 2018. The interpretivist and the learner. *International Journal of Doctoral Studies*, 13:1–8.

DeLamater, J.D. & Shibley Hyde, J. 1998. Essentialism vs. social constructivism in the study of human sexuality. *The Journal of Sex Research*, 35(1):10–18.

Detel, W. 2015. *Social constructivism*. in NJ Smeler & PB Baltes (eds), *International Encyclopedia of the Social and Behavioral Sciences.*Elsevier, pp. 14264-14267.

Digitale, E. 2008. *Stanford author explores struggles of intersex individuals, their families and doctors.* https://med.stanford.edu/news/all-news/2008/11/stanford-author-explores-struggles-of-intersex-individuals-their-families-and-doctors.html Date of access: 26 Nov. 2021 .

Donahue, R. 2019. The complicated benefits of coming out. https://www.allure.com/story/coming-out-process-physical-mental-pain-relief Date of access: 17 Nov. 2021 .

Eder, S. 2012. From 'following the push of nature' to 'restoring one's proper sex' cortisone and sex at Johns Hopkins's Pediatric Endocrinology Clinic. *Endeavor,* 36(2):69–76.

Elliot, V. 2018. Thinking about the coding process in qualitative data analysis. *The Qualitative Report*, 23(11):2850–2861.

Erol, R.Y. & Orth, U. 2016. Self-esteem and the quality of romantic relationships. *European Psychologist*, 21(4):274–283.

Eugenides, J. 2002. *Middlesex*. 1st ed. Alfred A. Knopf.

Farvid, P. 2015. Heterosexuality. In: C. Richards & M.J. Barker, eds. *The Palgrave book of the psychology of sexuality and gender*. Palgrave Macmillan, pp. 92-108.

Fausto-Sterling, A. 2000. The five sexes revisited. *Sciences*, 40(4):18–23.

Feder, E. 2009. Normalizing medicine: between ‘intersexuals’ and individuals with “Disorders of Sex Development”. *Health Care Analysis: An International Journal of*, 17(2):134–143.

Firth, S. 2014. *Study: infertile couples 3 times more likely to divorce.* https://www.usnews.com/news/articles/2014/01/31/study-infertile-couples-3-times-more-likely-to-divorce Date of access: 7 Nov. 2021 .

Fisher, A.D. Ristori, J. Castellini, G. Forti, G. Maggi, M., 2016. Gender identity, gender assignment and reassignment. *J Endocrinol Invest,* 1–18.

Florian, V., Mikulincer, M. & Hirscheberger, G. 2000. The anomaly of a problematic emotion - the conceptualization and measurement of the experience of pity. *Imagination Cognition and Personality,* 19(1):3–25.

Foucault, M. 1980. *The history of sexuality, vol 1.* Vintage Books.

Fouka, G. & Mantzorou, M. 2011. What are the major ethical issues in conducting research? Is there a conflict between the research ethics and the nature of nursing? *Health Science Journal,* 5(1):3–14.

Frader, J. Alderson, P. Asch, A. Aspinall, C. Davis, D. Dreger, A. Edwards, J. Feder, E.K. Frank, A. Hedley, L.A. Kittay, E. Marsh, J. Miller, P.S. Mouradian, W. Nelson, H. Parens, E., 2004. Health Care Professionals and Intersex Conditions. *Archives of Pediatrics and Adolescent Medicine,* 158(5), pp. 426-428.

Franck, L.S., Ferguson, D., Fryda, S. & Rubin, N. 2015. The child and family hospital experience. *Med Care Res Rev,* 72(4):419–437.

FRIDA, 2021. *Intersex South Africa (ISSA).* [Online]
Available at: https://youngfeministfund.org/grantees/intersex-south-africa-issa/#:~:text=Intersex%20South%20Africa%20(ISSA)%20was,ISSA's%20mission%20is%3A&text=To%20put%20an%20end%20to,consensual%20sterilization%20of%20intersex%20people
[Accessed 4 October 2021].

Gablin, A. 2014. An introduction to social constructivism. *Social Research Reports,* 26:82–92.

Garner, G. 2012. *Pros and cons of video interviewing.* http://www.thegarnergrp.com/blog/bid/89366/Pros-and-Cons-of-Video-Interviewing Date of access: 8 Nov. 2021 .

Geethika, M., Reddy, K.M., Ramreddy, K.V. & Moorthy, R. 2016. Complete androgen insensitivity syndrome in an adults - a rare Entity. *International Journal of Contemporary Medical Research,* 3(4):1016–1018.

Germon, J. 2009. *Gender: a genealogy of an idea*. Palgrave Macmillan.

Giddens, A. 1984. The constitution of society: outline of the theory of structuration. University of California Press.

Gillespie, W.H. 1969. Stoller, R. J. "Sex and Gender" (Book Review). *The International Journal of Psycho Analysis,* 50:251.

Goldhuhl, G. 2012. Pragmatism vs interpretivism in qualitative information systems research. *European Journal of Information Systems,* 21(2):135–146.

Goldie, T. 2014. *The man who invented gender: Engaging the ideas of John Money*. UBC Press.

Gregen, K. J., 2013. Relating with Self and Others. *InterAction,* 5(1), pp. 9-25.

Greil, A.L., McQuillan, J. & Slauson-Blevins, K.S. 2011. The social construction of infertility. *Sociology Compass,* 5:736–746.

Grissinger, M. 2017. Disrespectful behavior in health care: its impact, why it arises and persists, and how to address it—Part 2. 42(2):74–77.

Gulia, C. Baldassarra, S. Zangari, A. Briganti, V. Gigli, S. Gaffi, M. Signore, F. Vallone, C. Nucciotti, R. Costantini, F.M. Puzzuti, A. Bernardo, S. Porrello, A. Piergentili, R., 2018. Androgen insensitivity syndrome. *European Review for Medical and Pharmacological Science*, 12:3873–3887.

Gunawan, J. 2015. Ensuring trustworthiness in qualitative research. *Belitung Nursing Journal*, 1(1):10–11.

Gurevich, R. 2020. *8 Ways infertility impacts your relationship and ways to cope.* https://www.verywellfamily.com/how-infertility-impact-your-marriage-and-relationship-4121098 Date of access: 7 Nov. 2021 .

Haradhan, M. 2018. Qualitative research methodology in social sciences and related subjects. Journal of Economic Development, Environment and People, 7(1):23–48.

Hemmingway, A. 2017. *How my coming out helped others come out*. https://metrosource.com/how-my-coming-out-helped-others-come-out/ Date of access: 17 Nov. 2021 .

Hines, M., Ahmed, F. & Hughes, I. A., 2003. Psychological Outcomes and Gender-Related Development in Complete Androgen Insensitivity Syndrome. *Archives of Sexual Behavior,* 32(2), pp. 93-101.

Hirschowitz, S. 1969. Intersex: A simplified perspective. *S.A. Journal of Obstetrics and Gynaecology*, pp. 22-26.

Huber, W.B. 2012. Gynecomastia, hegemonic masculinity, and stigma: researching male corporeal deviance. Kent: Kent State University. (Dissertation – MA).

Hughes, I.A. Davis, J.D. Bunch, T.I. Pasterski, V. Mastroyannopoulou, K. MacDougall, M., 2012. Androgen insensitivity syndrome. *Lancet*, 380(9851):1419–1428.

Igwenagu, C. 2016. *Fundamentals of research methodology and data collection*. Lambert Academic Publishing.

InterAct Advocates for Intersex Youth. 2016. *InterAct Advocates for Intersex Youth.* https://interactadvocates.org/# Date of access: 6 Nov. 2020.

Intersex Society of North America, 2008. *Our Mission.* [Online]
Available at: https://isna.org/
[Accessed 8 October 2020].

ISNA. Intersex Society of North America. 2008. *Our Mission.* https://isna.org/ Date of access: 8 Oct. 2020 .

Isaacson, M. 2014. Sally Gross: The fight for gender equality loses a giant. https://www.dailymaverick.co.za/article/2014-02-25-sally-gross-the-fight-for-gender-equality-loses-a-giant/ Date of access: 30 Nov. 2021.

Jackson , R. L., Drummond , D. K. & Camara, S., 2007. What is Qualitative research?. *Qualitative Research Reports in Communication ,* 8(1), pp. 21-28.

Jenkins, T.M. & Short, S.E. 2017. Negotiating intersex: A case for revising the theory of social diagnosis.. *Soc Sci Med*, 175: 91-98.

Jia, Q. 2010. A brief study on the implication of constructivism teaching theory on classroom teaching reform in basic education. *International Education Studies,* 3(2):197–199.

Jones, C. 2019. Intersex, infertility and the future: early diagnoses and the imagined life course. *Sociology of Health and Illness,* 24(1).

Jones, T. Hart, B. Carpenter, M. Ansara, G. Leonard, W. Lucke, J., 2016. *Intersex stories and statistics from Australia*. Lighting Source for Open Book Publishers.

Kapoor, K., Sarkar, M. & Pal, D.K. 2016. Partial androgen insensitivity syndrome: a rare disease. *Scholars Journal of Medical Case Reports*, 4(11):815–818.

Karaca, S. & Macauley, J. 2017. *Being intersex is hard, our silence makes it harder.* https://www.eurasia.undp.org/content/rbec/en/home/blog/2017/4/7/Being-intersex-is-hard-our-silence-makes-it-harder.html Date of access: 28 Feb. 2020.

Karkazis, K. 2008. *Fixing sex: intersex, medical authority, and lived experience*. Duke University Press.

Katwala, A. 2019. *The controversial science behind the Caster Semenya Verdict.* https://www.wired.co.uk/article/caster-semenya-testosterone-ruling-gender-science-analysis Date of access: 14 March 2020 .

Katz, H. 2006. Global surveys or multi-national surveys? On sampling for global surveys.

Keays, M.A. & Dave, S. 2017. Current hypospadias management: Diagnosis, surgical management and long term patient-centered outcomes. *Can Urol Assoc J*., 11:48–53.

Kelly, M. 2015. *INTERSEX*Fact Sheet https://assets.gov.ie/26828/714c1f5aaa6a4f15be27f0a86407982f.pdf

Kemp, T. 2013. Three siblings with complete androgen insensitivity syndrome. *Case Study*, 18(3):159–163.

Kennedy, A. 2016. Fixed at birth: medical and legal erasures of intersex variations. *Thematic: Fixed at Birth*, 39(2):813–842.

Kerry, S. 2011. Representation of intersex in news media. *Journal of Gender Studies*, 20(3):263–277.

Kessler, J.Z. 2002. *Lessons from the intersexed.* Rutgers University Press.

Khiry, Z. 2020. Why is social media activism important? https://www.onlineoptimism.com/blog/social-media-activism/ Date of access: 3 Nov. 2021.

Kinsman, K. 2014. Intersex dating: Finding love across the intersection. https://edition.cnn.com/2014/04/15/living/intersex-dating-relate/index.html Date of access: 6 Nov. 2021.

Kivunja, C. & Kuyini, A.B. 2017. Understanding and applying research paradigms in educational contexts. *International Journal of Higher Education*, 6(26):26-41.

Klein, T. 2009. Intersex and transgender activism in South Africa. *Liminalis,* 15–41.

Ko, J. K. Y. et al., 2017. Hormone replacement treatment choices in complete androgen insensitivity syndrome: an audit of an adult clinic. *Endocr Connect,* 6(6), pp. 375-379.

Kouritzin, S.G. 2000. Bringing life to research: life history research and ESL. *TESL Canda Journal,* 17(2):1–35.

Koyama, E. 2007. Intersex initiative. http://www.intersexinitiative.org/popculture/middlesex-faq.html Date of access:3 July 2020.

Kumar, R. 2014. *Research methodology: a step-by-step guide for beginners*. 4th ed. SAGE Publications Ltd.

Laubscher, W.M. 1967. A male pseudohermaphrodite. *S.A. Tydskrif vir geneeskunde,* 929–931.

Leidolf, E. M., Curran, M., Scout & Bradford, J. B., 2008. Intersex Mental Health and Social Support Options in Pediatric Endocrinology Training Programs. *Journal of Homosexuality,* 54(3), pp. 233-242.

Leigh-Ann. 2021. Interview 2. [Virtual Interview] 21 Jan., Potchefstroom.

Lemay, E.P. & Clark, M.S. 2008. “Walking on Eggshells”: how expressing relationship insecurities perpetuates them. *Journal of Personality and Social Psychology*, 95(2):420–441.

Lev, A.I., LCSW & CASAC. 2006. Intersexuality in the family: an unacknowledged trauma. *Journal of Gay and Lesbian Psychotherapy,* 10(2):27–56.

Lock Swarr, A. 2012. *Sex in transition: remaking gender and race in South Africa*. SUNY Press.

Lopez, V. & Whitehead, D. 2013. Sampling data and data collection in qualitative research. in ZS Whitehead (eds), *Nursing & midwifery research: methods and appraisal for evidence-based practice*. Elsevier pp. 123-140.

MacKenzie, D., Huntington, A. & Gilmour, J. 2009. The experiences of people with an intersex condition: a journey from silence to voice. *J Clin Nurs*, 18(12):1775–1783.

Maese, J.J. 2017. Postmodern/poststructural approaches. in CRSL Lewis (eds), *The International Encyclopedia of Organizational Communication*. John Wiley & Sons, pp. 1-21.

Magubane, Z. 2014. Spectacles and scholarship: Caster Semenya, intersex studies, and the problem of race in feminist theory. *Signs: Journal of Women in Culture and Society*, 39(3):761–785.

Mama, A., 2009. 'Gender' and 'sex'. pp. 1-5.

Maquba, L. & Sehoole, J. 2018. National dialogue on the protection and promotion of the human rights of intersex people, Johannesburg: s.n.

Maree, K. 2007. *First steps in research*. 1st ed. Van Schaik.

Marshall, P.A., Adebamowo, C., Adeyemo, A. & Ogundiran, T.O. 2006. Voluntary participation and informed consent to international genetic research. *American Journal of Public Health,* 96(11):1989–1994.

Mazur, T. 2005. Gender Dysphoria and Gender Change in Androgen Insensitivity or Micropenis. *Archives of Sexual Behavior,* 34(4):411–421.

McKeown, G. 2014. Essentialism: The disciplined pursuit of less. Crown Business .

Mcnamara, B. 2016. Your body image actually has huge effects on your dating life. https://www.teenvogue.com/story/body-image-relationships-effects Date of access: 7 Nov. 2020.

Mendoza, N. & Motos, M.A. 2012. Androgen insensitivity syndrome. *Gynecological Endocrinology,* 1–5.

Meuhlenhard, C. L. & Peterson, Z. D., 2011. Distinguishing Between Sex and Gender: History, Current Conceptualizations, and Implications. *Sex Roles,* 64(11), pp. 791-803.

Millet, K. 1971. *Sexual politics.* Sphere.

Mills, J. E., Bonner, A. & Francis, K., 2006. Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice ,* 12(1), pp. 8-13.

Mitchell, J. 1971. *Women's estate*. Penguin.

Mokoena, N. 2015. *Remembering Sally, and the intersex movement in South Africa.* https://intersexday.org/en/remembering-sally-south-africa/ Date of access: 6 Dec. 2021.

Mondragon, N.I. & Txertudi, M.B. 2019. Understanding menstruation: Influence on gender and ideological factors. A study of young people's social representations. *Feminism and Psychology,* 29(3):357–373.

Mottier, V. 2012. Gender, reproductive politics and the liberal state. in R Duschinsky & LA Rocha (eds), *Foucault, the Family and Politics.* Palgrave Macmillan, pp. 142–157.

Ngun, T.C. Gharamani, N. Sanchez, F.J. Bocklandt, S. Vilain, E., 2011. The genetics of sex differences in brain and behavior. *Front Neuroendocrinol,* 32(2):227–246.

Noland, C.M. 2012. Institutional barriers to research on sensitive topics: Case of sex communication research among university students. *Journal of Research Practice*, 8(1):1–9.

Oakes, M., Eyvazzadeh, A., Quint, E. & Smith, Y. 2009. Complete androgen insensitivity syndrome-a review. *Journal of Pediatric and Adolescent Gynecology,* 21(6):305–310.

Oakley, A. 1972. *Sex, gender and society.* Temple-Smith.

Okechi, O.S. 2018. The indigenous concept of sexuality in African tradition and globalization. *Global Journal of Reproductive Medicine,* 6(1):1–5.

Ortner, S.B. 1974. Is female to male as nature is to culture? in MZ Rosaldo & L Lamphere (eds), *Women, Culture and Society.* Stanford University Press, pp. 68–87.

Ovidiu, B., Marcu, D. R., Mischianu, D. L. D., Poiana, C., Diaconu, C. C., Bungau, S. G., Tit, D. M., Cumpanas, A., and Bohiltea, R. (2021). The challenges of androgen insensitivity syndrome. Archives of Medical Science. https://doi.org/10.5114/aoms/125584

Padmanabhanunni, A. & Fenny, T. 2017. The menstruation experience: Attitude dimensions among South African students. *Journal of Psychology in Africa*, 27(1):54–60.

Park, S. & Park, K.S. 2014. Family stigma: a concept analysis. *Asian Nursing Research*, 8:165–171.

Parsons, T. & Bales, R. 1956. *Family socialization and interaction process*. Routledge and Kegan Paul.

Patroa, M.T.C.C., Silva, E.J.R. & Avellar, M.C.W. 2009. Androgens and the male reproductive tract: an overview of classical roles and current perspectives. *Arq Bras Endrocrinol Metab,* 53(8):934–945.

Payne, S., Swami, V. & Stanistreet, D. 2008. The social construction of gender and its influence on suicide: A review of the literature. *American Journal of Men's Health,* 5(1):23–35.

Pham, L. 2018. A review of key paradigms: Positivism, interpretivism and critical inquiry. Lan Thi Mai Pham. http://dx.doi.org/10.13140/RG.2.2.13995.54569

Pikoli, Z. 2021. Pastor, sangoma, genderqueer change agent: The journey of an intersex activist. https://www.dailymaverick.co.za/article/2021-11-24-pastor-sangoma-genderqueer-change-agent-the-journey-of-an-intersex-activist/ Date of access: 26 Nov. 2021.

Preves, S. 2001. Sexing the intersexed: an analysis of sociocultural signs. *Journal of Women in Culture and Society,* 27(2):523–556.

Pritsini, F. Kanakis, G.A. Kyrgio, I. Kotanidou, E. P. Litou, E. Mouzaki, K. Kleisarchaki, A. Goulis, D.G. Galli-Tsinopoulou, A., 2017. Psychological aspects of androgen insensitivity syndrome: two cases illustrating therapeutical challenges. Case Rep Endocrinol. http//doi.org/10.1155/2017/8313126

Pryce, J., Spencer, R. & Walsh, J. 2014. Philosophical approaches to qualitative research. In: *The Oxford Handbook of Qualitative Research Methods*. Oxford University Press, pp. 81–94.

Rare Diseases South Africa. 2021. *About Us.* Date of access: https://www.rarediseases.co.za/purpose Date of access: 7 Nov. 2021.

Raypole, C. 2021. *Why do i push people away? Explanations and 8 tips for embracing intimacy.* https://www.healthline.com/health/mental-health/pushing-people-away#causes Date of access: 6 Nov. 2021.

Rehman, A.A. & Alharthi, K. 2016. An introduction to research paradigms. *International Journal of Educational Investigations*, 3(8):51–59.

Reis, E. 2009. *Bodies in doubt: An American history of intersex.* John Hopkins University Press.

Risman, B.J. 2004. Gender as a social structure: theory wrestling with activism. *Gender and Society,* 18(4):429–450.

Ronel. 2021. Interview 5. [Written Interview]. 15 Okt., Pretoria.

Rose, M., 2020. *What Intersex People Want You to Know About Sex.* [Online] Available at: https://www.teenvogue.com/story/intersex-people-sex [Accessed 21 November 2021].

Rubin, G. 1975. The traffic in women: the political economy of sex. in R Reidter (eds), *Towards an Anthropology.* New York: Monthly Review Press, pp. 157–210.

Ryan, G. 2018. Introduction to positivism, interpretivism and critical theory. *Nurse Researcher*, 25(4):14–20.

Safdar, S. A. & Safdar, L., 2019. Grooming and etiquette as part of nurse's professionalism: An essential curricular competency. Pakistan Journal of Medical Science Online, 35(2), pp. 404-408.

Salaudeen, A. 2019. *Growing up intersex in a country where it is believed to be bad luck.* https://lite.cnn.com/en/article/h_1c54e790fcbd83b617b0f947517d7d23 Date of access: 8 Nov. 2020.

Sameera. 2021. Interview 3. [Virtual Interview]. 28 May., Potchefstroom.

Samy, M. & Robertson, F.A. 2017. From positivism to social constructivism: an emerging trend for CSR researchers. om D Cowther & L Lauesen (eds), *Handbook of Research Methods in Corporate Social*. Edward Elgar Publishing, pp. 437–462.

Schwandt, T.A. 1998. Constructivist, interpretivist approaches to human enquiry. In NK Denzin & YS Lincln (eds), *The Landscapes of Qualitative Research: Theories and Issues*. Sage Publications, pp. 221–258.

Scott, E.C., Greenberg, T.S., Arndt, S., Ramay, M. Shires, R. 2006. Complete androgen insensitivity syndrome in a black South African family: a clinical and molecular investigation. *Endocrine Practice,* 12(6):664–669.

Scott, J.W. 1988. *Gender and the politics of history.* Columbia University Press.

Searfoss, J. 2020. Informed consent: docs should ask permission to touch. https://www.medpagetoday.com/publichealthpolicy/ethics/84392 Date of access: 15 Nov. 2021.

Shenton, A.K. 2004. Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22:63–75.

Schick, V., Calabrese, S., Rima, B.N. & Zucker, A.N. 2010. Genital appearance dissatisfaction: implications for women's genital image self-consciousness, sexual esteem, sexual satisfaction, and sexual risk. *Psychology of Women Quarterly*, 34(3):394–404.

Simons, J., Gonzalez, J. & Ramdas, M. 2020. Supporting intersex people: effective academic and career counseling. *Journal of LGBT issues in Counseling*, 14(3):2–19.

Singh, C., Tebboth, M., Spear. D., Ansah. P., Mensah. A. 2019. Exploring methodological approaches to access climate change vulnerability and adaptation: Reflections from using life history approaches. *Regional Environmental Change,* 19:2667–2682.

Sladek, F.M. 2011. What are nuclear receptor ligands? *Molecular and Cellular Endocrinology*, 334(1-2):3–11.

Soliman, A.T., De Sanctis, V. & Yassin, M.A. 2017. Management of adolescent gynecomastia: an update. *Acta bio-medica: Atenei Parmensis*, 88(2):1–10.

Sousa, F.J. 2010. Metatheories in research: positivism, postmodernism and critical realism. *Organizational Culture, Business-to-Business Relationships, and Interfirm Networks Advances in Business Marketing and Purchasing*, 16:455–503.

Ssali, S., Theobald, S. & Hawkins, K. 2015. Life histories: A research method to capture people's experiences of health systems in post-conflict countries. https://healthsystemsglobal.org/news/life-histories-a-research-method-to-capture-peoples-experiences-of-health-systems-in-post-conflict-countries/ Date of access: 6 Oct. 2020.

Stone, J. 2019. The importance of empathy in healthcare: Advancing humanism. at: https://blog.medicalgps.com/the-importance-of-empathy-in-healthcare/ Date of access: 15 Nov. 2021.

Streefkerk, R. 2021. Qualitative vs. Quantitative research. https://www.scribbr.com/methodology/qualitative-quantitative-research/ Date of access: 14 Oct. 2021.

Suen, Y.T. 2015. Methodological reflections on researching lesbian, gay, bisexual and transgender university students in Hong Kong: to what extent are they vulnerable interview subjects? *Higher Education Research & Development,* 34(4):722–734.

Surmiak, A. 2018. Confidentiality in *Qualitative Research Involving Vulnerable Participants: Researchers' Perspectives*. *Forum: Qualitative Social Research,* 19(3):1-26.

Swami, V., Jones, J., Einon, D. & Furnham, A. 2008. Men's preferences for women's profile waist-to-hip ratio, breast size, and ethnic group in Britain and South Africa. *British Journal of Psychology,* 100(2):313–325.

Tamar-Mattis, A. 2014. Medical treatment of people with intersex conditions as torture and cruel, Inhuman or Degrading Treatment or Punishment, *Advocates for Informed Choice*: s.n.

Thandi. 2020. Interview 1 [Virtual interview]. 18 November., Potchefstroom.

Thanh, N.C. & Thanh, T.T.L. 2015. The interconnection between interpretivist paradigm and qualitative methods in education. *American Journal of Educational Science*, 1(2):24–27.

Thomas, C. 2017. The shock – and ironic relief – of hearing a serious diagnosis. https://myheartsisters.org/2017/09/10/ironic-relief-of-serious-diagnosis/ Date of access: 16 Nov. 2021.

Tripathy, P., Khosla, P. & Nayak, D. 2020. Coping after infertility: challenge for primary infertile women. *European Journal of Molecular & Clinical Medicine*, 7(10):3820–3826.

Tuli, F. 2010. The basis of distinction between qualitative and quantitative research in social science: reflection on ontological, epistemological and methodological perspectives. *Ethiop. J. Educ. & Sc*, 6(1):97–108.

Tulyakul, P. & Meepring, S., 2020. Ethical Issues of Informed Consent: Students as Participants in Faculty of Research. *Global Journal of Health Science,* 12(3), pp. 86-90.

Uzuegbunam, C. E., 2013. Sensationalism in the media: the right to sell or the right to tell?. Journal of Communication and Media Research, 5(1), pp. 69-78.

Van de Grift, T.C. & Kreukels, B.P.C. 2019. Breast development and satisfaction in women with disorders/differences ofsex development. *Human Reproduction ,* 34(12), pp. 1-8.

Van Jaarsveld, N. 2018. A sociological analysis of the lived realities and narratives of women diagnosed and living with Turner syndrome and how they conceptualize their gendered identities. Johannesburg: University of the Witwatersrand. (Dissertation – MA).

Vannatta, K., Gartstein, M.A., Zeller, M.H. & Noll, R.B. 2009. Peer acceptance and social behavior during childhood and adolescence: How important are appearance, athleticism, and academic competence? *International Journal of Behavioral Development*, 33(4):303–311.

Ward, L.M., Merriwether, A. & Caruthers, A. 2006. Breasts are for men: media, masculinity ideologies, and men's beliefs about women's bodies. *Sex Roles ,* 55: 703-714.

Webb, C., Jacox, N. & Temple-Oberle, C. 2019. The making of breasts: Navigating the Symbol of Breasts in Woman facing Cancer. *Plastic Surgery ,* 27(1):49–53.

West, C. & Zimmerman, D.H. 1987. Doing gender. *Gender & Society*, 1(2):125–151.

Westmarland, N. 2001. The quantitative/qualitative debate and feminist research: a subjective view of objectivity. *Forum Qualitative Social Rese1arch,* 2(1):1-12.

Wiles, R., Crow, G., Heath, S. & Charles, V., 2006. Anonymity and Confidentiality. *National Centre of Research Methods .*

Williams, M. & Moser, T. 2019. The art of coding and thematic exploration in qualitative research. *International Management Review,* 15(1): 45–55.

Wood, W. & Eagly, A.H. 2015. Two traditions of research on gender identity. *Sex Roles*, 73(11):461–473.

XOTurner (2021)Twitter7 November . Available at: https//twitter.com/xo83766320/status/1457334474367197187?s=24

Yellappa, S.C. & Venkatesh, N. 2015. Psychological aspects of androgen insensitivity syndrome- a case report. *Journal of Psychology and Psychotherapy*, 5(3):1–3.

YG. 2016. *What is gene expression?* https://www.yourgenome.org/facts/what-is-gene-expression Date of access: 28 Apr. 2020 .

Zeeman, L. & Aranda, K. 2020. A systematic review of the health and healthcare inequalities for people with intersex variance. *Int J Environ Res Public Health,* 17(18): 6533.

Zieselman, K. 2017. *In the intersex community, we're desperate for quality care. Doctors aren't listening.* https://www.statnews.com/2017/10/26/intersex-medical-care/ Date of access: 1 Dec. 2021.

Zieselman, K. 2020. *XOXY, A memoir: intersex woman, mother, activist*. 1st ed. Jessica Kingsley Publishers.

Zola, I.K. 1972. Medicine as an institution of social control. *The Sociological Review,* 20(4):487–504.

Zwane, D. 2021. "Our beauty is in our breasts": A culture-centered approach to understanding cancer perceptions in KwaZulu-Natal, South Africa. *Qualitative Health Research,* 31(1):148–159

APPENDIX A: INFORMED CONSENT

INFORMED CONSENT STATEMENT

North West University, Potchefstroom Campus

Masters Dissertation: A sociological investigation of the lived experiences of people with Androgen Insensitivity Syndrome (AIS) in South Africa

Field of Study: Sociology

Researcher: Lize-Marié Loubser

Cell: 076 661 6955

lmloubser@gmail.com

Dear participants

You are being invited to take part in a research project that forms part of my Master's Degree in Sociology. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher (me) any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. Before the publication of the study's results (or the point that publication is in the process), you may also withdraw the data you generate.

This study has been approved by the **Human and Social Sciences Research Ethics Committee (HSSREC) of the Faculty of Humanities of the North-West University (NWU)** and will be conducted according to the ethical guidelines and principles of the international Singapore Statement on Research Integrity (2010) and the ethical guidelines

of the National Health Research Ethics Council. It might be necessary for the research ethics committee members or relevant authorities to inspect the research records to make sure that we (the researchers) are researching ethically.

What is this research study all about?

- ☐ This study will be conducted in South Africa and will involve an investigation of the lived experiences of people with Androgen Insensitivity Syndrome (AIS). The researchers have been trained to use suitable and appropriate research methods

- ☐ As close as possible to 10 participants will be included in this study.

- ☐ The objectives of this research are: To investigate the lived experiences of people with AIS in South Africa.

- To explore how the medicalisation of AIS have affected the lives of people with AIS in South Africa

    - o To explore how people with AIS experience their interactions with health care professionals

        - ☐ To explore the possible ways in which interactions with medical professionals have helped or hindered living with AIS

        - ☐ To explore the recommendations that people with AIS would make concerning the practices of health-care professionals concerning their healthcare

    - o To explore how the diagnosis and treatment of AIS have shaped the ideas and experiences ofgender of persons with AIS

    - o To explore how the diagnosis and treatment of AIS have influenced family and other relationships

    - o To draw conclusions and recommendations from the study

Why have you been invited to participate?

- ☐ You have been invited to participate because you are someone who has an AIS variation

- ☐ You will be excluded if: You have not been medically diagnosed with an AIS condition and if you are younger thaneighteen

- ☐ If you suffer from severe depression or have symptoms of severe depression, you must discuss your potential participation in this study with your psychologist before finalising your decision to participate.

What will your responsibilities be?

- ☐ You will be expected to participate in approximately three separate face-to-face in-depth interviews. The questions will be sent to you in advance. With the COVID-19 restrictions still in place, it is important to adhere to the rules of each Lockdown level. For levels 1-2, interviews will be held either face-to-face or via online platforms like Skype, Zoom, WhatsApp, or telephonically if you find it more comfortable. For lockdown levels 3-5, it will be necessary to conduct these in-depth interviews via online platforms like Skype, Zoom, Whatsapp, or telephonically.

- ☐ In the case of a face-to-face interview, you may choose the venue for the interview. If you prefer it to be at your residence, it is required that the interview takes place outside. Alternatively, the setting of the interview can be in a secure public area of your choice. Please note that all Covid-19 regulations will be adhered to. These include the wearing of masks by both the researcher and you as the participant, observing social distancing (2 meters), and sanitation (with an alcohol content of at least 80%). I will provide the sanitizer.

- ☐ If you do not wish to conduct interviews in person or via an online platform, you may write down your life story and we can discuss the details via email or telephonically.

Will you benefit from taking part in this research?

- ☐ The direct benefits for you as a participant will likely be to break the silence and tell your life story as someone who has or continues to live with AIS.

- ☐ The indirect benefit will probably be that more people in South Africa and across the world will be able to form an understanding of the real and personal experiences of people who have AIS. This will help to combat the silence and stigmatization that exists around AIS. This study can also help to enable more effective communication between the communities of people who have variations of sex development and medical practitioners involved in their treatment and care.

Are there risks involved in your taking part in this research and how will these be managed?

- ☐ The risks in this study, and how these will be managed, are summarised in the table below:

Probable/possible risks/discomforts	Strategies to minimize risk/discomfort
You will be expected to participate in one tothreeface-to-face in-depth interviews (depending on the time you are able to set aside).	You can specify the location and setting of the interviews and the researcher will meet you at these settings. Times and dates will also be scheduled to suit you.
As the interviews will be in-depth interviews between 30 minutes and one hour per interview, you might experience fatigue during the interview period.	The researcher will provide you with refreshments and short breaks in-between if you require it. She will askevery 20 minutes whether you comfortable to continue with the interview.
Because the researcher will ask you questions about what has been hard for you in your life, you will need to think about difficult times in your life. This could make you feel	Arrangements have been made with an HPCSA registered psychologist, Dr. Delan Naidoo. He will be available telephonically or via video call to discuss any distress that you may feel

uncomfortable.	you need professional support with. This will be at no cost to you as the participant. As agreed with Dr. Naidoo, the first consultation will be paid for by the supervisor (Ms. Carolé Cilliers). Dr. Naidoo will ensure that you deal with immediate feelings of distress. If you feel that it is necessary, PsyCaD (at the University of Johannesburg UJ) will be contacted for 4 to 5 additional follow-up sessions. They offer reduced rates. The supervisor, Carole Cilliers will cover any costs of these additional sessions.

☐ However, we do believe that the benefits to you and to science (as noted in the previous section) outweigh the risks we have listed. If you disagree, then please feel free not to participate in this study. We will respect your decision.

☐ Should we learn, in the course of the research, that someone is harming you, or that you are intending to harm someone, then we must tell someone who can help you/warn the person you are intending to harm.

Who will have access to the data?

☐ Anonymity (that is, in no way will your results be linked to your identity) will be implemented in this study as the researcher will make use of a pseudo name (a name chosen by you at the beginning of the interview that is not your real name) and used to protect the participant's identity when reporting the findings of the study. Thus, only the researcher and the participant (you) will know your identity.

- ☐ Confidentiality (that is, I/we assure you that we will protect the information we have about you) will be ensured as the researcher will not discuss the content of the interviews with anyone outside of the interviews. No information will be linked to you as a participant. All data that is gathered in the interviews will be kept in a locked cabinet to which only the researcher will have access. All electronic data will be password protected.

- ☐ The interviews will be audio-recorded only if you consent to this. The recordings enable me to focus on the interview (and not on writing information down) and allow me to listen to the interview again, which helps to get a better understanding of your experiences. Audio-recorded data will be transcribed by the primary investigator (me) after the interview. As soon as data has been transcribed, it will be deleted from the recorder. The transcriptions will be stored on a password-protected computer. After the primary investigator (me) has transcribed one or two of the interviews, it will be sent to the supervisor for additional guidance and assistance. The supervisor will be the only other person who has the password of the documents.

What will happen to the data?

The data from this study will be reported in the following ways: In the findings of this study.

In this reporting, you will not be personally identified. This means that the reporting will not include your name or details that will enable others to know that you participated (e.g., your address or the name of your school).

This is a once-off study, however, the data of this study might be used again to publish the findings in an academic journal.

Will you be paid/compensated to take part in this study and are there any costs involved?

No, you will not be paid/compensated to take part in the study, but refreshments will be provided to you during the contact interview by the researcher. In this study, you as the research participant will decide upon and select the location of the contact interview. The interviewer will thus meet you at this destination. There will thus be no costs involved for you. In the event of online interviews via platforms such as Skype, Zoom, WhatsApp, or

telephonically, the researcher will compensate you for data costs incurred to conduct the interviews.

How will you know about the findings?

- ☐ The general findings of the research will be shared with you by the researcher via email before the submission of the study.

Is there anything else that you should know or do?

- ☐ You can contact the researcher, Lize-Marié Loubser at lmloubser@gmail.com or 076 661 6955 if you have any further queries or encounter any problems
- ☐ You can also contact the research supervisor, Mrs. Carolé Cilliers at 22573143@nwu.ac.za or 072 606 2960.
- ☐ You can contact the chair of the Human and Social Sciences Research Ethics Committee (Prof C van Eeden) at 016 910 3441 or chrizanne.vaneeden@nwu.ac.za if you have any concerns or complaints that have not been adequately addressed by the researcher.
- ☐ You will receive a copy of this information and a consent form for your records.

Declaration by participant

By signing below, I …… agree to take part in a research study entitled:

I declare that:

- ☐ I have read and understood this information and consent form and it is written in a language with which I am fluent and comfortable.
- ☐ I have had a chance to ask questions to both the person obtaining consent, as well as the researcher (if this is a different person), and all my questions have been adequately answered.

☐ I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.

☐ I understand that what I contribute (what I report/say/write/draw/produce visually) could be reproduced publically and/or quoted, but without reference to my identity.

☐ I may choose to leave the study at any time and will not be penalized or prejudiced in any way.

☐ I may be asked to leave the study before it has finished if the researcher feels it is in my best interests.

☐ I consent to the interviews being audio recorded.

Signed at (*place*) .....…..…….. on (*date*) ……..…….. 20....

Signature of participant Signature of witness

☐ You may contact me again ☐ **Yes**☐**No**

☐ I would like a summary of the findings of this research☐ **Yes**☐**No**

The best way to reach me is:

Name & Surname:_____

Postal Address:_____

Email:_____

Phone Number: _____

Cell Phone Number:_____

In case the above details change, please contact the following person who knows me well and who does not live with me and who will help you to contact me:

Name & Surname:

_____

___

Phone/ Cell Phone Number /Email:

_____

___

Declaration by the researcher who is responsible for obtaining consent and conducting the interview

I *(name)* …….…… declare that:

- ☐ I explained the information in this document to ……..
- ☐ I encouraged them to ask questions and took adequate time to answer them.
- ☐ I am satisfied that they adequately understands all aspects of the research, as discussed above
- ☐ I did/did not use an interpreter.

Signed at (*place*) .....…….…….. on (*date*) ……..…….. 20....

Signature of researcherSignature of witness

APPENDIX B: INTERVIEW GUIDE

Interview guide

Note: The format of the interviews is unstructured. The reasons for this are to allow for a conversation-style interview in which participants can discuss their life history freely, in the order that they recall it, without their flow of thought being interrupted by structured questions. The unstructured format is also to give participants more control over the interview so that they only discuss the aspects of their life history that they wish to discuss.

Below are some themes and questions that will serve to prepare and aid the researcher. However, depending on each interview, the questions may not be needed or only some of them used as prompts during different points in the interview.

Diagnosis:

When did you find out about your diagnosis?

What led to you receiving a diagnosis?

What was your emotional response to receiving a diagnosis?

What helped you come to terms with your diagnosis?

Did you receive psychological support after receiving your diagnosis?

How did your parents react to your diagnosis?

Childhood:

Can you tell me more about where you grew up?

Did AIS impact your childhood at all?

Do you remember any visits to the doctor as a child? What are the memories you have of these visits?

Were your parents informed by doctors about the AIS when you were a minor?

How did they discuss the topic of AIS with you?

What message did your parents communicate to you?

Was there secrecy surrounding your diagnosis?

Did you or your parents receive psychological support when receiving the diagnosis?

Has AIS impacted your relationships with your parents or other close family members?

Adolescence:

Did AIS impact your adolescence at all?

How did you handle not going through the same milestones as your peers? E.g. not menstruating, delay in growing breasts?

Do you remember any visits to the doctor as a child? What are the memories you have of these visits? Were you able to ask questions during these visits? Did you fully understand what was being explained to you?

Relationships:

Has AIS been a factor in your romantic relationships? In what way?

How have you dealt with the issue of infertility?

Has AIS impacted your relationships with your parents or other close family members? In what way?

Has AIS impacted your relationships with your friends? In what way?

As someone living with AIS what advice do you have for family, friends, or partners of people with AIS?

Support and mental health:

What are the hardest parts of having AIS?

Are there any good parts to having AIS?

Has AIS impacted your mental health in any way?

From which sources have you received support for your AIS?

Have you connected with other people with AIS? What has this meant in your life?

Do you think secrecy and silence still surround a diagnosis of AIS? What do you think has changed?

Do you tell people about your AIS or do you keep it to yourself? What are your reasons for these decisions?

From your experience, what advice would you give to someone who was recently diagnosed?

Relationship with the medical establishment

What do you remember about your interactions with health professionals?

Is there anything you would want to tell the doctors who have treated you for AIS?

Would you say that you have seen changes in the medical care of AIS from the time you were diagnosed until now? What are they?

What changes in medical care would you like to see?

What do you think are the main issues the AIS community would like to see addressed?