Born This Way: The Healthcare, Sexuality, and Social Experiences of People with Intersex Variations

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List of Publications

The following peer-reviewed research publications include elements which originate from work completed towards this thesis:

Papers and a report on the data discussed in this thesis were submitted to a 2018 Australian Human Rights Commission Inquiry into medical interventions for people with variations in their sex characteristics.

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Henningham, M. & Jones, T. (2017). Cut it Out: Rethinking Surgical Intervention on Intersex Infants. In Tiffany Jones (Ed)(2017). *Bent Street*. Clouds of Magellan: Melbourne. pp.55-67. ISBN 9781925283167 (paperback); 9781925283174 (ebook) https://bentstreetjournal.wordpress.com/

Conference Papers

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Authorship Attribution Statement

In addition to the statements above, in cases where I am not the corresponding author of a published item, permission to include the published material has been granted by the corresponding author.

Mandy Henningham 28/08/18

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Supervisor Name, Signature, Date

Tiffany Jones, 29/08/18

Statement of Originality

Except where reference is made in the text of the thesis, this is to certify that to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

Mandy Henningham

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Abstract

Surgical intervention on infants with intersex variations is done largely for social reasons to create a ‘typical’ boy or girl at an age where the individual cannot yet express their consent. The literature review identified that individuals who had non-consensual surgical interventions as infants were more likely to experience mental distress, trauma, and poor sexual satisfaction and experiences in adulthood. Sex assignments may create social issues subjecting them to potential discrimination; creating difficulties accessing some health services, discrimination at school, from peers, or within their own families. This thesis reports on a study via a critical lens used to challenge the essentialist paradigm used by health professionals and institutions that operate under the two-sex binary.

The aim of this study was to explore the long-term psychosocial repercussions of interventions on intersex infants and other lived experiences from adult, retrospective voices; reflecting on experiences in healthcare, in school, on forming friendships, family relationships, reflecting on their reared gender experience, navigating dating and intimacy, and sexual satisfaction, experiences, and desires.

This study obtained data via an online questionnaire (n=86) and included both those who did and did not experience interventions on an international scale. The dataset was investigated via a qualitative process using a modified ground theory approach, in addition to a quantitative approach via SPSS.

Most of the participants were from Western countries, likely as this was distributed through support organisations as well as a snowball effect, as well as only being available in English.

Almost all the participants found surgical intervention to be inappropriate. The appropriateness of their reared gender was another strong predictor of negative life experiences. Participants reported a greater need for education for healthcare providers, including better transitions from adolescent to adult care. Some participants often preferred to be alone or have few close friends at school, and some harboured negative feelings towards their parents regarding their interventions or imposed genders in childhood.

Results showed that the imposition of sex and gender, and unwanted interventions had negative impacts on intersex people. By gaining a greater understanding of these impacts, health professionals, schools and families may be able to improve their practices, policies and attitudes to become more supportive of bodily diversity.

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Symbols and Abbreviations

47 XXY/48 XXXY/49 XXXXY

Main variation of Klinefelter Syndrome followed by more rare chromosomal variations

5-ARD

5 Alpha (5α) Reductase Deficiency

ADA

Americans with Disability Act

AIDS

Acquired Immune Deficiency Syndrome

AIS

Androgen Insensitivity Syndrome

AISSGA

Androgen Insensitivity Syndrome Support Group Australia

APEG

Australasian Paediatric Endocrine Group

AUS

Australia

BDSM

Bondage/Discipline/Sadomasochism

CAH

Congenital Adrenal Hyperplasia

CAIS

Complete Androgen Insensitivity Syndrome

CSA

Child sex abuse

df

Degrees of freedom; the statistical abbreviation for the number of values in the final calculation of a statistic that may be variable

DSD

Disorders of Sex Development/Differences of Sex Development (see context).

ESPE

European Society for Paediatric Endocrinology

GD

Gender Dysphoria

GID

Gender Identity Disorder

GII

Gender Identity Interview

GP

General Practitioner

HRQOL

Health Related Quality of Life

HRT

Hormone Replacement Therapy

IRB

Institutional Review Board

IVF

in vitro fertilisation

LGBT

Lesbian, gay, bisexual, transgender

LGBTI

Lesbian, gay, bisexual, transgender, and intersex (not all literature includes ‘intersex’)

LGBTIQ

Lesbian, gay, bisexual, transgender, intersex and queer/questioning people

MRKH

Mayer-Rokitansky-Küster-Hauser syndrome

n

Statistical abbreviation for the size in the discussed sample

NZ

New Zealand

PAIS

Partial Androgen Insensitivity Syndrome

PCOS

Poly-cystic Ovary Syndrome

PID

Participant identification number

PIV

Progestin Induced Viralisation (see context for which PIV definition is being used)

PIV

Penis in vagina sex (see context for which PIV definition is being used)

PTSD

Post-traumatic Stress Disorder

SD

Sexual deviant

SM

Sadomasochism

SSAGQ

Same sex attracted or gender questioning

UK

United Kingdom

USA

United States of America

WHO

World Health Organisation

$\chi 2$

The statistical test based on the Chi-square distribution

XX

‘Typical female’ karyotype on the XY sex-determination system

XY

‘Typical male’ karyotype XY sex-determination system

Chapter One: Introduction to the Thesis

It was during my sexual health degree that I first learned about what the intersex community had been going through for decades; subject to barbaric practices that were still occurring to this day. This international injustice fuelled me to become and advocate and years later, to develop my own research proposal to invite intersex people to share their experiences with me and trust me with their stories. This thesis aims to share insights from the intersex community by sharing their experiences and hopes for the future via qualitative and quantitative research.

Society is seemingly becoming more progressive in terms of diversity and acceptance, particularly in areas of sexual and gender identities. There have been huge strides in achieving more equal rights for gay, lesbian, bisexual and transgender people; however, very little has changed for the rights of individuals who have diversity in sex development. Western society is still functioning under the two-sex binary model of ‘male’ and ‘female’, with little room for variation in between. It is for that reason, that health professionals and parents have uncertainties when a child is born and fits into ‘neither sex’. These infants have what is known as a variation of sex development and are labelled under the broader term, ‘intersex’ (Diamond, 2010).

An existing treatment for non-consenting intersex infants often results in them being surgically crafted as either male or female for them to be deemed ‘socially acceptable’ or ‘normal’ rather than for legitimate health concerns (Creighton & Liao, 2004; Diamond & May, 2005). Intersex activists have been speaking out against this practice, however, genital reconstruction is still performed on intersex infants without their consent. The following thesis explores the lived experiences of intersex people to share their stories via a mixed method survey to provide a retrospective insight to the psychosocial experiences of being intersex; their experiences in healthcare, school experiences, developing friendships and relationships, family relationships and their gender rearing, and their sexuality, sexual satisfaction and sexual desires.

A comprehensive literature review (chapter 2) was conducted on medical literature, narratives from intersex individuals. The literature review gives context to intersex history, ethical issues, and contemporary global issues and progress towards intersex rights. It begins by defining intersex, including the most prevalent intersex variations, and terminology. It then explores the historical context behind surgical intervention and sex and gender assignments on intersex infants, followed by the issues faced in healthcare, including difficulties with transitional care from adolescent to adulthood, and the education of healthcare professionals. The chapter then moves into exploring some of the ethical dilemmas faced in intersex healthcare, such as the debate surrounding functionality versus social emergencies, a Western female genital mutilation lens, and the difficulties surrounding the lack of consent for infants and children, including problematic genital examinations and prenatal treatments. Once the physical aspects are explored, the chapter goes on to discuss psychosocial implications of interventions such as rates and reasons behind depression and trauma in the intersex population such as incorrect sex and gender assignments, body image concerns after surgical intervention, the causes for secrecy, and existing counselling management frequencies and recommendations. The last psychosocial aspects to be explored are the minimal literature surrounding family relationships and school experiences. The chapter opens up globally, exploring contemporary issues and progressions in intersex rights around the world with deeper insights into Australia and the United States of America (USA). The chapter concludes by discussing other recommendations found in literature as to how to move forward to improve ethical and sufficient healthcare for intersex populations, including the aims and research questions created as a result of the needs analysis formed from this literature review.

Chapter three offers a theoretical framework for exploring and contextualising the results of this study. It begins by exploring the primary lens for this study; a critical and postmodern lens. This continues with an exploration of challenging the essentialist and positivist approaches used internationally in medical discourses, including the concept of bodily autonomy. This chapter goes on to challenge essentialist gender claims and citizenships, followed by an exploration of the frameworks of sexuality. Once this is introduced, queer theory is applied to discuss gender performativity, Foucauldian ideas of power, and the queer dilemma are applied to intersex studies. Psychosexual frames are used to gain further insights into the complexities of sexual fantasy in relation to the self to better understand this connection. Finally, this chapter concludes with explorations of power, including authoritative institutions such as schools, families, and healthcare models, bio-politics, gender structure theory; and structural functionalism to gain further insight to how certain behaviours are elicited by authoritative institutions for social control.

Chapter four explores the methodology and research approach used for the study. It describes the mixed method research strategy; the qualitative and quantitative approaches followed by the development of research design. This development informed the sampling strategy and subsequent implementation of the survey to an international audience. Following this, the chapter discusses the research sample including initial outcomes and reach. Chapter four continues to explore the research procedures that took place, including ethics applications, approvals and amendments and recruitment strategies for participants. Data collection approaches and subsequent analysis strategies are discussed, followed by ethical considerations that must be acknowledged for marginalised populations, including specific considerations for intersex populations. Chapter four closes with justifications surrounding the validity and reliability of the methods and analyses used for this study.

Chapter five introduces the first of three results chapters with a focus on intersex people’s experiences and needs in healthcare management. This chapter opens with an exploration of demographics for participants to give an overview of this sample. Chapter five continues by reporting on participants’ intersex status, including age of diagnoses and whether they received surgical intervention. Following this is a quantitative and qualitative reporting on intersex people’s attitudes and experiences surrounding their physical healthcare, following by an exploration of their use of mental health services and experiences. The chapter concludes with participants’ ideals around healthcare management, access, and draws conclusions on these findings.

Chapter six provides a more thorough analysis on participants lived experience of gender; first discussing impacts of their reared gender from birth and whether they found this gender to be appropriate, and how this impacted other facets of their lives; this includes statements on who made the decisions on their gender and attitudes towards these figures. This chapter continues to explore current gender identities, including any changes in gender identity for applicable participants, and when these participants first identified these feelings.

Following this, the chapter reports on findings regarding sexual experiences, sexual satisfaction and sexual desire to examine the connections between these themes to determine if sexual experiences differ to desires to gain further understanding of the relationship between the body and mind in this population.

Chapter seven is the last of the results chapters, and explores other relationships and experiences including school experiences, friendships, and family relationships. The chapter opens with exploring experiences as an intersex student, followed by reports on friendships during primary/elementary school. Similar questions are then applied to high school years to examine changes over time, and after the commencement of puberty. Additional themes are explored for adolescence including dating comfortability and sexual activity. Chapter seven continues to inquire about friendships and relationships in adulthood; allowing participants to reflect on these relationships and experiences across the three life stages of childhood, adolescence and adulthood to gain a comprehensive insight to their lived experiences as an intersex individual. Additionally, this chapter explores family dynamics, including changes over time and attitudes towards parents and siblings.

Chapter eight considers this data in light of the theoretical framework and existing research to discuss the new learning offered by the study about early *intervention* and support, the *imposition* of gender and sexuality on people with intersex variations, and *isolation* in social settings. Building on this discussion, this chapter then draws conclusions in response to the study's aim of identifying the needs of people with intersex variations in healthcare; sex, sexuality and gender; and in social settings. It then presents the limitations of this study, followed by implications for a range of stakeholders. This chapter will conclude with future directions moving forward in intersex research.

Chapter Two: Born this way: Ethical issues in the healthcare management of infants with intersex variations and their psychosocial implications

2.0 Introduction

There is much to consider when investigating the lived experience of intersex individuals. This includes psychosocial experiences such as family relationships, school experiences, navigating relationships, friendships, and sexual experiences. To gain greater insight into this population, one first needs to gain an understanding of the historical context and existing ethical dilemmas faced in understanding contemporary intersex issues.

This chapter will explore the literature surrounding the current global ethical issues related to healthcare practices that are faced by people with intersex variations and the intersex community. This review will first consider the more common variations of intersex conditions including congenital adrenal hyperplasia (CAH), androgen insensitivity syndrome (AIS) and 5 alpha reductase deficiency as well as the chromosome related intersex variations Klinefelter syndrome and Turner syndrome. This chapter then covers a brief history of intersex management including some dilemmas that arise regarding the treatment and management of intersex individuals; including lack of adolescent to adult healthcare and the education of healthcare professionals. Delving into healthcare further, current ethical dilemmas in healthcare will be explored such as why surgery may occur, issues surrounding consent, problematic examinations, and ethical considerations for prenatal treatments. This chapter will move onto exploring some of the psychosocial issues related to interventions, such as resulting depression and trauma, incorrect sex and gender assignments, insufficient counselling management and sexual satisfaction following surgery. From here, the chapter will investigate studies surrounding family relationships and school experiences to obtain a deeper insight into social experiences. Finally, the chapter will conclude by investigating contemporary issues faced by individuals with intersex variations globally, including recent developments in advocacy. As a final point, the overall consensus amongst contemporary literature on what needs to be accomplished in order to achieve complete, ethical and supportive management of individuals with intersex variations will be discussed; including the aims and research questions for the study in this thesis.

2.1 What is Intersex?

'Intersex' is an umbrella term used to describe an individual who is born with 'atypical' sex characteristics which may be anatomical, hormonal, and chromosomal; this extends to secondary sex characteristics such as body hair (Jones, 2017). Developmental sex differences sometimes result in genitalia that do not conform to the two-sex binary of wholly male or wholly female. On occasion, the genitalia of the individual congenitally develops into 'atypical genitalia' or they may exhibit typical genitalia that looks 'typically male or female', contradicting the chromosomal sex (Diamond, 2002). Some clinicians do not consider certain variations of sex development as intersex if they do not have 'atypical' genitalia, such as chromosomal intersex variations like Klinefelter syndrome and Turner syndrome (Topp, 2013).

It is important to differentiate intersex variations from sexuality and gender. Intersex is not a form of sexual orientation, nor is it a gender identity (Feder, 2009). Intersex individuals and communities may identify with lesbian, gay, bisexual and transgender (LGBT, or LGBTI with Intersex) movements and advocacy groups as they are subject to the same homophobic responses or discrimination from others, despite intersex variations being more common than one might think (Feder, 2009).

2.1.1 Prevalence

The prevalence of intersex variations is difficult to verify given the previous medical ambiguity and that numerous health professionals have different viewpoints on what conditions classify as intersex, in addition to previous medical record ambiguity (Jorge, Echeverri, Medina, & Acevedo, 2008). Some authors claim the prevalence of intersex variations is as common as 1.7% (Blackless et al., 2000), whereas other studies state the frequency to be one in 4,500 (Hughes, Houk, Ahmed, & Lee, 2006) to one in 5,000 (Warne & Raza, 2008), 0.018% (Sax, 2002). Larger percentages, such as those described in Blackless et al. (2000), included such as Klinefelter syndrome and Turner syndrome that have various chromosomal intersex variations and may present with typical genitalia (Diamond, 2004). Further, some researchers include polycystic ovary syndrome (PCOS) due to its prevalence of having Hyperandrogenemia as a symptom (Barak, Boniel-Nissim, & Suler, 2008; Huang, Brennan, & Azziz, 2010; Jones et al., 2016). The smaller prevalence figures indicate a more specific range of intersex individuals that are (or have the capacity to be) exclusively born with ‘atypical genitalia’ (Diamond, 2004). This includes intersex variations such as complete Androgen Insensitivity Syndrome (cAIS) and Congenital Adrenal Hyperplasia (CAH) (Hughes et al., 2006; Jorge et al., 2008; Zainuddin, Grover, Shamsuddin, & Mahdy, 2013).

Whilst there are no national registries in Australia, there are some statistics that may offer insight into diagnoses at birth. The *New South Wales* (*NSW) Mothers and Babies* report found the following, ‘49,442 (51.3%) babies were male, 46,934 (48.7%) were female, and 12 were of indeterminate sex. This compares with babies born in 2011, when 50,006 (51.4%) babies were male, 47,200 (48.5%) were female, and 12 were of indeterminate sex’ (Centre for Epidemiology and Evidence, 2016, p.19). This means that in 2015, 0.012% of babies born were intersex in NSW. However, it is important to note that this percentage of frequency does not account for less initially obvious intersex variations as some are not diagnosed until puberty or later in life.

2.1.2 Common intersex variations

Congenital Adrenal Hyperplasia

Congenital Adrenal Hyperplasia (CAH) is the most common intersex variation that may result in ‘atypical genitalia’ (Hughes et al., 2006; Jorge et al., 2008; Zainuddin, Grover, Shamsuddin, & Mahdy, 2013). CAH deficiency of enzymes involved in the synthesis of aldosterone, cortisol or a combination (steroidogenesis; a biological process that occurs when steroids are transformed into other forms of steroids via cholesterol). This results in a complete or partial deficiency of enzymes (commonly 21-hydroxylase) that create both cortisol and aldosterone with 90% of cases (Diamond, 2010; Jorge et al., 2008; Nimkarn & New, 2010; White & Speiser, 2000).

In terms of external characteristics, CAH may present with atypical genitalia in the form of a slightly enlarged clitoris varying to a micropenis, partial to complete fusion of the labia or empty scrotums and an atypical urethra (Jorge et al., 2008). Individuals with CAH are some of the few intersex people who still maintain their fertility (Diamond, 1994).

There are a number of ways in which CAH may be diagnosed. Diagnosis may be conducted via MRI scans or ultrasounds to identify reproductive structures, karyotype testing, investigating levels of 17-OH progesterone levels in plasma as well as the identification of atypical genitalia that presents in the more severe cases (Jorge et al., 2008; Nimkarn & New, 2010).

Individuals presenting with XX karyotype are often assigned as females accordingly, despite any male aesthetics or virilisation of their genitals which may occur as a result of the androgens (Jorge et al., 2008). However, this gender assignment is not always accurate and some XX karyotype females prefer to live as men (Jorge et al., 2008; White & Speiser, 2000).

Androgen Insensitivity Syndrome

Androgen insensitivity syndrome (AIS) is the other most common intersex condition presenting with ‘atypical genitalia’, occurring in approximately 2-3 out of every 1000 people (Diamond & Watson, 2004). AIS is split into two basic types; complete androgen insensitivity syndrome (cAIS) and partial androgen insensitivity syndrome (pAIS). AIS is a genetic condition in which a receptor absence of cells causes either a partial or complete inability to respond to androgens produced in the testes (Diamond, 2010; Garg & Gupta, 2012). Individuals born with AIS have 46XY chromosomes and testes that may or may not be descended. Some individuals with AIS may have no uterus or ovaries and as such, will not have menses (Garg & Gupta, 2012). Additionally, the vagina may be blind and shallow with a more pouch like resemblance (Garg & Gupta, 2012; Sharma, Balwan, Kumar, & Gupta, 2012).

Individuals with cAIS result in ‘typical external female genitalia’ as the body has a zero response to androgens (Froukje, Slijper, Stenvert, & Drop, 1998). Identification is therefore unlikely at birth and these individuals are usually reared as girls (Diamond & Watson, 2004; Froukje et al., 1998).

Where partial androgen insensitivity syndrome (pAIS) is present, there are variable responses to androgen hormones, resulting in external genitalia in varying degrees from female phenotypic characteristics to ‘atypical genitalia’, to male phenotypic characteristics. Fertility is one of the issues concerned with AIS. Many surgical interventions may interfere with fertility instead of preserving it (Schober et al., 2012) and may also result in the individual needing lifelong hormonal treatment (Crouch, Minto, Laio, Woodhouse, & Creighton, 2004). Although an intersex woman with pAIS may have testes, the fact that she does not contain ovaries may lead some health professionals to assume they are rendered infertile. The absence of the uterus and ovaries for XY cAIS individuals results in the individual being unable to carry children. However, the internal testes of pAIS individuals may produce healthy sperm which, with medical assistance, could allow for reproduction to occur via current or future medical advances (Giwercman et al., 2000; Ieuan A Hughes et al., 2012; Tamar-Mattis, 2012b). Despite this, testes are often removed, sometimes due to concerns of a perceived malignancy risk (Hughes et al., 2012).

Gonadal malignancy risk in individuals with AIS is a highly debated topic in the literature. Some studies state that gonadal malignancy risk is as low as 0.8% to as high as 22% in individuals with cAIS, therefore maintaining no clear estimations on risk (Deans, Creighton, Liao, & Conway, 2012). Some have stated that the testes in individuals with AIS have a low risk of malignancy and it would be more likely to appear at a later age, however, there is no consensus on an optimal age for gonadectomies in individuals with AIS (Kravarusic et al., 2011; Lin, Shamszadeh, Pisit, 2012). Frader (2015) provided their own narrative, reflecting on their (and others) suggestions for removing gonadal tissue for perceived or potentially imagined cancer risk and ‘corrective’ methods, particularly as these gonads can allow for a future ‘natural’ form of hormone production for patients. Further, testicular germ cell cancers peak during late adolescence thus, if any biopsies must occur, this should be done during this time rather than infancy (Cools et al., 2018).

Diagnosis of AIS at birth stems from the recognition of ‘atypical genitalia’ (Garg & Gupta, 2012). For individuals with cAIS born with typical female genitalia, diagnosis may be more difficult and may be left undiagnosed until later in life when menses do not appear during puberty (Garg & Gupta, 2012). Given AIS is a genetic condition, a family history of AIS often prompts a diagnostic investigation (Garg & Gupta, 2012).

5 Alpha (5α) Reductase Deficiency

Another intersex classification that may occasionally result in ‘atypical genitalia’ is 5 alpha (5α) reductase deficiency. 5α-Reductase is a steroid enzyme that develops testosterone into 5α-dihydrotestosterone, an androgen hormone vital for the virilisation of external genitalia and development of the prostate in XY males in utero (Hekimsoy, Hatipoglu, Oz, Alarslan, & Ozmen, 2012). Despite the individuals carrying an XY karyotype, this inability to convert the testosterone triggers the development of external typical female genitalia, resulting in the individuals often being reared as girls (Hekimsoy et al., 2012). For this reason, the deficiency may not get diagnosed until puberty, when virilisation of secondary sex characteristics begins and menses does not occur. However, it may occasionally result in ‘atypical genitalia’ that bares a similar resemblance to that exhibited in individuals with pAIS and is commonly misdiagnosed as such (Maimoun et al., 2010). Physical characteristics may involve hypospadias, micropenis, testes residing in inguinal canals, blind vagina pouch and the absence of a uterus, ovaries or prostate, often discovered via ultrasounds and MRI’s (Hekimsoy et al., 2012; Imperato-McGinley, 1992).

There are a number of ways to diagnose 5α-Reductase deficiency. Identification may be recognised by using ultrasounds, sonagraphs and MRI’s to confirm the absence of the prostate, ovaries and uterus (Hekimsoy et al., 2012; Imperato-McGinley, 1992). Additionally, a molecular analysis of the SRD5A2 gene or urinary steroid profiling may be used for further confirmation of the deficiency (Chan et al., 2013).

Klinefelter syndrome

Not all intersex classifications result in ‘atypical genitalia’, such as chromosomal intersex variations like Klinefelter syndrome. This is the most common sex chromosomal variance, occurring in approximately 0.2% of the population (Diamond & Watson, 2004). Klinefelter syndrome is a variation of karyotype, resulting in chromosomal combinations such as 47XXY, XXYY and XXXY, although some cases have been reported as XXX, despite the lack of the Y chromosome (Diamond & Watson, 2004). It is often asymptomatic at first glance meaning it often remains undiagnosed until later in life and may also occur concurrently with AIS (Diamond & Watson, 2004). Klinefelter syndrome is said to be a variation that only effects men; a small clinical Australian study suggested that not all people with XXY should be diagnosed with Klinefelter syndrome as some identify as women, therefore, the 'feminising' symptoms may not be 'abnormal' to those patients (Herlihy & Gillam, 2011). However, this notion may reinforce gendered expectations around bodies.

Individuals with XXY chromosomes often exhibit reduced muscle mass and bone density when compared to males with XY chromosomes and may present with hypogonadism and increased gynecomastia (Bojesen et al., 2011; Selice et al., 2010). Additionally, Klinefelter syndrome is the most common cause of fertility issues in the general population (Lanfranco et al., 2004). Men who have Klinefelter syndrome also are more prone to historically ‘female’ illnesses such as osteoporosis, breast cancer and autoimmune diseases due to the lower rates of testosterone (Dillon et al., 2011; Ferlin, Schipilliti, Di Mambro, Vinanzi, & Foresta, 2010). Cognitively, individuals with Klinefelter syndrome also exhibit some learning and language difficulties depending on severity of the syndrome (Anders Bojesen, Stochholm, Juul, & Gravholt, 2011; Bruining, Swaab, Kas, & van Engeland, 2009).

Treatments such as testosterone replacement are often prescribed for androgen deficiencies, particularly if the syndrome is caught early in life (Lanfranco et al., 2004). There are some treatments available to aid with fertility such as testicular sperm extraction and intracytoplasmic sperm injection which have been shown to be beneficial (Denschlag, Tempfer, Kunze, Wolff, & Keck, 2004; Lanfranco et al., 2004).

Turner syndrome/Gonadal dysgenesis

Another karyotype intersex variant is Turner syndrome also known as ‘gonadal dysgenesis’. Turner syndrome has 45, X chromosomes and occurs in 1 in 2000 births (Davenport, Ross, & Backeljauw, 2013). The absence of the X chromosome is either absolute, or only partially missing, appearing in some cells. This partial absence is called mosaicism (or in this case, Turner mosaicism) a pattern which is also seen in Klinefelter syndrome. Typically, women with Turner syndrome are infertile as a result of non-working ovaries and the subsequent lack of menses. This gonadal dysgenesis creates an oestrogen deficiency which may result in increased likelihood of osteoporosis (Kodama, Komura, Kodama, Nishio, & Kimura, 2012). Turner syndrome may exhibit some physical characteristics such as webbed necks, broad chests and short stature. Additionally, individuals with Turner syndrome may also experience concurrent health problems such as thyroid complications, hearing loss, diabetes, strabismus, heart disease and autoimmune diseases (Bakalov et al., 2012; Davenport et al., 2013; Davenport, 2010).

2.1.3 Issues with terminology

There are several ethical dilemmas when discussing the political correctness of intersex terminology. Having ‘atypical genitalia’ is a congenital developmental differentiation, just like any other part of the body that may grow differently. Many organisations have spoken out against the term ‘Disorders of Sex Development’ as an umbrella term stating it is offensive and demeaning (Diamond, 2009). Lin-Su, Lekarev, Poppas, & Vogiatzi (2015) also found that people with intersex variations are dissatisfied with the term ‘DSD’ in their study of terminology preferences amongst individuals with CAH and their parents.

Some international organisations have kept the clinical acronym of ‘DSD’ but applied it to ‘*Differences* of Sex Development’, removing some of the stigma associated with term ‘disorder’, that may also cause unnecessary panic in parents and individuals (Diamond, 2009). Diamond & Beh (2008) advocate moving away from the term ‘*Disorders* of Sex Development’, supporting the change of ‘DSD’ to mean ‘*Differences* of Sex Development’ and additionally, have proposed their own term, ‘Variations of Sex Development’ (Diamond & Beh, 2008; Diamond, 2009; Feder, 2009).

In contrast to the aforementioned negative association with the term ‘Disorders of Sex Development’, Vilain (2007) stated that the medicalisation of the term Disorders of Sex Development may encourage less criticism from the public, as they are more empathetic towards health issues than sexual identity. Feder (2009) similarly debates that some medicalisation may be positive, allowing for stricter adherence to a more ethical approach to management. This is supported by Topp (2013) suggesting that the benefits of medicalising it outweigh the vagueness of the term ‘intersex’, but maintained advocacy for the new DSD; Differences of Sex Development. Diamond (2009) rejects the idea that medicalised terms like ‘disorder’ are favourable in scenarios like insurance claims, stating that other conditions requiring medical attention are covered without using the word ‘disorder’.

Davis (2011) had a more sociology-based approach in gender scholarship; they described how health professionals use DSD language to justify the medicalisation of intersex people. This use of language allows health professionals to reassert their authoritative position over intersexuality despite the efforts of intersex activists who reframed intersexuality as a social rather than biological concern.

The term ‘intersex’ may mean different things to different people. Some individuals find that the term ‘intersex’ may be identity based, rather than an objective term. For example, one person might say ‘I am intersex’ whereas another may not see this as an identity and prefer to refer to themselves as someone with an intersex condition or variation (Topp, 2013). Whilst many individuals with intersex variations identify as men and women, some intersex individuals may identify with intersex as a gender, rendering identity subjective (Australasian Paediatric Endocrine Group, 2013). If ‘intersex’ is described as an identity, this then removes emphasis on medicalization, which may be problematic for people who require medical attention or medical intervention (Topp, 2013). Reis (2007) stated that some parents also find the term ‘intersex’ distressing, as it may imply a third gender or that their child is neither male or female and therefore not ‘normal’.

Further, how language is used may impact parents’ decisions for surgical intervention. A Swiss study by Streuli, Vayena, Cavicchia-Balmer, Huber (2013) conducted a study on medical students with hypothetical infants to determine if they would subject them to surgical intervention. The amount of medicalised language (compared to psychology-based language) used impacted whether or not these hypothetical parents consented to surgery for their infants. Those who were exposed to a more pathologised diagnoses were more likely to approve such surgeries. This emphasises the role that authoritative language may have in this decision-making process.

Additionally, a small study (n=36) by Davis (2015a) explored the use of diagnosis-related language amongst the North American intersex community, including parents and health professionals. They found that terminology had different uses in different contexts; where sometimes it was useful in gaining access to (wanted) treatments, other times it felt pathologising. Overall, several of the intersex participants rejected the DSD language (Davis, 2015a). As a result of this, as well as the results the consultation with reference group members, this study uses the term ‘intersex’.

2.2 Historical issues in intersex management

2.2.1 The influential John/Joan case

The history of intersex variations is a controversial one. In the 1950s, research into gender at birth was conducted by Dr. John Money, who had developed studies claiming that nurture ruled over nature in terms of the gender identity of children. Money believed that individuals were gender neutral at birth and could therefore be reared as either gender (Kipnis & Diamond, 1998; Money, Hampson, & Hampson, 1955). This theory was developed further in 1972 by a case study infamously known as the ‘John/Joan case’ involving an infant (‘John/Joan’ who’s actual name was David Reimer) whose circumcision went awry, rendering him without a penis (Diamond, 2004). Money believed that he could not be reared as a male without a penis and recommended that John/Joan undergo female surgical sex reassignment and be reared as a girl. John/Joan also had a twin brother, making it an ideal scenario for Money to conduct his research to prove his theory about intersex individuals accepting their given identity at birth, using John/Joan's brother as the control subject (Kipnis & Diamond, 1998).

Money declared that his research was a success with John/Joan being reared a girl, exhibiting completely different behaviours and interests to his twin brother. Although Money deemed this social experiment a success, he claimed that John/Joan was no longer available for follow up, so a long-term retrospective study could not be conducted. These beliefs lead to the common practice of surgically re-assigning infants with 'atypical genitalia' at birth, with parents being told to rear the child in the gender to which they had been surgically reassigned. Surgeries were usually reassigned to female, as it was considered to be easier to fashion female genitals rather than create a phallus (Diamond, 2010; Lev, 2006).

This study resulted in this treatment being standard practice until John/John resurfaced years later. Sex researchers Milton Diamond and H. Keith Sigmundson were able to locate the 'lost' John/Joan in 1997, who had become David Reimer who had married and adopted children (Kipnis & Diamond, 1998). Diamond's investigation unveiled that John/Joan never accepted being raised as a girl, rejecting feminine toys and behaviours that were being forced upon him (Kipnis & Diamond, 1998). The investigation also found that John/Joan feared visits to the clinic to see Money and would threaten to kill himself if he had to go back there. John was subjected to various poking and prodding in the clinic and was forced to look at images of naked bodies, all of which was a disturbing experience for John/Joan (Kipnis & Diamond, 1998). At the age of 14, David began to discard his oestrogen treatments, requested male hormones and a surgical sex reassignment back to male

(Diamond, 2004; Kipnis & Diamond, 1998). David had suffered greatly from Money's experiment, not only physically from several reconstructive surgeries, but mentally as well, suffering severe depression leading to his eventual suicide in 2004, two years after his brother's overdose.

New information about gender at birth created much questioning amongst the medical community. Money's established routine procedures and management plans for individuals with intersex variations were void and some physicians began to advise that 'atypical genitalia' be left as is, and allow the individual to identify with a gender of their choosing at maturity (Diamond, 2010). Despite this revelation in surgical sex assignments, it still took some years for change to begin regarding the management of intersex infants with 'atypical genitalia'. Surgical sex re-assignment in infancy then began to slowly decline and parents were given as much information as diagnostically possible via ultrasounds and karyotype testing, rather than the previous guesswork approach. Doctors began to educate parents that the gender or sexual orientation of the child was not guaranteed and that this diagnostic information was a rough guideline and not a 'promise' (Diamond, 2010).

2.3 Issues in healthcare practices

2.3.1 Transitional care to adult healthcare services

There appears to be a lack in adult care services for people with intersex variations. Adolescents often have difficulty finding specialist adult care for their intersex needs (Cools et al., 2018). Crouch & Creighton (2014) noted that there are minimal studies exploring evidence-based models of transitional care when it comes to intersex healthcare management.

Psychological support is needed for the transition process from adolescent to adult care. Barriers may include a lack of understanding for both parties, and the financial burdens of a long-term illness.

Scientific and medical language can be difficult to understand and subsequently, some appointments might not be deemed important to the patient (Crouch & Creighton, 2014). As such, transitioning the patient to new care requires clear communication and understanding to facilitate discussions surrounding all aspects of care. The financial burden of a long-term 'illness' may also impact adherence to appointments and may subsequently impact education and employment for the individual and possibly their parents. It is noted that the transition from adolescent to adult care is a process that may take years for intersex patients, and that psychological support is essential for all parts of the process (Crouch & Creighton, 2014). Further, they recommend further research on transition of care for intersex patients to better inform future practices.

Additionally, a change in approach towards emotion-centred care rather than a medicalised approach. Liao (2015) discussed how this change in approach from clinicians may allow for both clinicians and parents to have more time to reflect together and gather information with more compassion. Liao (2015) continued to state that the industry needs to let go of the ideal that medical interventions can bypass the emotional suffering experienced by intersex people; that these procedures itself are not without emotional cost.

Further, a small UK study of 14 young intersex women found that many participants were frustrated in communications with health professionals; as their 'conditions' were lifelong; health professionals needed to be prepared to have empathetic ongoing conversations with them, particularly through development phases (Sanders, Carter & Lwin, 2015).

2.3.2 Lack of base knowledge by health professionals

Accessing the right healthcare may be an issue for some people with intersex variations. For example, Somers xxy, Reibel, & Whyatt (2008) found that healthcare professionals may not have the right foundations of knowledge to care for intersex patients. This is supported by (Cools et al., 2018) who noted it is rare to find specialists who are well informed about intersex variations. They conducted interviews with primary health care practitioners and found a lack of consistent understanding of terms surrounding intersex; this included confusion with terms like transgenderism, transsexuality and androgyny. They stated that this pointed to a lack of professional knowledge in healthcare providers, which may inhibit their ability to identify and give appropriate treatment and care to someone with an intersex variation. They also reiterated the importance of full disclosure to intersex patients regarding their variations and similarly, that intersex patients are given an opportunity to disclose their variations (Somers xxy et al., 2008).

2.3.3 Intersex and disability

Whilst intersex and disability are two disparate concepts, they are both groups that have been subjected to years of marginalisation. Some lenses view medical intervention as a means of creating disabled bodies. For example, a penis subject to surgical intervention may result in a loss of pleasure or lifelong pain, resulting in a ‘disabled penis’ (Kerry, 2017). Despite having some benefits of including intersex in disability, including access to required medical attention (Topp, 2013), this association is problematic as it fosters a ‘dual-marginalisation’ for intersex groups. Both of these groups are often treated similarly by the state and even family level where they are expected to be ‘normalised’ (Das, 2014). However, the inclusion of intersex with disability may be beneficial to further intersex rights. More recently, a committee in India campaigned for the inclusion of intersex in national laws surrounding disability, however it was opposed by intersex activists and disability activists alike (Das, 2014).

Whilst people with a disability are not a homogenous group, they too are often subject to involuntary surgical intervention to normalise their bodies (Das, 2014). This may also include involuntary sterilisation. In more recent years, the Australian senate opened a *Senate Inquiry on involuntary or coerced sterilisation*, which allowed for organisations such as OII Australia[1] to enter submissions that vocalised the concerns regarding the unethical treatments of people with intersex variations in Australia. This submission covered key concerns such as the lack of data and support for intersex people, clinician uncertainty, and controversy regarding sterilisations and genital ‘normalising’ surgeries (Carpenter, 2013). Therefore, by associating intersex with disability, activist groups are able to have a platform to voice their human rights concerns before Parliament in Australia. This is particularly useful in Australia as an Australian study found 27% of intersex participants also had disabilities (Jones et al., 2016).

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[1] Note that since the commencement of this thesis, OII Australia has since changed its name to Intersex Human Rights Australia (IHRA). As their previous publications referenced in this thesis are under their former name, that is what will be used for the duration of this thesis.

2.4 Ethical dilemmas in treatment

2.4.1 Functionality or 'social emergency'?

Exploring the ethical treatment of individuals with intersex variations involves consideration of why certain procedures have been practiced. More critical intersex studies have discussed how people with intersex variations are first seen as 'freakish crises' or medical emergencies that are then 'surgically corrected' as a highlight of modern medicine; to illustrate the adherence to sexual dimorphism (Holmes, 2008). Whilst treatment between types of intersex variations vary, however many have the commonality of this non-consensual surgical intervention at birth. While sometimes surgical intervention is required in order to function correctly, such as instances of hypospadias or urinary passage obstructions, the surgeries are often conducted to 'fix' short-term social problems to create 'normal' genitals. (Warne & Raza, 2008). Infants are typically reassigned as females, despite how virilised they may appear as it is surgically easier to create a vagina rather than a phallus (Diamond, 2010; Lev, 2006). The use of language itself to describe this part of anatomy is sexual dimorphism in practice, with doctors naming the tissue either a clitoris or a phallus. Fausto-Sterling (2000) satirically refers to this sexing of the body as 'phall-O-metrics', used to determine whether an appendage is 'medically acceptable' by doctors. This approach of 'surgically sexing' aims to uphold social ideals of what males and females 'should' look like at the cost of sexual pleasure and function which is disregarded (Lev, 2006). Surgical intervention often involves recessing the clitoris which strips the organ of many pleasure nerves due to the accumulation of scar tissue (Creighton & Liao, 2004; Lev, 2006).

If women have fertile gonadal tissue, surgically altering the genitals may imply the social expectation that these women will want to bare children and/or have heterosexual intercourse. This may suggest that the desire to have penile intercourse is socially ‘normal’ or expected without considering other sexualities (Lev, 2006). This promotes a heteronormative approach to intersex healthcare.

In contrast, the criteria for assigning males is reliant on the infants’ genitalia and the size of the phallus, rather than concentrating on the preservation of the internal reproductive organs (Lev, 2006). Newborns who present with a micropenis at birth may be reassigned as females, even if they exhibit no other medical problems (Lev, 2006). Similar to the previously mentioned surgically intervened females, this places emphasis on the social expectations that the individual will be heterosexual and may suffer psychological harm if they reach adulthood with a small penis or may not be able to ‘effectively penetrate’ a woman or urinate whilst standing up (Lev, 2006).

As surgical sex reassignment at birth is used as an initial treatment, this ‘normalisation’ may create more health problems later in life as opposed to creating a positive change. The surgery itself comes with a potential myriad of complications. This includes the aforementioned reduction of sensation as well as initiating a long list of (often traumatic) follow up surgeries until adulthood (Lev, 2006).

Some doctors defend their surgical practices, stating that most of their patients have no complaints regarding their results (Aliabadi, 2004), yet there have been no strong voices from intersex people in favour of these surgical practices. Tamar-Mattis (2006) noted that an intersex voice coming forward to defend or support these practices would gain attention.

Some non-surgical treatments may also result in adverse effects on individuals with CAH. For example, individuals with CAH treated with glucocorticoid (GC) therapy or steroid therapy are at greater risk of developing decreased bone mineral density, which may develop into osteoporosis (Loenchner, Patel, Fordham, & McLaughlin, 2010; Schober et al., 2012). Elevated blood pressure may occur depending on the time of the treatment as well as insulin resistance and obesity as part of the metabolic syndrome (Schober et al., 2012). Over-treating with GC therapy may also result in advanced bone maturation, allowing the epiphyseal closure to seal early, stunting growth. Height potential is also compromised with this treatment for patients with cAIS (Schober et al., 2012).

Some research has highlighted a reduction in some surgical practices. Michala, Liao, Wood, Conway, & Creighton (2014) initially conducted an observational study of adolescent girls born with ‘atypical genitalia’ in 2001 and repeated the same study (n=30) with a similar cohort over a decade later. The aim of this study was to identify any changes in practices in the treatment of children with intersex variations. Some improvements were identified over time, for example, concomitant vaginoplasty was performed less frequently (65% compared to the previous 81% of participants). However, clitoral surgery remained frequent at 93% compared to the previously recorded 100% of participants. This was reported as surprising given the existing evidence of the negative impacts of surgical intervention on clitoral sensations and sexual functions (Michala et al., 2014).

2.4.2 A Western Female Genital Mutilation issue

Female genital mutilation (FGM) is often thought to only occur in Africa, the Middle East and the Philippines. This practice varies from minor to highly invasive genital mutilation and is perceived universally as a violent and barbaric social practice (M. Jones, 2017). Despite women being perpetrators as well as victims, FGM is perceived to be an extreme version of male violence and patriarchy; removal of the labia and clitoris is a cultural practice to curb female sexuality (Kulish, 1991).

These practices occurred in England and France in the 1800s with these surgeries happening to young girls in efforts to stop excessive sexuality, masturbation, and madness (Kulish, 1991). Whilst on the surface this may no longer seem like a non-Western issue, intersex children are subject to equivalent treatments also for social purposes, but the practice goes unnoticed or even endorsed. Both children of FGM and intersex children who have undergone surgical intervention are denied basic human rights including the right to bodily autonomy and integrity, freedom from violence, and freedom from gender and sex-based discrimination (M. Jones, 2017).

Chase (1998) commented that Western feminists in industrialised societies have failed to acknowledge or defend against FGM on intersex children in their own countries despite fighting against FGM in African countries. Given that one such surgical intervention on intersex infants is clitoral reduction, this counts as ‘unnecessary cutting of the clitoris’ which is the definition of FGM, and is a crime under American federal law, and in many state statutes (Fraser, 2016).

2.4.3 Lack of informed consent

A lack of informed consent regarding treatments on intersex infants and children is a prominent theme in much of the previous literature, including large national studies (Jones et al., 2016) and other qualitative studies including published, personal narratives (Davis, 2015a, 2015b; (Inter, 2015; Pagonis, 2015).

Anderson (2015) explored the application of moral principles for informed consent using the four moral principles developed by Beauchamp and Childress (2010). They noted that whilst parents are legally allowed to authorise medical procedures, they may not be in the best position to do so. The first moral explored is autonomy; an exercise in self-determination where one is the best person to make decisions for their own best interests. Anderson (2015) discussed how parents are exercising their own autonomy to make caring decisions for 'what may be best' for their child. However, parents and health professionals are failing to acknowledge the autonomy of the infant with an intersex variation, as autonomy is closely linked with informed consent, of which the infant has not given. Whilst the clearest approach would be to respect this autonomy of the infant at the time of diagnosis, health professionals often tend to paternalistic decision-making, and confused or anxious parents defer to the expertise of health professionals (Anderson, 2015).

The second moral explored is the interconnectedness between autonomy, and beneficence and nonmaleficence. As beneficence involves acting within the best interests of someone, and nonmaleficence is to assist others when they are in need of treatment and to 'do no harm', they impose a sense of social duty (Anderson, 2015). However, when considering autonomy for parents and infants, the decision as to whether to surgically assign a sex creates a possibility for both benefit and harm. Anderson (2015) reiterated that important questions must be asked when considering these moral stances, including weighing advantages and disadvantages of waiting until the child is of consenting age, or initiating surgical intervention in infancy.

2.4.4 Problematic genital exams and photography

Consent surrounding medical examinations and taking photographs of infants or children is also a concern expressed in literature, which may result in future psychological trauma. A recent clinical study in Berlin recognised that genital exams were both unnecessary and potentially traumatic for intersex children (Tica & Eugster, 2017). Despite this knowledge, they found that one third of intersex children were still receiving physical genital exams despite published guidelines calling to limit the practice. This paper did not mention whether consent was obtained for these genital examinations.

Genital examinations, photography, and a lack of consent is an ongoing problem; a systematic review by Jones (2018) found three recent papers show photographs of intersex genitals arranged by not gloved hands for display (Ahmed & Fadl-Elmula, 2016; Brasileiro et al., 2016; Ekenze et al., 2015). Further, these papers offer no further insight as to what ethical consent permissions they received for the photography process, or any international exposure given the accessibility of these papers. This demonstrates how these bodies are intimately accessible without clear hygiene or ethical considerations to international medical experts, online. Additionally, Cools, et al. (2018) called for a cessation on the practices of photography, repeated genital exams, and being ‘on display’ for multiple health professionals without informed consent, as past negative experiences may affect body image in intersex people.

2.4.5 Ethical issues in prenatal treatments

In some cases, measures are taken to ‘manage’ CAH before an infant is even born. Prenatal dexamethasone is a steroid given to pregnant women who are ‘at risk’ of carrying an infant with CAH in order to repress atypical genitalia in female foetuses (Dreger, Feder, & Tamar-Mattis, 2012). This prenatal treatment has been occurring in ‘at risk’ women since 1984 and still continues today in many countries (Meyer-Bahlburg, Dolezal, Haggerty, Silverman, & New, 2012). Whilst some may deem this acceptable in order to create a more typical looking female without the need of surgical intervention after birth, this drug may also be repressing traits such as masculine behaviours in women and even sexual orientations (Dreger et al., 2012). Prenatal dexamethasone treatment is used globally. A 2002 survey across Europe found that 57% of a total of 125 centres associated with the European Society for Paediatric Endocrinology (ESPE) gave the prenatal diagnosis as well as prenatal dexamethasone treatments as a standard measure spanning 6,553 CAH individuals (Riepe, Krone, Viemann, Partsch, & Sippell, 2002). While still occurring globally, it is currently not being conducted in Australia, however the amniocentesis testing for CAH infants is available and has led to a decrease in live births (AIS Support Group Australia, 2003).

This prenatal dexamethasone treatment becomes less about the reproductive outcomes and more about the social expectations of the child. Although the child may be reproductively healthy, their atypical genitalia does not meet the expected social norms, meaning the child could not fulfil the typical gender role that is expected by society. Despite being physically capable of carrying a child, if the child's personality is more inclined towards typical masculine behaviours and interests or if she identifies as lesbian, this conflicts with typical social expectations, rendering this treatment as a social solution rather than a reproductive one. This creates a 'GLBT issue' by trying to repress the sexuality that may occur, placing it at greater emphasis by physicians than both the mental and physical risks that could occur as a result of the dexamethasone treatment (Dreger et al., 2012). This raises the question of whether it is ethical to control infants' personality and sexuality at the expense of creating 'socially acceptable genitalia'.

Hirvikoski, Nordenström, Wedell, Ritzén, & Lajic, (2012) acknowledged that there are few long-term follow up studies on prenatal dexamethasone treatment, resulting in a lack of true understanding of what other potential harmful results this treatment could cause. Hirvikoski, et, al. (2012) conducted a study of 43 Swedish children who were treated with dexamethasone; they found three deaths within the first year and another infant had a developmental delay. Additionally, one child had hypospadias and two were born small for their age; one of whom had an intellectual disability and another child had hydrocephalus. The control group only had one child reporting Down's syndrome (Hirvikoski et al., 2012). However, the follow up study on the 40 children remaining reported regular IQ measures, were well adapted and had an average school performance compared to the control group (Hirvikoski et al., 2012). Short-term uses of dexamethasone treated children displayed impaired verbal working memory and increased anxiety, illustrating that the treatment has adverse effects. Their paper recommends that it should not be used as a treatment, particularly without long-term follow up and urges for further retrospective studies (Hirvikoski et al., 2012).

2.5 Psychosocial implications of surgical interventions

2.5.1 Depression and trauma

Experiencing depression or suicidal thoughts is common in this population. A large (n=439), multi-clinic study by Lux et al. (2009) explored some short-term follow ups for intersex children, their parents, and adults. They found that over 80% of participants had received surgical intervention with almost 50% presenting some level of psychological distress; nearly two thirds of which had identified sexual difficulties due to their surgical interventions. This caused disturbances in family relationships (particularly if the child was coerced to have surgery by their parents), and are less likely to experience masturbation or petting compared to their non-intersex peers (Lux et al., 2009). Despite identifying these problematic results, the study did not conclude that surgical interventions before an age of consent should cease.

Jones et al. (2016) also found instances of trauma and depression in their study, with 21 comments from participants that related to negative wellbeing due to receiving medical interventions. These included unwanted surgeries, grieving the loss of body parts, and negative responses to other treatments such as dilation therapy.

2.5.2 Incorrect sex and gender assignments

Surgical intervention on infants with intersex variations has obvious physical repercussions, however it also has some psychological ramifications. For example, the psychological distress of being assigned an incorrect sex and gender. It is crucial to acknowledge that, whilst often correlated, sex and gender are not the same; that biology is not absolute for determining gender identity (Anderson, 2015). Most children gravitate towards gender-specific toys by their second year of life and display gender self-awareness of being a ‘boy’ or ‘girl’ by age three. Gender identity is often not solidified until adulthood, and there is often further variability for people with intersex variations (Anderson, 2015; Berenbaum, 2006).

Preves (2003) reported that 24% of intersex individuals had reversed their gender assignment, indicating that there are high levels of dissatisfaction with their initial gender assignment amongst the intersex community. Additionally, Furtado et al., (2012) identified transgender traits in 8.5-20% of intersex patients and stated that this was more likely to occur in those with 5α-reductase 2 (5α-RD2) and 17β-hydroxysteroid dehydrogenase 3 (17β-HSD3) deficiencies, with traits identified up to 63% of these intersex variations. Further, they noted that the desire to be a different gender is lower in those with CAH and accordingly recommend surgical intervention for the majority of patients. Tamar-Mattis (2012a) noted that 10% of XX CAH individuals identifying as male, exhibiting similar findings to Furtado et al. (2012) though does *not* recommend surgical intervention.

Conversely, a study from the German DSD Network of 86 children (aged 8-12 years) by Jürgensen et al. (2014) found that surgical intervention had no reduction in health-related quality of life (HRQOL) for intersex participants, but that self-esteem was considerably low in girls with CAH and had a lower HRQOL which they attributed to those who exhibited gender dysphoria. They then compared how participants’ lower HRQOL to that of the experiences of children with chronic health conditions, finding impacting factors such as family, dealing with their diagnoses, and experiences in healthcare. Further, they identified 11 participants (12.7%) who scored high on the gender identity interview (GII) to determine traits of gender dysphoria. However, a limitation of this study is that it notably lacks retrospective data from an adult perspective to accurately assess long-term implications of interventions.

Jones et al. (2016) conducted a large Australian study which found most intersex participants were not transgender, with a rate of 8%. Similarly, a clinical European study by Kreukels et al. (2018) of 1,040 intersex participants found only 5% of participants changed genders with just 1% changing after puberty. A further 4% identified as another gender variance and noted that this group had lower self-esteem and higher rates of depression than other participants. This yields different results to other studies, including the findings of this study (see chapter 6), however this may be due to the clinical methodology used; a shortened version of the Utrecht Gender Dysphoria Scale to measure gender dysphoria rather than simply asking participants to self-report their gender identity.

An Indonesian study found vastly different results; most participants did not have surgical intervention (due to a lack of access), and observed gender changes in all age groups, but mostly adults. The majority of gender changes were from female to male gender identities who experienced masculinisation during their lives (particularly for those with CAH) (Ediati et al., 2015).

2.5.3 Body image and interventions

Whilst there are different rates exhibited by different studies in terms of changing genders or sex markers, it is clear that being given an incorrect gender or sex assignment may have negative repercussions. Dissatisfaction with gender assignment not only causes gender identity issues, but may also result in body image issues (Lev, 2006). These sentiments were echoed by Cools et al. (2018) who stated that prior negative experiences in healthcare may result in a negative body image. These issues may rouse feelings of anger or resentment towards family members or physicians in addition to experience depression, anxiety and isolation. Some procedures that follow surgery such as the need for repeated vaginal dilation may also cause some psychosexual harm or trauma (Jones et al., 2016; Lev, 2006). This trauma alone may come with its own set of symptoms such as mood instability, further sexual dysfunction, difficulties in concentrating, dissociation and flashbacks (Lev, 2006). Anonymous (2016) echoed similar sentiments, with a statement from Craig Waterworth of Massey University describing how these decisions on sex and gender may be traumatic for intersex individuals later in life if their gender identity did not match their imposed sex assignment. Further, they suggest that nurses could play a more active role in advocating for intersex infants.

2.5.4 Secrecy

Secrecy may also be an unethical aspect of surgical intervention or sex reassignment on infants (Beh & Diamond, 2005). Often, physicians advise parents to withhold information from the intersex individual regarding their ‘true condition’ until or even during adulthood (Jones et al., 2016; Lev, 2006; Preves, 2003). This is due to a belief that it is socially better for the child if they are unaware that they are ‘different’. This therefore theoretically avoids any psychological implications from knowing that they are different to others as their intersexual differences can be ‘erased’ (Lev, 2006). However, by maintaining secrecy and surgically altering children to meet the social expectations of what is normal for each gender, physicians are not avoiding psychological trauma, but (unintentionally) causing it (Kessler, 1998; Lev, 2006). Some intersex adults reflected that the secrecy between parents and doctors and the mismatching stories they were given lead to them feeling like they had a ‘defect’ so severe that no one would discuss it openly to them (Kitzinger, 2000). Open communication is essential for intersex individuals throughout childhood and adolescence as they begin to explore themselves as sexual beings (Lev, 2006). Shutting off communication from family members or physicians appears to increase feelings of isolation, anger and depression (Lev, 2006).

Encouraging an intersex child to keep their intersex status a secret from others may also result in negative, long-term outcomes. This may create a stigma for the child and even cause feelings of shame when they reflect on how they were treated as a medical object throughout their childhood/adolescence (Beh & Diamond, 2005). Beh & Diamond (2005) suggest that de-medicalising the individual could prevent some of these stigmatic social issues and assist with the intersex individual feeling less abnormal. These issues of secrecy and stigma may even result in a delay of exploring sexual relationships, causing some social problems for intersex individuals (Lev, 2006).

2.5.5 Counselling management

Individuals with intersex variations often require counselling support but are seldom offered it (Diamond & Watson, 2004). An earlier study by Froukje et al. (1998) stated that 39% of their intersex participants developed severe psychological issues as a result of surgical or medical interventions. While only 53% of participants and families were referred to psychologists immediately after sex assignment, psychological problems were twice as prevalent in those who were not immediately referred (Froukje et al., 1998). Similarly, Diamond & Watson (2004) also stated that only 16% of participants in their study were referred to counselling by physicians and over half of the participants pursued counselling on their own accord. Additionally, Thyen, Richter-Appelt, Wiesemann, Holterhus, & Hiort, (2005) mention that 81% of individuals in their study with intersex variations sought counselling for intersex related difficulties. More recently, a study of 80 intersex children reported significantly lower overall self-esteem, school functioning and physical wellbeing via a HRQOL test when compared with the reference data (Martina Jürgensen et al., 2014). Another study found that 69% of endocrinologists were offering mental health support to intersex patients and their families, but 58% had mental health specialists on site (Leidolf, Curran, Scout, & Bradford, 2008). Further, only 19% of patients received any emotional support during diagnosis. They identified two barriers to access; a lack of training in intersex-specific mental health support, and that some families were refusing help. The Jones, et al. (2016) Australian study found that 30% of intersex participants found their mental health support to be neutral, and 23% found it to be ‘bad’ or ‘very bad’ and nearly 19% were not offered this service. Further insights showed similar results to other studies; that mental healthcare professionals demonstrated a lack of training in intersex specific concerns or were unwilling to be educated on the matter.

In qualitative literature, Liao (2015) explored and reflected on 13 narratives on intersex medicine as a therapist, finding a large amount of ‘stonewalling’ in these scenarios, that is, instances in which healthcare and family exchanges bring about instances of silent, emotional suffering. Some of these instances illustrate the concept of the ‘remembering body’, in which intersex people reflect on recurring dreams that are actually very early memories of traumatic surgeries, or recalling repeated examinations and how that currently impacts their adult sex life; these are instances where the body remembers and creates or informs a part of an intersex persons' identity (Liao, 2015). Other stories that Liao (2015) analysed included doctors exhibiting other emotional detachment, offering no sympathy, empathy and how they may even block parents from asking certain questions, stonewalling families. This may reflect that doctors too struggle with emotion during these cases (Liao, 2015). Doctors need to abide by the duty of candour, which includes apologising for any wrong doing towards patients and provide honest and true information. Liao (2015) concluded by discussing the need for more emotion-centred care and highlighted how medical doings come with emotional cost. The study emphasises how critical it is to have access to counselling as soon as possible to reduce the decline in the mental health of intersex individuals, particularly those who have encountered non-consensual sex assignments.

2.5.6 Sexual satisfaction and function

One of the main issues that arises frequently in research of intersex treatment is the lack of long-term follow up studies (Jones et al., 2016; Lev, 2006; Schober et al., 2012). There is also a lack of consistency between data as well as irregular methods of assessing quality of life (Schober et al., 2012). There are some papers that have recorded sexual function in intersex adults (often under clinical methods), but few in the area of sexual satisfaction in relationships (Schober et al., 2012).

The World Health Organisation (WHO) stated that sexual health is:

> …a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled. (World Health Organization & Department of Reproductive Health and Research, 2010, p.3).

Therefore, sexual satisfaction is a component of sexual health, an element that could be greatly affected by surgical intervention. While there is limited literature on this aspect, a more recent study involving a surgical follow up study on 57 participants with AIS found that 47.1% were dissatisfied with sexual functioning following surgical intervention (Köhler et al., 2012). Individuals with AIS had a high percentage of 47.4% for dissatisfaction with clitoral arousal, reporting an overall dissatisfaction of their sex lives at 37.5% and sexual anxieties at 44.2% (Köhler et al., 2012). Issues with desire were the highest complication in Köhler's study at a high 81.8% for cAIS, and 70.6% for those with pAIS and noted that painful intercourse, or dyspareunia was experienced in 56.3% of participants with pAIS; 0.4% lower than those with cAIS (Köhler et al., 2012).

Fagerholm, Mattila, Roine, Sintonen, & Taskinen (2012) also acknowledge poor sexual satisfaction in this population, with 20.8% of participants stating as such; though the study also suggested an overall 'normal' quality of life. However, this paper had a small sample size of 25 participants (Fagerholm et al. 2012).

A study of 50 participants by Warne, et al. (2005) investigated psychological outcomes for intersex participants against two control groups who had other 'medical conditions'. They found that the intersex group did not differ from controls regarding results of their physical or mental health. However, these control groups had unrelated medical diagnoses and were smaller in number. They did note that the intersex group were more likely to experience painful sexual intercourse and were less likely to experience orgasm or engage in sexual activities.

Another large (n=80) study of Chinese participants with intersex variations also identified reduced sexual experiences compared to other populations, post intervention; finding only 13.79% participants experienced sexual activity (Wang & Tian, 2015); however this may be particularly low due to the younger ages of participants as well as traditional cultural values in China. They suggested future research in this subject matter and recommended that clinicians pay more attention to this area, as well as provide mental health support.

A study from the UK used interpretive phenomenological analysis on the submitted diaries and interviews of 14 (aged 14-19) intersex women (Sanders, et al. 2015). Three discussed being concerned that their vaginal surgeries would result in painful sex, and one decided to try dilation therapy again in hopes to improve their perceived ability to be a potential sexual partner. This study stated that many participants reflected on a need to have personal control over their own bodies including its limitations and potential performance in intimate scenarios (Sanders, et al. 2015). This reflected a greater need for bodily autonomy as well as highlighting concerns regarding surgical intervention and how it impacts sexual function and pleasure.

2.5.7 Sexual desire and fantasy

Sexual desires are often explored in heterosexual participants, particularly when looking into the differences between behaviours and desires, as seen in Morales Knight & Hope (2012). This is important to explore as sexual fantasy may help to further understand the connections between the body and mind, how feelings such as shame may impact fantasy (Knox, 2005; Levine, 2005). This research does extend to other areas of the LGBTI population, showing that ‘sexuality’ often involves the umbrella of behaviour, pleasure and desire even though these aspects may not correlate to a sexual identity, making it an important area to study to understand these differences (Smith, Jones, Ward, Dixon, Mitchell, Hillier, et al., 2014).

Whilst there are some studies that explore sexual function and orientation, there are no studies, at the time of this thesis, that explore sexual desire in the intersex population. Whilst their own desires are not studied, they may be subjected to fetishism; Frank (2018) found some intersex people were occasionally being exploited, sought by non-intersex for personal fetishes. Further, Christmas (2013) had issues finding intersex websites as they were often directed to voyeuristic, fetish-based sites rather than sites *for* intersex people in intersex internet searches. This may indicate that they are often exploited as the *subject* of fantasy; therefore, some may not see intersex people as subjects capable of fantasising and being sexually empowered, but rather only the subject of fantasies.

2.6 Family relationships

There are minimal existing studies on intersex people and their families with the exception of Jones (2017). This Australian study found that intersex people have turbulent relationships with their families due to the secrecy surrounding the disordering of their intersex variation, a finding also supported by Davis (2015a).

The German, Austrian, and Swiss Lux et al. (2009) study identified 80% of participants had been subjected to surgical intervention on their DSD registry, and noted that family had great influence (coercion or urging) to succumb to these interventions. Further, this resulted in significant disturbances in family relationships, however they did not conclude that surgical intervention therefore may put family relationships at risk.

Parents may also be distressed at the time of diagnosis for their children. A more recent study from the United Kingdom (UK) explored the prevalence of post-traumatic stress symptoms (PTSS) of parents of children with intersex variations (n=47); 31% of mothers and 18% of fathers were identified as having post-traumatic stress disorder (PTSD) (Pasterski, Mastroyannopoulou, Wright, Zucker, & Hughes, 2014). Further, they suggest that parents may find diagnoses for their children to be traumatic. However, they stated that these results stemmed from cognitive confusion rather than emotional distress and suggested direct cognitive interventions.

Further, there is minimal literature that has explored the depth and complexities of inter-family relationships, such as relationships with siblings, or whether intersex children are treated differently to their non-intersex siblings by their parents. Karkazis (2008) described how some parents may read into gendered behaviours more for their intersex children. For example, if girls with pAIS or CAH have an interest in sports, parents may wonder if that is influenced by their androgens and may interpret other interests that are particularly masculine as their child being confused about their gender identity. As a result, parents may reinforce gendered behaviours to mitigate gender-atypical behaviours to minimise their own anxieties about gender deviance (Karkazis, 2008). Given this scarcity of literature, this topic became of interest to this study.

2.7 School experiences as an intersex student

School experiences were also rarely explored in previous intersex studies, beyond Jones (2016) and Jürgensen et al. (2010). Jones (2016) found that 75% intersex students were bullied during school, however, most bullying occurred from physical differences stemming from intersex variations rather than from a knowledge of an intersex variation itself. Intersex students stated wanting better prevention policies, more intervention from staff, and further support from the school for students with intersex variations if they are attacked (Jones, 2016). Further, this study found that 46% intersex students experienced depression or thoughts of suicide, though 24% reported having a positive experience during school. Jürgensen et al. (2010) looked at friendship development for intersex students and identified that intersex children tended to befriend both boys and girls at school compared to non-intersex children who were more likely to befriend members of the same sex.

A small UK study of young intersex women (aged 14-19) showed some participants expressed uncertainty, confusion and insecurity about how they fit into friendship circles and who they were (Sanders, et al. 2015). These women reported wanting to achieve secure and safe friendships and relationships. Some remained guarded (particularly of personal information) in efforts to prevent being subjected to bullying or hostility. Despite this, three participants stated positive experiences of sharing their stories with others. Given the high incidences of bullying and overall lack of previous literature on school experiences, exploring this area became a key theme for this study.

2.8 Intersex around the world

2.8.1 Current issues in Australia

Whilst surgical intervention rates have slowed in recent years, the practice is still existent. OII Australia claims in a report to the senate (2012b) that whilst overall numbers have decreased, a Melbourne hospital currently (at the time of publication) still performs up to 10-15 genital reconstructions per year on infants under two years of age, as well as one to two gonadectomies on cAIS infants with undescended testes. Whilst health professionals of the hospital believe they are removing social stigmas and promoting function for these infants in the future, a submission to the senate from Australasian Paediatric Endocrine Group (APEG) (2013) suggested that there is a reduction in sexual function and sensation. They also acknowledge that there is a lack of long-term follow ups and recommended a patient registry to improve long-term follow ups on intersex individuals. APEG also note that Australia has no defined multi-disciplinary team (particularly psychosocial support) to assist with intersex management effectively to ensure the long-term mental and physical wellbeing of intersex individuals (Australasian Paediatric Endocrine Group, 2013). This is a key component where Australia is lagging behind more proactive countries such as the UK, US and some countries in Europe who have funded, multidisciplinary clinics for intersex individuals and their families (Australasian Paediatric Endocrine Group, 2013).

At present, there are no clear Australia-wide guidelines for care for intersex children or adults. However, an updated version of the '*Australian standards of care and treatment guidelines for transgender and gender diverse children and adolescents'* released in 2018 by the Royal Childrens' Hospital Melbourne does provide some insight regarding surgical intervention on transgender and gender diverse children and adolescence. These guidelines by Telfer, Tollit, Pace, & Pang (2018) state the following:

> Genital surgery performed before the age of 18 years remains a relatively uncommon practice internationally. Surgeons' attitudes towards specific guidelines on undertaking vaginoplasties in minors vary. Decisions regarding an individual adolescent's best interest and ability to consent for genital surgery are more complex than that of chest reconstructive surgery. This is partly due to greater risks associated with such major surgery, as well as the impacts on the adolescent's long-term sexual

> function and reproductive potential. Given this complexity, delaying genital surgery until adulthood is advised’ (p.25).

The guidelines additionally discussed the transition to adult healthcare services for trans and gender diverse adolescence; they stated that this may be a source of anxiety for patients as they have already built up therapeutic relationships with existing clinicians and staff (Telfer et al., 2018). These adolescents are not only dealing with the stresses of physical changes from potential hormone treatments but may also be battling anxieties with finishing school and associated responsibilities. These guidelines suggested early discussions in the years prior to any transition of care and recommended that the adolescent’s general practitioner (GP) facilitates a smooth transfer and to monitor mental health, particularly for those in rural or regional areas which may not offer gender specific services (Telfer et al., 2018).

Whilst both particular recommendations in these guidelines are aimed at trans and gender diverse youth rather than intersex youth, some of these recommendations may be of benefit to the intersex community as they too may benefit from such individualised, client-centred care.

The Department of Health (2013) in Victoria put forth a framework for intersex management, a positive step towards change to occur within Australia. The framework stated that surgical intervention is no longer mandatory, however a policy change has not occurred as yet (Department of Health, 2013). Despite this, there have been some recent positive legislative changes for intersex individuals. Whilst this framework is a step towards the right direction, it does not necessarily privilege or prioritise the need for consent of the individual. In education progress, there was a 2007 Victoria-state policy based on guidelines for schools (discussed in Jones, 2016), this has since been removed, leaving a gap in policy for caring for this group in educational settings (Jones, 2016).

While the Department of Health in Victoria has not yet set any policy changes, there have been some legislative developments, nationwide. There has been a change of the inclusion of intersex in the Anti-Discrimination Act at a federal level, hopefully the first of many positive changes for the intersex community within Australia. The Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill was passed in 2013, making Australia one of the first countries to have intersex people recognised in anti-discrimination legislation, after Dr Sally Gross' work in South Africa in 2003. An earlier positive step in Australian legislation was in 2003; intersex individuals are now permitted to have 'X' as their gender on a passport. Some contentions with organisations such as OII Australia arose as to whether this is a positive step, as it allowed intersex individuals to not specify male or female, but may increase stigma or try to allocate intersex individuals to a 'third' sex (Wilson, 2013). This notion 'others' intersex people and further solidifies the two-sex binary. Whilst medicalisation aims to prevent othering by surgically creating them into a two-sex binary, lawful othering on identity documents saves intersex individuals from medicalisation, these two concepts become contradictory (Carpenter, 2018).

A concerning issue for several years was the allocation of a 'sexual deviant' registry on intersex people who required Androcur prescriptions, a restricted anti-androgen drug. A prescription request is streamlined under the current PBS scheme which only offered Androcur under two item codes; one for men with prostate cancer and one to reduce the sexual drive in males (Talbot, 2012). This item code is allocated to sex offenders in order to reduce testosterone levels who then get marked on records as a 'Sexual Deviant/SD' (Human

Rights and Equal Opportunity Commission [HREOC], 2008; OII Australia, 2012b). Not only does this stigmatise intersex individuals, but places upon them a highly negative label, and may even prevent them from certain employment (Noble, 2012). Whilst this may be avoided by purchasing the drug privately without the PBS scheme, this increases the cost fourfold.

As of February, 2011, the PBS added a new code for moderate to severe androgenisation in non-pregnant women (Department of Health and Ageing, 2011). Whilst this has allowed the existence of a suitable code for intersex and transgender women, there is no evidence to suggest that individuals previously under the SD code have been removed from the SD list and subsequently are possibly still being treated as sex offenders. There is very limited literature on this topic, however three separate organisations (Changeling Aspects, LGBTI Health Alliance, OII Australia) have mentioned this issue via their websites and within submissions to government sectors to initiate change via senate inquiries. Given the scarcity of information on this topic, there needs to also be more current resources for intersex and transgender patients in addition to future research in this area.

As part of these senate inquiries, the report from the Senate gave 15 recommendations regarding intersex issues, including the regulation for the use of dexamethasone for prenatal treatment of CAH and for it to be only used in research projects with ethics approval; government support for an intersex patient registry; core funding for intersex support groups; for all states and territories to give jurisdiction with the Family Court for authorisation on intersex medical interventions proposed for children; all medical treatment of intersex people to be conducted under guidelines managed by multidisciplinary teams; and government funding for multidisciplinary teams for intersex medical care with sufficient record-keeping and research support (Commonwealth of Australia, 2013).

2.8.2 Current issues within the United States of America

The United States of America (USA) is one of many countries conducting dexamethasone ‘treatments’ for pregnant women who are ‘at-risk’ of carrying infants with CAH in order to minimize the virilisation of intersex infants foetuses (Dreger et al., 2012). As previously mentioned, this raises many ethical questions and additionally, there is some debate over whether it may cause cognitive development issues. While there is substantial literature on the ethical matters of the issue, this treatment is still practiced.

Another issue within the USA is the lack of legislative protection for individuals with intersex variations (Menon, 2012). However, the Americans with Disability Act (ADA) was recently amended to include ‘impairments’ such as the endocrine and reproductive system, provided it affects one or more major life activities or if there is a record of impairment. Still, courts usually adapt this to sexual orientation and transgender or gender identity cases rather than intersex individuals (Menon, 2012). Whilst this Act does offer some protection against discrimination, Menon (2012) stated that utilising the ADA may be a drawback for the intersex community as it associates intersex with disabilities and may perpetuate social stigmas of abnormality rather than further intersex rights by creating a ‘dual marginalisation’ for the intersex community. This would also perpetuate the medicalisation of intersex, which as previously mentioned is a global major issue expressed by organisations and communities.

A recent qualitative study from the USA used gender structure theory to explore the experiences of 16 intersex youth and found that young intersex people are having more positive experiences compared to previous generations (Davis & Wakefield, 2017). They exhibited little concerns regarding their diagnoses as doctors have previously feared and find value in peer support groups. However, as this is a small group where data was collected from one event, this may not be reflective of all intersex youth experiences and further research on intersex youth should be explored to include the voices of children in this research area (Davis & Wakefield, 2017).

Whilst this may indicate some progressive change in the area, there are still several global papers that do not frame intersex interventions under a problematic lens, including Khadilkar et al. (2015), Palanisamy et al. (2015), and Ahmed & Fadl-Elmula (2016). These perspectives may inhibit positive future change in this area.

2.8.3 Intersex in developing countries

Further education is needed globally regarding intersex management, however, this is particularly difficult to execute in developing countries due to lack of resources and difficulties in communication (Warne & Raza, 2008). This lack of resources and education may also end in difficulty with follow up care, resulting in patients seeking alternative medicines. With limited funding, health budgets are primarily distributed for public health care such as immunisations or malnutrition (Warne & Raza, 2008).

Many developing countries also have a cultural preference for sons, as they often hold more power within these cultures and play a hand in caring for family in the later stages of their lives (Warne & Raza, 2008). This is a common preference in Malaysia, Thailand, Turkey, Saudi Arabia and India. Therefore, children who are born with ‘atypical genitalia’ are more likely to reared or surgically assigned as male (Anderson, 2015).

2.8.4 Cultural interpretations of intersex

It is important to note that there are numerous different attitudes and terminologies for intersex in non-Western cultures around the globe; such as being included in the ‘hijra’ group of India (Lal, 1999; Monro, 2007), the ‘third sex’ in Papua New Guinea, ‘kwolu aatmwol’ (Herdt, 1990), the ‘guevedoche’ people of the Dominican Republic (Herdt, 1990), and the ‘true nadlehee’ and ‘true berdache’ of the Navajo people in North America (Navajo people have five genders and three sexes in their culture) (Lang & Kuhnle, 2008) to name a few. As no participants in this study used any of these terminologies or identities, to discuss these at length is beyond the scope of this thesis. The word limit for this thesis and lack of culturally-specific identities in the data its later chapters report on, made further detail on these identities less relevant here than noting their existence alongside many other counterpoints to Western psycho-medical DSD discourse.

2.8.5 Rise of advocacy groups and change

Support and advocacy organisations for intersex rights began as early as 1987. Toby formed ‘Finding Our Own Ways’ for people who considered themselves to be a ‘neuter’ in the USA (Kessler, 1998). Shortly after in 1988, the ‘Androgen Insensitivity Syndrome Support Group’ was formed in the UK, as was the ‘Turners’ Syndrome Society’ (Chase, 1998). The ‘Intersex Society of North America’ (which has since been renamed ‘Accord Alliance’ due to some individuals objecting to the term ‘intersex’) and global Organisation Intersex International (OII) groups have protested and urged for further rights and changes in intersex management (Diamond & Beh, 2008; Kipnis & Diamond, 1998). Some of these changes were accomplished in 2006 when a conference in Chicago provided a statement declaring that parents and physicians should not rush into surgical reassignment and management should be approached with an experienced multi-disciplinary team (Topp, 2013).

In 2003, South Africa included ‘intersex’ in anti-discrimination laws. Dr Sally Gross included ‘intersex’ within the definition of ‘sex in the nation’s *Promotion of Equality and Prevention of Unfair Discrimination Act* which administered the judicial interpretation of the *Equality Clause*. Following this, Gross assisted in drafting legislation on the *Alternation of Sex Description and Sex Status Act 49 2003,* which allowed intersex citizens to change their sex descriptors on their identification documents (Wilson, 2011).

2.8.6 Recent developments

In 2012, the United Nations released *Born Free and Equal: Sexual Orientation and Gender Identity in International Human Rights Law* which supported the protection of people with intersex variations against discrimination (United Nations, 2012). Further, the Swiss National Advisory Commission on Biomedical Ethics (2012) made a similar statement, calling for the need for people with intersex variations to be involved in any decision-making about their sex or potential intervention needs instead of imposing a two-sex binary on them without consent.

More recently, the Council of Europe developed the *Human Rights and Intersex People* document, which outlined eight recommendations for treating people with intersex variations (Agius, 2015). These recommendations included calling member states to end medically unnecessary ‘normalising’ irreversible genital surgeries and treatments without fully informed consent of the individual. Other recommendations included being given access to interdisciplinary counselling and peer support, as well as access to one’s own medical records. Further, the document also reiterates the need for further research into the status quo of intersex treatments and human rights, as well as the need for more public awareness and training in professional settings.

The UN Special Rapporteur on Torture as well as the UN Special Rapporteur on Violence Against Women both stated that FGM is torture and the claim that medicalising FGM does not exclude it from the classification as a violation of human rights (Mendez, 2013). Further, the World Health Organisation stated:

> …intersex persons, in particular, have been subjected to cosmetic and other non-medically necessary surgery in infancy, leading to sterility, without informed consent of either the person in question or their parents or guardians (World Health Organization, 2015).

With all these organisations making these acknowledgements, it is evident that surgical intervention on intersex infants is a violation of human rights and additionally, no more excusable than FGM.

In 2015, Malta introduced the Gender Identity Gender Expression and Sex Characteristics Act which outlawed non-medically necessary, cosmetic genital surgeries on intersex infants including sex assignments on minors. This was a positive step forward towards bodily autonomy and self-determination; a first in the worldwide protection of intersex infants (OII Europe, 2015).

2.9 Other recommendations from existing research

Diamond (2011) discussed the need for a national intersex variations registry, similar to the existing cancer registry in the USA that began in 1992. The purpose of this registry would be to collect, review, manage and assess data on the existing management of intersex and would be used to plan and evaluate further management (Diamond, 2011). Having this readily accessible information would allow for healthcare professionals to develop more effective management plans based on larger sample sizes of data, in addition to learning more about patterns amongst intersex variations. A registry of this nature has already been established in Europe named the European DSD Registry, as previously mentioned.

Another recommended requirement is the need for a moratorium on surgical intervention on infants with ‘atypical genitalia’ (unless there are large health risks) as these individuals are unable to yet give consent; a notion supported by intersex support groups globally (Kipnis & Diamond, 1998). As part of this amendment, all previously ‘hidden’ medical records should be accessible and disclosed to those individuals with intersex variations for them to further understand their differences and seek management accordingly. This would not only aid further understanding of their past, but also may allow a new opportunity to rebuild trust and confidence in physicians (Kipnis & Diamond, 1998).

Once this amendment has been achieved, people with intersex variations will be more fully informed, allowing for further detailed, retrospective studies. These future studies will provide grounds for further evidence and information for future physicians and parents of individuals with intersex variations.

2.10 Conclusion

From the previous discussion and comparison of the literature, there appears to be a lack of large, long-term follow up studies on intersex individuals that have experienced some form of early non-consensual surgery or treatment. While there have been some progressions over the last twenty years in acknowledging the need for intersex rights and the need for the cessation of non-consensual surgery, it is evident that more change needs to occur in order to achieve equality for the intersex community to improve overall quality of life.

In some of this literature, there appears to be a clear indication that there needs to be a multi-disciplinary team to effectively meet the needs of intersex individuals and their families. This would achieve holistic wellbeing of the individuals involved, given their physical, hormonal, mental and social needs could be addressed via a multidisciplinary team such as paediatricians, endocrinologists, mental health practitioners and other relevant health professionals. This multidisciplinary approach could lead to changes that may ensure that any surgeries or treatments are only performed when necessary for bodily functions (for example, some cases of hypospadias or urinary passage obstructions may require surgery in order to urinate effectively and reduce reoccurring urinary tract infections (Warne & Raza, 2008) rather than for social aesthetics. It is also recommended that the multidisciplinary team may also consist of mental health professionals to counsel the intersex individuals and their families to minimise feelings of shame, depression and isolation. Further, there needs to be better education for health, and mental health professionals to provide adequate care for people with intersex variations.

In addition to this, a moratorium is recommended on surgical intervention on infants with atypical genitalia in the more critical elements of the literature (Jones et al. 2016). This is due to infants' inability to consent to such procedures in addition to the limited large long-term follow up studies showing positive repercussions. Further information for future studies could be gathered on national registries which could also aid the development of more effective management plans for individuals with intersex variations.

A greater amount of accessible information is needed for intersex individuals and communities regarding treatment options and legal rights in their countries. There is no current global management of intersex issues guidelines, resulting in management differing in each country. This lack of information for intersex individuals may result in a lack of clear, ethical management from healthcare professionals. People with intersex variations ought to be able to acquire medication (such as the aforementioned Androcur issue in Australia) or without fear of discrimination. Additionally, this calls for a greater need for public awareness and education of intersex variations, including in school settings.

Ethical terminology is still being debated. Some literature and organisations are opposed to the term ‘intersex’, although it is the predominantly preferred term for individuals with intersex variations amongst organisations and activists. There appears to be an overall consensus, from an ethical standpoint, that ‘Disorders of Sex Development’ (DSD) is politically incorrect as it pathologises intersex individuals. There is some support from literature and organisations for terms such as ‘Differences of Sex Development’ or ‘Variances of Sex Development’ as it emphasises the varieties or differences that may occur with reproductive development, rather than medicalize or imply other negative connotations that ‘disorder’ may imply. Parents may also be more inclined to accept ‘differences’ in their child rather than ‘disorders’.

Currently, with the exception of Jones (2017), there is a lack of studies on intersex people and their families. A potential reason for a lack of existing literature on these relationships is that this would require seeing intersex people as humans who experience complex relationships with others; as most constructions of intersex people are seen as people with DSD and are often dehumanising. Further, research is dominated by medical discourses, with large volumes of clinical studies that do not thoroughly explore the lived experiences, or more importantly, people with intersex variation's own narratives. In efforts to humanise people with intersex variations, this project will therefore proactively consider the complex relationships intersex people have with their families, friendships, and relationships.

More research is highly recommended in order to discover more about the long-term repercussions on surgical intervention on individuals with intersex variations. Research is needed for the academic/medical community to gain a greater mental, social, political and physical level of understanding. Many ethical questions on other treatments have also been raised (such as the dexamethasone treatment for 'at-risk' CAH foetuses) which furthers the need for further retrospective investigations on intersex adults.

Therefore, it is clear that more research is needed to support and facilitate both legislative and medical change for the ethical treatment and support of intersex individuals to gain greater equality for the community.

2.10.1 Aims of this study

The aim for this study was to identify the needs of intersex individuals both in Australia, and on a global scale. As this literature review has illustrated, there needs to be changes in healthcare experiences and access, as well as health professionals having a greater understanding of the complexities of gender, sex and sexuality; as there is limited literature on the sexual satisfaction and sexual fantasies of intersex people, these aspects will also be explored. Further, there is limited research in the exploration of intersex peoples' experiences in social settings such as at school, in developing friendships and exploring family relationships. Therefore, this study explores the socio-cultural experiences of intersex people via reflections of their lived experience in these areas.

Thus, the research questions for the study this thesis reports on include intersex people's concerns and experiences in healthcare management; intersex people's lived experiences with gender, sexuality, sexual satisfaction, and sexual fantasy; and their social experiences in school, developing friendships and family relationships. The need for these research questions is justified by the recommendations found in this literature review, as well as in Davis (2015a); Jones et al. (2016); and Fraser (2016). Therefore, the research questions are as follows:

- *Research question 1:* What are intersex people's concerns and experiences in healthcare management*?*
- *Research question 2:* What are intersex people's lived experiences with gender, sexuality and sexual satisfaction, including sexual fantasies?
- *Research question 3:* What are their social experiences in school, developing friendships and family relationships?

Given these questions, the theoretical concepts necessary to explore for the project follow a focus on the three topic areas central to these questions on intersex people and health; gender and sexuality; and relationships.

Chapter Three: Theorising Intersex - critical exploration of essentialist impositions of power

3.0 Introduction

The study on which this thesis reports applied predominantly a critical and post-modern frame in its theoretical perspectives on health care, gender and sexuality, and the power of institutions. This chapter begins by exploring critical and postmodern frames, and the usefulness of narratives in research. Following this, it explores theory challenging the positivist paradigm and the essentialist view of gender by exploring gender essentialism, citizenships and other feminist frameworks. The chapter then navigates theories on sexuality including the othering of non-heteronormative identities, and queer theory including performative gender, power and sex, and the queer dilemma in advocacy. These discussions lead into psychological theories of sexual fantasy, including the involvement of empowerment, shame, and internalised homophobia. Finally, the chapter will explore the compliance view of institutions including bio-politics, challenging power in institutions, exploring gender structure theory, the usefulness of structural functionalism, and theories surrounding the protection of children from sexual knowledge. The chapter concludes by bringing together the applications of these theories to the broad development of the study.

3.1 Critical and postmodern frame

A critical approach to intersex research frames the study by questioning the status quo. Often, this approach tends to take the perspective of marginalised (in this case, intersex) groups rather than the institutions who serve them (Jones et al., 2016). There are many critical theories surrounding human bodies and sex development, which is especially evident in lenses surrounding intersex studies. These frames view people with intersex variations as a marginalised group whose human rights of bodily autonomy, non-discriminative care and empowerment are threatened by the institutionalised two sex binary mode of care (Jones, 2016). Using these critical approaches allows for advocating empowerment of intersex individuals by questioning the necessity of surgical interventions as well as contesting the institutionalised bias that reins against this population (Davis, 2015a; Jones, 2017; Liao & Simmonds, 2014).

3.1.1 Aspects of critical theory

Critical theory can be considered as a form of rationalism; that all knowledge stems from the fact that we are all rational beings, rather than sense-experience (Scott, 2014). From this view, people can form a rational society, in which everyone participates in to create or change their environment. Those societies who exclude groups, particularly from economic or political participation, or render a group powerless are irrational societies (Scott, 2014). The work of Habermas illustrated a different critical theory model which focuses on the universality of the use of language rather than rational thought (Scott, 2014). This is an ‘ideal speech situation’ where everyone has equal access to information and debate. Critical theory here is viewed dialectically, identifying internal contradictions or gaps in a system of thought and using these to create something different. This differs to rationalism which instead holds one set of standards or rules against another, and instead looks within. The second model's equal access ideal embraces communication free from external oppression, social equalities, and internal repression (Scott, 2014) and is applied in this thesis.

3.1.2 Postmodernist views on Intersex

Postmodernists or poststructuralists see sex as either a complex spectrum between two extremes (female and male), a singular category with a number of outcomes, or an array of combinations and expressions interpreted socially into further biological groupings (Fausto-Sterling, 2012; Jones, 2017). Morland (2006) noted that research under this frame is useful for exploring the different understandings of intersex. Morland (2006) stated that this equivocal postmodern approach is also apt for the diversity in the views and identities of intersex people, despite how this lens may not wholly support the reformist agenda of medical health and social inclusion driven by intersex activists. This deconstructive plural view of sex and identities privileging the views of intersex people in relativist way.

3.1.3 Narratives in research

In general, there is a lack in social research when it comes to intersex studies, particularly as the field is dominated by medical/clinical frames (Jones, 2016). Often, these discourses have discussed intersex bodies as something that needs to be corrected rather than what constitutes as a healthy body and mind. There are minimal studies that give intersex voices a chance to be heard on a large scale, however, there are some authors who write from a critical perspective of their own experiences (Davis, 2015; Holmes 2008; Holmes, 2009; Morland, 2008; Pagonis, 2015).

Morland discussed how both critical and post-modern frames underscore the importance of non-authoritative voices to exploring the lived experience of being intersex (Morland, 2008). This lived experience may be described as the narrative of 'living in a body' (Morris, 2004 cited by Morland, 2008). This experience is internal/interior and emotional; an embodied, lived experience. Given the qualitative nature of these lived experiences, there is more than a single intersex story to be told in these narratives. The 'corrective' approach by the medical narrative is exterior focused, with its superficial genital appearance fascination focused on appeasing others (such as family members) (Morland, 2008). This approach is focused on 'fixing' rather than living with an intersex body. This narrative ignores the embodied needs and feelings of the patient. Morland (2008) discussed the need to appeal to the embodiment of the patient's personhood, 'their life in their body' (interiority) rather than the superficiality of genital appearance (exteriority). Dreger (1998) also mentioned the value of marginalised voices in a medicalised narrative and stated how medical professionals may be able to read intersex stories as instructive feedback. Dreger (1998) highlighted how previous groups have used voicing their lived experience to instigate institutional change and how this is a precursor for intersex voices. By listening to these narratives, it is clear that this group of people's bodies are medically 'corrected'. Therefore, both narratives of medical correction and the narrative of the lived experience of being intersex overlap.

The study reported on in this thesis combined both a critical and postmodern lens to explore the perspectives of intersex people to privilege their own empowerment via their own voices and viewpoints; valuing the importance of the non-authoritative narratives of the population itself to explore their lived experience. Further, this study was developed under the perspective that the constructions of this population are socially determined, and as such, many sources of these social constructions were explored in this study including institutions (medical and education) as well as family and romantic relationships. How these social institutions and relationships influenced the participants' wellbeing and sense of self were thus central to this study.

3.2 Theory Challenging the positivist paradigm for doctors

3.2.1 Problematic Positivism

A positivist approach is to gain knowledge via the positive (scientific) method of observation rather than abstract rationalisations. That is, to base knowledge on scientific statistics or experiments to understand how society functions. Building upon this was the notion of 'social facts' (coined by Emile Durkheim), a social rule, duty, sanction or practice that may be observed (i.e. Positivist approach) to unearth universal social laws to use a baseline to judge the wellbeing of a society (Morrison, 2006). Therefore, this view examined the subject matter or social facts, correlations or relationships between variables. A final value of a positivist approach is the concept of 'value-free observation' which was introduced by Max Weber (1864-1920) dictating that observations should be free from any bias to be truly objective (Morrison, 2006). However, values are not this simple, and may impact the topic matter chosen by some researchers; this is known as value reference. When applying this notion of positivism to intersex matters, there is a clear positivist approach by doctors and healthcare professionals when it comes to the treatment of people with intersex variations. Research on intersex is often clinical, basing ‘successes’ on clinical measures rather than any subjective voice of the participant. These scientific studies become the basis for the knowledge of health professionals who go on to ignore intersex voices and continue the positivist paradigms’ dominance in healthcare. The study reported on in this thesis challenges this dominant lens through considering how positivism contributes to notions of deviance and challenges bodily autonomy around intersex variations.

3.2.2 Five-stage model of deviance

Looking at the sociology of diagnosis itself, the five-stage model of medicalised deviance developed by Conrad & Schneider (1992) can be used to illustrate the institutionalised medicalisation of treating intersex variations. The model demonstrates how medical claims are developed in ways to frame deviance (something that deviates from the ‘normal’) as a ‘medical problem’ with a diagnosis, and treatment for the deviance or subsequent deviant behaviour. Conrad and Schneider (1992) propose stages of this model include:

- Stage one – a condition or behaviour is labelled as deviant;
- Stage two – medical discovery;
- Stage three – medical and other relevant bodies make decisions about the condition or set of behaviours discussed;
- Stage four – reinforcing legitimacy and medical ownership;

- Stage five – condition or behaviour is institutionally recognised as a medicalised deviance.

Davis (2015a) suggested this model can be used to illustrate the trajectory of the medicalisation of people with intersex variations. For example, stage one sees intersex as a deviation from the two-sex binary. Stage two highlights the development of medical discovery, the technological advancements that led to identifying and describing chromosomes to define sexes and doctors reporting other intersex trait findings to medical journals. As a result, this develops into stage three of healthcare professionals gaining knowledge and claiming expertise by stating that intersex was a medical problem that could be corrected. During this phase, intersex activism rises to challenge how doctors view and treat intersex variations. Faced with this resistance, doctors and other medical bodies were prompted to engage in stage four – a debate over diagnoses and terminology. Despite the best efforts of the intersex activists and allied researchers, the dominance of positivism in healthcare finalised this process for a considerable time at stage five, where intersex was (and remains) institutionally recognised as an ‘abnormality’ under the newer terminology, Disorders of Sex Development (DSD) (Davis, 2015a).

3.2.3 Concept of bodily autonomy

The concept and need for bodily autonomy is a key theme expressed by several intersex people and activists in the literature in response to the positivist paradigm of healthcare and the use of DSD terminologies and therefore, treatments. The journal *Narrative Inquiry in Bioethics* released a special edition exploring the stories of intersex people, many of whom expressed this sentiment of the need for consent and desire for bodily autonomy. One author reflected on the journey they were put through regarding assignment:

> Enough is enough! I’ve had six pharmaceutical sex changes, without informed consent; all without psychiatric care that is requisite for transgender people. Please set us free from this medical nightmare. Leave us alone to grow and mature as the mythical beings we are (Sanderlin, 2015. p.111).

Another contributor reflected on being talked about rather than to, and never being consulted in the process of their treatment:

> I was never asked what I wanted, nor was I asked how I felt. My hate and contempt for my doctors by age eight was already so significant that I never even spoke to them. They took my silence as a sign that I was mentally retarded or maybe mentally ill… I was in the room as I was being spoken about, though I was rarely spoken to (Kreuzer, 2015, p.58).

Reflected in both stories is the important question of consent and bodily autonomy; a sense that surgeries and decisions may be happening to and around intersex people rather than with them. Intersex people, they argued, are left out of the conversation and consent of surgical intervention in infancy, childhood, adolescence and sometimes even adulthood. Further, these same sentiments are expressed in many published personal reflections (Garcia, 2015; Inter, 2015; Pagonis, 2015; Quinn, 2015; Truffer, 2015). These usually one-off stories also illustrated the sense of regret surrounding interventions and a general resistance to interventionist methods. Finally, these stories highlighted the need for narratives in the space of navigating lived experiences in marginalised groups specifically on their views of bodily autonomy in healthcare.

This study uses the five-stage model of deviance to explore the details and perspectives of intersex people on their viewpoints of healthcare and how these are represented in their experiences, countering how the majority of studies in the field are clinical studies overlooking their views. Further, this study explores the marginalised group's perspective that body autonomy is central to discussions of surgery and considers the extent to which body autonomy is exercised in the relationship between health professionals and their patients, using quantitative data to explore the concepts that arose in smaller narrative offerings.

3.3 Theory Challenging the essentialist view of sex, gender and sexuality

3.3.1 Gender essentialism – a biological lens

Essentialism is the understanding that all people or phenomenon have an underlying and unwavering 'essence'; for example an essentialist argument is sometimes made that men are more aggressive than women due to biological hormone levels (Twine, n.d.). This argument is built on the foundation of biological difference to develop an unwavering truth about social behaviour or difference. However, this approach fails to consider any psychological, sociological or cultural attributes – or how theories of biology and biology itself varies (Jones et al., 2016). Essentialism is also seen in broad statements without considering cross-cultural or historical differences; discussing the experiences of white women with disabilities presents a more specific context or argument than making generalisations about just women or just people with disabilities, however this is still problematic (Twine, n.d.). Therefore, with this understanding, gender essentialism is a 'hardwired' gender and subsequent gendered behaviours that match the corresponding binary sex. Doctors are using this biological lens with an essentialist view to medicalise intersex bodies. This is used to justify DSD terminology, and further, to modify intersex bodies which deviate from this binary to fit into a ‘normal’, consistent binary body (Davis, 2015a). Further, this is used for sex assignment, as doctors may consider genotype, genital appearance, testosterone exposure in utero, potential for fertility, and even cultural considerations of the family to determine the sex and subsequent gender. However, once more this essentialist approach ignores psychological and social factors that may determine gender identity later in life (Davis, 2015a). A gender assignment recommendation under a biological lens means the validity of this decision remains unchallenged, allowing the rationalisation of surgical intervention.

An essentialist view also allowed for medical professionals to evade responsibility for their interventions by offering a ‘choice’ to parents. If parents opt for no surgical intervention, they are subsequently ‘choosing abnormality’, but only because it was presented as an abnormality by medical professionals (Davis, 2015a; Feder, 2014). To truly engage in nondirective counselling, parents should be involved in the DSD meetings to see the medical uncertainty which subsequently may lead to them wanting to delay making a medical decision. Photographs are often used in such meetings, which may be helpful in that it limits physical examinations and can be used for education. However, being photographed itself may be traumatic and a deeply shaming experience, as confirmed in the Consensus Statement on Management of Intersex Disorders discussed by Lee, Houk, Ahmed, & Hughes (2006) and reiterated by an ethnographic study by Davis (2015a). Further, whilst medical professionals may be conveying information and options to parents, they are delivering this information from an authoritative position of power which in itself, plays a large role in the decision-making process for parents. For example, Streuli, Vayena, Cavicchia-Balmer, Huber, & Sex Med (2013) conducted an experimental study of students playing the role of ‘parents of intersex children'. Participants were randomly assigned to watch either a medicalised video about intersex by an 'endocrinologist' or a video about intersex that was de-medicalised by a 'psychologist'. After they watched their respective film, participants filled out a questionnaire about their understanding of intersex and to decide whether 'their child' should have surgery. Those who watched the medicalised video were far more likely to opt for surgery, showing the role that authoritative medical professionals play in the decision-making process for parents, and the way medicalisation and essentialism can be communicated in ways impacting treatments (Davis, 2015a).

3.3.2 Citizenships

The meaning of 'citizenship' is described by Lauren Berlant as a 'status whose definitions are always in process. It is continually being produced out of a political, rhetorical, and economic struggle over who will count as 'the people' and how social membership will be measured and valued' (Berlant, 1997. p.20).

Whilst there are a few differing opinions on the working definitions of citizenship, the primary concepts revolve around rights, identity, and participation in society (Grabham, 2007). This theory chapter now considers biological, social flesh and intersex citizenships.

Biological citizenship

As essentialists believe there is an unwavering essence (in this instance, hardwired biological factors), this theory informs the understanding of biological citizenship. This concept of biology influencing the rules or projects surrounding citizenship in society is described where 'biological presuppositions, explicitly or implicitly, have underlain many citizenship projects, shaped conceptions of what it means to be a citizen, and underpinned distinctions between actual, potential, troublesome and impossible citizens' (Rose & Novas, 2005. p.2). When using this theory as a lens for intersex health, intersex individuals may be seen as these 'troublesome and impossible citizens' as they do not fall clearly within the two-sex binary that operates in society today.

Davis (2015a) argues that terminology preferences may prevent or allow access to this biological citizenship. In nomenclature of Disorders of Sex Development (DSD), the phrasing itself states that something is disordered, that it is outside of this two-sex binary. Those who adhere to this terminology are required to believe that they are living with an 'abnormality' and are then granted access to biological citizenship; an essentialist, two sex binary world delivered by authoritative institutions of health. Conversely, Davis (2015a) noted that those who prefer 'intersex' as terminology typically view gender as something that is socially, rather than biologically constructed, which often comes with an acceptance of their bodies. However, this approach results in the prevention of access to biological citizenship and consequential lack of support from medical practitioners or even family members. Davis (2015a) found that those who embraced DSD terminology were granted this access to biological citizenship also tended to experience a more essentialist view of gender. This may manifest as struggling with their gendered selves or perceived 'illegitimate gender', creating anxiety about their bodies, particularly in intimate scenarios. With the access to biological citizenship comes less resistance towards doctors and the comfort of knowing they were not alone throughout their diagnoses, despite not relieving their anxieties (Davis, 2015a). Further, those who use both terminologies have the advantage of switching to whichever term will be the most beneficial in each scenario; they may use ‘intersex’ to embrace their body positivity and gain self-assurance, and then DSD terminology to foster positive relationships with doctors and family members to gain further access to biological citizenship. Note that using both these terms for one’s advantage also comes with the understanding that gender is a social construct as well as acknowledging that ‘medical conditions are only as real as its definition’ (Davis, 2015a. p.115).

Social flesh citizenship

Beasley and Bacchi (2000; 2012) reflected on political and feminist literature and critiqued the lack of relationship between the analyses of bodies in body theory, and the lack of body in analyses of citizenship. This highlighted the disembodied models of autonomous and universal patient-citizens frequently explored in existing citizenship literature; emphasising the split between the mind and body in theories. Beasley & Bacchi (2012) evaluated what was missing from these conversations, and found that most literature on citizenship disembodied politics, and theories often correlated with the ‘public sphere’ rather than the private (seen as a barrier to the public sphere), and minimised the barriers to public spheres participation faced by women. They discussed how flesh is largely talked about in the political theorising of ownership and control in the public sphere, for example, in bodily integrity and autonomy issues surrounding rape and abortion (Beasley & Bacchi, 2012). This illustrated how feminist literature is often more symbolic of social context rather than the physical or subjective sense.

Bacchi & Beasley (2000; 2012) therefore came up with the theory of ‘social flesh’ to intertwine body theory and citizenship. Social flesh highlighted human embodied interdependence. Similar to care ethics, this theory promotes the notion that sociality is embodied, and that embodiment is interconnected with the pre-existing condition of human life and thus, sociality. Therefore, ‘social’ is interpreted as the spectrum of bodily experiences involving communication and movement; the bodily need for attention and sustenance and relationships around touch. The use of ‘flesh’ is to illustrate the existence of embodiment (Bacchi & Beasley, 2002). Bodies are often seen as things to be owned, or depicted in terms of disadvantages to be overcome for political goals or reform. The challenge is to ensure that ‘political subjects are not defined against embodiment and are enabled rather than disqualified by their bodies’ (Beasley & Bacchi, 2000, p.351). To place this theory into context, an ethnographic study by Schlosser (2018) explored the embodied and social experiences and tensions of two individuals in an addiction clinic in America. Their results showed experiences of bodily disconnection via drug use, followed by participants feeling that their knowledge of their own bodies and subsequent drug effects on their bodies was ignored by health professionals. Further, they experienced disconnection from their own bodies, socialities and psyches during medicated sedation. This study supported the need for Bacchi & Beasley’s (2000) theory to give greater attention to bodies in citizenship literature and vice versa. This is applied to this study to explore the experiences between intersex peoples’ body, citizenship and experience with healthcare professionals.

Intersex citizenship

Grabham (2007) uses these citizenships to formulate the concept of intersex citizenship. Plummer's (2003) depictions of intimate citizenship can be applied to intersex children and adults who are subjected to medical treatments as part of the same medical discourse that controls and creates reproduction via medications which may impact the child they create. These treatments are often administered early in life before the child they affect can consent, meaning that these decisions are made by family and physicians, making their corporeality often acutely affected by those relationships (Grabham, 2007). This formation of intimacy in kin formations is vital to understanding the relationship between treatment decisions, autonomy, and intersex corporeality. Weeks et al., (2001) considers concepts of kin formations useful for research on intersex citizenship to assess the implications of these new intimacies of relationships between families and doctors, as well as looking at the future relationships between the intersex adult and their partners and families (Grabham, 2007).

Plummer's (2003) concepts around intimacy and digitisation are additionally relevent to illustrating how intersex healthcare citizenship rights movements are gaining momentum via the internet. As well as peer counselling, awareness and organising events, there are some groups and chat rooms such as Bodies Like Ours and Intersex Initiative that enable intersex people to talk to one another and find peers. The development of the internet and the intersex movement gained momentum during the same time, particularly as it was the first social identity movement to emerge exclusively online (Dreger, 1998; Still, 2008). As such, this momentum allowed for the creation of techno-identities in leading activitism (Grabham, 2007). When looking at intersex under the neoliberal discourses of consumerism, one could argue that the 'person-centred' approach of intersex activism groups may be seen as ‘consumer citzienship’ within medical discourse. The patient is a consumer expecting a certain level of care and to be offered treatment options with the ability to exercise their own personal choice in making these decisions. However, as intersex people are often operated on as children, they do not get to exercise this personal choice once they have the autonomy to do so. Grabham (2007) stated that delaying surgery to gain consumer citzenship, whilst individually helpful, does not challenge the idea that the medical sphere is not the place to negotiate intersex issues, but that a more non-interventionalist strategy may be a better approach for contesting the existing domination medical discourses have over intersex issues. These concerns reiterate the importance of exploring intersex issues through a critical approach (Grabham, 2007).

Bodies of intersex people are also subject to citizenship. Theorists have discussed ‘citizen bodies’ and the distinction in policy-making regarding being ‘controlled by’ or ‘having control’ over your body when accessing health services (Bacchi & Beasley, 2002). For example, women who are seeking services for cosmetic surgery are deemed as having ‘control over’ their bodies and are viewed as consumers whereas women accessing services regarding procreation are largely seen to be ‘controlled by’ their bodies and are often subjected to more intervention from doctors or partners (Bachi & Beasley, 2002). A similar relationship can be applied to intersex children. As a pregnant woman may be reduced to her body, an intersex infant with ‘atypical’ genitalia is also objectified and reduced to their body; a hyper-embodiment subject to higher levels of intervention by others (Grabham, 2007). Conversely, if the intersex person, as an adult, decides to have surgery they then achieve this autonomy and become the consumer, and as such, this concept of citizenship may be positive for the intersex community (Grabham, 2007).

Intersex alignments with other citizenships in activism

As well as feminist theory, the intersex movement in activism may face some issues when aligning with other health-care rights movements such as queer, lesbian and gay, and trans activism due to the differing goals perceived by each movement. For example, some straight intersex advocates at the Intersex Legal Symposium in New York, 2005, perceived the vast majority of intersex people in the USA to be gender- and hetero-normative. In this context, or under this narrative, aligning intersex issues alongside that of trans or lesbian and gay issues may be challenging (Grabham, 2007). Intersex issues and transgender issues may overlap in some areas, such as experiencing issues of shame and encouraged silence, as well as being subject to medicalising discourses surrounding gender and sexuality (Grabham, 2007). There is an overlap with transgender citizenship and sexual minority citizenship, both of which are built on the foundations of founding ideologies of feminist citizenship. Despite having this in common, these three citizenships may have specific concerns which creates tension (Monro & Warren, 2004). For example, gay, lesbian and bisexual identities revolve around sexual exclusively and therefore see transgender as relating strictly to gender. In turn, transgender citizenship recognises a range of genders, unlike feminist citizenship models (ibid). Further, the alignment of trans and intersex activism may be hindered as intersex people may not change their assigned gender or sex.

Intimate citizenship is also of particular interest, and is a broader part of sexual citizenship, focusing on family life, reproductive technologies, sexuality and the relationships between public and private as well as how all these issues relate to recognition. Plummer (2003) discussed how globalisation, media and new technologies have taken over the control of individual lives and builds on feminist viewpoints by combining the private and public spaces. Some examples are the ‘digitisation’ of internet chatrooms as well as the medicalisation of intimate concerns such as the distribution of Viagra, or the ‘technologizing’ of intimacy such as in vitro fertilisation (IVF) (Plummer, 2003). With this blend of private, public, technology and globalisation, the meaning of intimacy is evolving. Intimacy is redefined by Weeks, Heaphy, & Donovan (2001) who describe it as ‘personal life experiments’ surrounding the various formations of family and kin and the decline of non-heteronormative nuclear families. Weeks, et al. (2001) discussed the importance of choice in how these individuals are living in their families of choice, and emphasises the importance of invention, creativity and transformation that occurs when ‘non-heterosexuals’ live their lives. This creativity is described as a ‘moment of transgression’, reflective of the lesbian and gay movement, and equates to a ‘moment of citizenship’ (Weeks et al., 2001).

3.3.3 Feminist theories of sex, gender and intersexuality

Debated topics within different feminist lenses is the need to critique beyond essentialism; to stop reducing gender to a biological essence that is related to their procreative functionality. The feminist movement introduced the construction and deconstruction of gender itself and brought theories of gendered science to the forefront which allowed for the later emergence of intersex theories (Grabham, 2007). However, some aspects of feminist theory examine gender in a way that both obscures yet relies on naturalistic assumptions about sex. The concept of ‘authentically experiencing woman’ in some waves of feminism means that this lens may not respond to the criticism of the cultural and biological divide on sexual difference, meaning that it can therefore not be utilised to sufficiently theorise intersex (Hird, 2000). Therefore, to adequately comment on this concept of sexual dimorphism illustrated in some aspects of feminist theory, the culture surrounding biology must be considered. Morland (2001) responded to Hird's (2000) work and built upon this critique by examining theories about sex and gender as well as exploring concepts surrounding 'genitals means gender'. For example, if a surgeon is operating on genitals to modify their appearance, they are 'changing one's sex', despite not altering chromosomes or genes (Morland, 2001). This alignment is also seen in the concept of 'cultural genitals', the assumption of what genitals are under one's clothing (Morland, 2001; Kessler, 1998). This change in genitals is perceived as a change in sex by the authoritative surgeon and legalities. Intersex contests the conceived notion of the alignment of genitals with corresponding sex which goes against some feminist theory. Both Hird (2000) and Morland (2001) have discussed the relevance of the terms 'nature', 'sex', 'know', 'gender' as other cultural words, similar in definition to cultural genitals, and are key words in progressive feminist discourse. Like how the patriarchal use of these terms and concepts is invasive and oppressive to women, these terms used in a feminist discourse may hurt those with intersex bodies.

Morland (2001) critiques Hird's (2000) usage of quotation marks as an opportunity for questioning genitalia and the classification of sex, similar to how Hird (2000) used quotation marks to question 'nature', 'sex', 'know', and 'gender'. There are noticeable differences when comparing the uncritical, day-to-day usage of 'genital tissue' to the classificatory usage. Uncritical usage is passively unnoticed, sometimes diseased, sometimes excretory, whereas the classificatory usage of the term is unequivocally the connection between genitalia and sex (Morland, 2001). This equation dictates, as an example, that ovaries make a body female, and testes make a body male. Therefore, intersex genitals question this notion of genitality and classification of sex. Despite being able to (usually) pass urine, catch sexually transmitted infections, and experience sexual pleasure in the same uncritical usage of the term ‘genital tissue’, intersex genitalia is ‘difficult and dangerous’ to classify (Morland, 2001). For example, intersex genitals may be viewed as a ‘small penis’ or a large clitoris’; both opinions are classified under a male or female classification, without being either; it may perform some functions of male and female genitals in terms of sensitivity and function (such as potential for erection), yet was not classified as male or female. Further, intersex genital tissue challenges the very classification of differences in sex. As a result, genitals are often cut down to fit an existing classification (Morland, 2001). In these instances, the uncritical and classificatory usage of ‘genital tissue’ is violently eradicated rather than questioned. This eradication disallowed the acceptance of people with intersex genitals to have normal cultural genitals whilst having ‘atypical’ material/physical genitals, as well as prohibiting people with intersex variations to have genital tissue that is a ‘quotation’, (therefore may be subject to questioning) of the genital tissues of males and females (Morland, 2001). Further, the existence of intersex genital tissue questioning this classification of ‘typical’ genitalia exposes the desire for phantasmal genitalia; large penises, dainty clitorises, and capacious vaginas that surgeons are idealising for their patients (Morland, 2001). This may also be known as nostalgic genitalia, ‘a nostalgia for something that never was’ (Garber, 1998. p.168 cited in Morland, 2001, p.365).

3.3.4 Sexuality, pleasure and fantasy

Frameworks of sexuality

To understand the relevance of sexuality in this thesis' study, it was vital to explore the various theories surrounding the origins or nature of sexuality. Sexuality is more than the functionality of one's reproductive system; it may be an identity, an experience, an orientation, or a desire, it may be one or all of these. Further, the notion of sexuality changes across various cultural and historical contexts (Sullivan, 2003). For example, does the 'modern homosexual' experience the same sexuality as the 'paederast', the classical Greek married man who engages in penetrative sex with adolescent males? Even modern homosexuality experiences subjectivity, with married men stating they identify as heterosexual whilst engaging in sex with other men (Sullivan, 2003). This highlighted the difference between sexual identity and sexual behaviours. Whilst essentialists are largely seen as conservative and constructionists are often viewed as being progressive or even radical, it is important to acknowledge that both approaches have been used in homophobic and anti-homophobic political interventions. The argument that people are born homosexual (essentialist) has been used to obtain civil rights for those who identify as homosexual, whereas the concept of 'acquiring' homosexuality (constructivist) through other factors has been used by homophobic groups to suggest that homosexuality can be corrected. As seen in this example, the two frameworks are often used side by side for both political agendas (Sullivan, 2003).

Dawn of the modern homosexual identity

Essentialists see gender as being ‘fixed’ and natural, and the same frame can be applied to their notion of sexuality. Therefore, the same may also be said for a constructionist frame seeing both gender *and* sexuality as culture-dependant, relational and fluid (Sullivan, 2003). Further, a constructionist viewpoint sees that sexual acts that are same-sex have diverse cultural meanings throughout history, and therefore are not identical experiences throughout space and time. There are thus different meanings tied to the same sexual acts; sexual identity is not so much an empirical category, but more of a product of the process of identification itself (Sullivan, 2003). This is also affirmed by Foucault who discussed how homosexuality is a relatively new concept given that same-sex sex acts happened well before there was ever a category for it (Foucault, 1981). Foucault (1981) continued to state how the very categorisation of homosexuality (in the Westphal’s 1870 article on ‘contrary sexual sensations’) itself saw the medicalisation of such a person, it created an identity based on specific sexual acts. Whilst these sex acts were lawfully and religiously illegal, it was not tied to an identity; a type of person, ‘the sodomite had been a temporary aberration; the homosexual was now a species’ (Foucault, 1981, p.49). There is no consensus on the date of which this modern homosexual was created, though other academics have also debated this origin. Bray (1982) suggested an origin date in the late seventeenth century when an urban homosexual subculture emerged in a system of ‘molly houses’ in the north of Thames, where men would gather to have sex with other men. This gave way to the beginnings of a discreet culture, where there were certain ways of dressing, their own jargon and distinctive gestures (Bray, 1982). Therefore, this beginning of a new community existed independently of seemingly random sexual acts between men and other men, forming an identity.

D’Emilio (1992) agreed with Foucault’s statements; this emergence of the modern homosexual arose in the late nineteenth century for the USA, stemming from a Marxist approach. The progression of capitalism, in particular, the free-labour system paved the way to establish homosexuality as an identity. D’Emilio (1992) highlighted how the family unit became less about being self-sufficient in relation to their consumption and production of goods and more about their happiness and emotional satisfaction. This development of happiness and emotional satisfaction above procreation gave way to developing a culture and subsequently, homosexual communities (D’Emilio, 1992). Similar sentiments are shared by Weeks (1977) who also expressed this identity as originating from a restructuring of family and sexual relationships in response to the uprise of industrial capitalism and urbanisation. The theories about the origins of homosexuality discussed are largely about the development of male homosexuality, not just as a particular or preferred example, but because female homosexuality has had a different path of development (Sullivan, 2003). Males and females have not had the same historic positions when it comes to examining the discources of medicine or law. For example, sexual acts between men were criminalised in Britain under the Labouchére Amendment of 1885 which became the foundation for a number of anti-homosexual laws in Western society. As it specified ‘male-persons’, it ignored homosexual sex acts between women by default (Sullivan, 2003). As there was no existing legal ramifactions at the time, there was a much slower emergence of a female homosexual subculture or community.

Faderman (1985) discussed an analysis of historical literature spanning the sixteenth to nineteenth centuries that explored the sexual or highly affectionate relationships between women. She found that romantic relationships between women were socially sanctioned and not pathologised or condemned; there was no indication that these relationships or desires were perceived as ‘abnormal’ by these women. Faderman (1985) goes on to question why this behaviour was once condoned but is now challenged in contemporary society. She suggested that this may be reactionary to first-wave feminism or even the pathologisation of female homosexuality by sexologists who suggested abnormality (Faderman, 1985). Whilst her arguments may seem similar to Foucault’s conclusions about pathologisation, Faderman discussed this as a devaluation of existing female homosexual identity rather than the foundations of the identity itself (Sullivan, 2003). Similarly, Traub (1995) also studied texts exploring female and female relationships. She identified some persistent linkage of the clitoris to ‘tribadism’, an almost precursor to ‘lesbianism’. Coming from a more constructionist standpoint, Traub (1995) confirmed that she is not aiming to identify any ‘pre-lesbian’ identities, or combines the two terms, but suggested that her work aims to highlight the environment in which such an identity may later emerge (Traub, 1995). All of the origins of homosexuality theories discussed have one commonality (except Faderman) – the development from homosexual acts or behaviour to homosexual identity as a result of particular historical contexts. This illustrated how the construction of these othered sexual identities, which more than half of all intersex people relate to in some way (Jones et al., 2016), and even a sense of othering or differing from the norm are a result of sociocultural influences. The condemnation of deviant sexual identities stems from institutions of power, such as governments outlawing such acts, and can be a factor in health-care and parental decisions around intersex youths’ bodies (Jones et al., 2016).

Theories of heterosexuality

When looking at the historical formation of the concept of homosexual identity, it is seen as a ‘deviation of the norm’ or deviation from the ‘stable construction’ that is heterosexuality. This is clear in discourses of power such as in psychology, law, and religion. For example, in some popular psychology discourse, homosexuality is perceived as passing stage in adolescence prior to adulthood. Both religious and legal discourses share similar attitudes towards the definition of family which may state that homosexual partnerships or parents are illegitimate or lesser than heterosexual partnerships (Sullivan, 2003). These discourses, as well as the emergence of the homosexual identity highlight the heteronormative society we currently live in. Whilst heterosexuality is often represented as a norm, or ordinary, it is vital to the emergence of the homosexual identity, as it could not have separated and developed without the existence of its ‘normal’ twin, the heterosexual identity (Cohen, 1993). Given the ‘norm’ status of heterosexuality, it is not deconstructed nearly as often as homosexuality, despite both categories being important. It is not as often examined as a category with a historical and cultural context which in turn, makes it a naturalised, self-confirming norm. Therefore, it is crucial to denaturalise *both* homosexuality and heterosexuality to allow them to both be contextualised to minimise the naturalised, descriptive terminology (Sullivan, 2003).

Whilst one may argue that both heterosexuality and homosexuality are now both naturalised, especially when discussing ‘modern homosexuality’ or ‘homosexuality today’ referring to the historical shift from act to identity as we now know it, contemporary categories of sexual identification are still unclear. Sedgwick (1990) highlighted this by discussing how contemporary knowledges of homosexuality are referred to as fixed or certain when compared to the unstable precursors of the shift from act to identity. She critiques that the development of the Foucauldian framework of viewing these identity formations under the historical context has led to the current formations not being scrutinised to the same standards. Sedgwick (1990) theorised how the modern crises of these identity definitions come as a result of a contradiction of homophobic and anti-homophobic viewpoints. There are two views on how homosexuality is delimited; the *minoritising view* sees a small population who are homosexual as an exclusive population invested in these same-sex sex acts, and *a universalising view* which sees homosexuality as being important to all sexualities in one way or another without belief in a stable erotic identity (Sedgwick, 1990). These may also be viewed as essentialist and constructivist viewpoints, respectively. Sedgwick (1990) used the example of the AIDS crisis to highlight how these views are exercised. For example, AIDS was incorrectly identified as a 'gay disease' (a minoritising view), angering activists who felt targeted. Activists suggested that government agencies broadened their scope from minoritised 'risk groups' to a more universalised 'risk practices'. By doing this, there was better outreach to those who are impacted such as men who have sex with men but do not identify as homosexual, highlighting the importance of targeting acts rather than identities. In thinking about intersex bodies, it is worth considering how much their 'treatment' presumes a minoritising view of homosexuality, instead of the need to support the wide possibility of universal homosexuality.

The absence of sexuality

Sexuality is of course not as black and white as simply heterosexuality and homosexuality, and there is a myriad of sexualities across the spectrum. We need to be rethinking what sexuality is as it goes beyond the scope of heterosexual, reproductive sex to enjoying an array of pleasurable sexual acts and experiences. It is additionally equally important to discuss the absence of sexuality, or asexuality. Butler (1993) refers to asexuality as the ‘constitutive outside’ of normative sexuality. To gain a better understanding of asexuality, one qualitative study explored the needs of those who identify as asexual in a clinical setting and found three themes that contributed to a better understanding of asexuality; ‘romantic differences coupled with sexual indifference, validation through engagement with asexual communities, and a diversity of subasexual identities’ (C. Jones, Hayter, & Jomeen, 2017). By gaining insight into these needs, clinicians can improve the experiences of this group in healthcare. The study also found that a number of participants chose not to disclose their asexual status to avoid being pathologised. This is also a reflection of a lack of education in healthcare as well as lack of general research.

Some literature describes that sexual desire is normal for all groups, a mentality that erases the asexual identity as they are mislabelled as being victims of a ‘damaged sexuality’ (H. Gochros, Gochros, & Fischer, 1986). Further, they compared asexuality to forcibly desexualised identities (terminally ill, institutionalised mentally ill patients, victims, etc.) which furthers the essentialist idea that all people are sexual beings. Tiefer (2006) discussed the influence of the pharmaceutical company on sexuality by presenting things such as ‘female sexual dysfunction’ as an illness to be treated. This further perpetuates the essentialist view of sex or sexual desire being natural and true for everyone. Tiefer (2006) and Scherrer (2008) call for a resistance to medicalisation and to join forces with other sexual minorities to fight for a reform in the medicalisation of sexuality. For example, there may be benefits to the asexual community by joining political forces with disability advocates. Often, people with disabilities are (incorrectly) labelled as asexual beings, however this is often a myth perpetuated by society (Eunjung, 2014). In turn, the asexual community insist that asexuality is not a disorder, deficiency or illness. This mutual negotiation of negating each perception is an effort to be a part of normalcy. However, there is still a need to consider intersectionality between the two groups in order to deconstruct both the desexualisation (disability) and hypersexualisation (asexual) of sexual individuals. Understanding these historical conjoining of the pathologisation of both asexuality and disability gives a greater stance to those working for each respective movement. Cripping asexuality pushes against the intersectional pathologisation and initiates a stronger standpoint for each movement (Eunjung, 2014).

3.3.5 Queering Sex, Gender and Sexuality

The performative nature and subordination of gender

Butler (1990) argues that there are no pre-existing gendered core identities, and that gender is instead performative, a concept that rejects essentialist values; further these theories about gender are considered a postmodern lens. As gender is an act of cultural expectations, this therefore constitutes no universal gender, meaning that all acts of ‘women’ and ‘men’ are open to ‘resignification’. Butler (1990) went on to say that this allowed for subversive action, to use these constructs against patriarchy through acts of gender performance. Sullivan (2003) also discussed the unfixed nature of gender and sexuality, noting how all sexual identities are non-fixed, fractured, and fluid. Butler (1996) describes how there is no proper or original gender. This concept continued with how heterosexuality is an imitation of itself; a phantasmatic ideal performed through an imitation that sets itself up as the original identity and the ground for all other imitations. It lives in a cycle of trying to succeed and always failing, becoming a compulsive and compulsory repetition of itself. This cycle produces the *effect* of its originality, particularly in creating the effects of ‘man’ and ‘woman’ that make up heterosexuality.

With this in mind, consider the homophobic viewpoint that queens or butch women are imitations of the ‘heterosexual real’ or origin. Though, as the original itself is a cycle of copies, these imitations are a copy of nothing, of no true origin. As there are no other grounds for the origin or heterosexual real, it needs its own derivations or imitations to establish itself as the origin; without having homosexual as an imitation, there would be no construct of heterosexuality. However, if this origin needs homosexuality to exist, then homosexuality is the true precursor and becomes the origin, but this only exists in the vacuum where homosexuality precedes heterosexuality. However, as previously established, there *is* no true or original gender or sexuality. Therefore, homosexuality is not attempting to imitate heterosexuality, but to expose it for the cyclical, panicked self-imitation that it is. Whilst heterosexual norms re-emerge in homosexual identities, it affirms that they are constructed but not determined by dominant heterosexual frames. The example that Butler uses is that of drag queens; some may see this as an imitation of women, but if women, as part of the heterosexual origin are itself a cyclical imitation of itself, drag queens are an imitation of nothing, or an imitation of an imitation. The ‘being’ of any gender is achieved through this repetition and creates the illusion of something prior. Gender is not a performance that someone choses to do, but it is performative; it is an *effect* of the subject it aims to express.

This performative nature connects sex, gender and sexual desire. Butler uses the Aretha Franklin lyrics, ‘you make me feel like a natural woman’ to illustrate the connection between how her biological sex is legitimised by her participation in the cultural construct or expression of ‘woman’ as an object of heterosexual recognition. There is a continuity between sex, essence and gender, and sexuality in this statement, and is validated by the heterosexual recognition. Similar to the drag analogy, gender is therefore a performance that creates the illusion of an inner essence or sex (Butler, 1996). For this thesis, it could be argued that institutions or health professionals use this construct of the heterosexual origin to determine ‘derived imitation’ that is intersex; that surgical intervention and imposed gender roles will ‘allow’ them to be an object of heterosexual recognition. Their assigned gender roles are a performance they are required to do to be accepted by social norms. A quote from *Gender Trouble* by Butler perfectly equates the performativity of gender and the connection to institutionalised power; ‘The ‘naming’ of sex is an act of domination and compulsion, an institutionalized performative that both creates and legislates social reality by requiring the discursive/perceptual construction of bodies in accord with principles of sexual difference’ (Butler, 1990, p.145). In the context of this study, this quote summarises the obsession of imposing a sex and gender immediately onto child or infant from authoritative figures like health professionals regardless of their intersex status. Further, this concept of performative gender backgrounds the struggle of going against a compulsive need to adhere to imposed, rigid gender roles throughout life.

Foucauldian ideas of power and sex

Foucault theorised that sex is subject to a series of social regulations that are directed by law, a form of power; this creates the formative aspects of one’s sex as well as gender, pleasures, and desires, therefore making sex a regulated entity governed by power (Butler, 1990). This argument continues to describe how sex is not essential or inevitable, but rather is linked to other discourses such as politics, science or religion. For example, sex became an object of knowledge so that governments may gain further insights into statistics of their populations, highlighting links to the science and politics discourses (Foucault, 1988). Therefore, these beliefs are constructed rather than essential. Foucault also theorises how intersex is disruptive to this discourse as it refutes these regulative laws of sex categorisations. He discussed the concept of ‘biopower’, recognising how knowledge across the sciences in biochemistry through to psychology and surgery have allowed physicians to ‘control the very sex of the human body’. Fausto-Sterling (1993) noted that this concept must be scrutinised, how the initial concept of ‘managing’ intersex variations came from a place of wanting to free people from perceived psychological pain (be it perceived to be by parents’, physicians’ or infants’), and is deemed ‘successful’ if one prescribes to the sex-divided culture where one can only be happy and productive if they belong in one of two sexes. However, these medical ‘successes’ can also be a form of discipline. These bodies are controlled as they embody ‘both’ sexes and subsequently challenge the two-sex system and other beliefs about sexual difference.

Symbolic interactionism – a discourse for dating experiences

The concept of symbolic interactionism is made up of three assumptions: humans responses towards things based on the meanings they attribute to them, how the meaning attributed to a particular thing (such as an act, person, event, place, etc) is a product of social interaction, and meanings are developed, evolved or assessed via an interpretative process unique to that person and are used by someone dealing with their experiences (Blumer, 1986). For example, whilst many people may experience the same event, each person will attribute a different meaning or interpretation of the event based on their subjective social interactions. This may be applied to how one might experience and interpret relationships. For example, Toscano, (2007) used the framework of symbolic interactionism to back the use of grounded theory for their study of dating violence and adolescence; that intimacy and abuse are interpreted as being present as a result of symbolic interactions to the individual within society. Further, that the acceptance and perpetration of violence may exist in a relationship due to skewed perceptions of the development of healthy relationships. Applying this framework to the theme of this study, people with intersex variations may have different experiences in dating and exploring relationships compared to those who are cis-sexed and cis-gendered (meaning their gender or sex identity matches their assigned sex at birth) due to their subjective experiences of being surgically intervened against their will in infancy or childhood. Further, this may also skew their perceptions and experiences of healthcare and may not be willing to access some healthcare services due to traumatic previous experiences.

The queer dilemma in activism

Intersex, both as a community and activist group, is often painted into the LGBTI umbrella. Intersex is often included as a member of this group as they may share similar adversities with lesbian, gay, bisexual and transgender groups in society. For example, the intersex community also experience oppression, being a minority group, denial of freedoms, and a lack of rights. Being part of a larger, public collective identity builds on these adversities, however there are concerns with identity-based organising. It may be difficult to build politics from the common causes when each group in the LGBTI umbrella may have different needs, and may need to be singled out for political ‘usefulness’ (Gamson, 1995). Gamson (1995) argues that fixed identity-based movements are both the basis for oppression as well as the foundations for creating political power. This is known as the ‘queer dilemma’. As a constructionist perspective may show, sexual identities are socially produced (gay/straight, men/women), it is these binaries that form the basis of oppression; fluid sexualities/identities or experiences become a socially controlled fixture. Therefore, by disrupting or blurring these fixed identities or binaries, liberation may be achieved. This deconstructionist standpoint highlighted how clear collective categories may be a barrier to change (Gamson, 1995). Butler (1993) argued that this blurring or disidentification as a political queer feminist strategy allows for a reconceptualisation of bodies as well as a space for emerging bodies that are yet to be factored (such as intersex bodies). Therefore, being a part of an existing movement (LGBT) gives the intersex community a platform of shared adversities in which to build upon existing political powers, however, by identifying with a minority group may also be the basis for oppression in terms of still being on the fringe of a larger group; this may detract from the group’s primary concerns like bodily autonomy (Norris, Covington, & Goodman, 2015) – identifying with only a smaller medical group may for some feel more empowering. Social movements and collective identity evolve and change in ‘a continual process of recomposition rather than a given’ (Schlesinger, 1987. p.237) and are an emergent and dynamic aspect of collective action. Further, identifications of sex, gender and sexuality may be situational and tangible depending on the contexts of interactions.

3.3.6 The complexities of sexual fantasy and desire

Psychological theories of shame and fantasy

In considering sexuality, it is useful to note the work done on sexual fantasy which has largely overlooked intersex issues thus far but may still hold some relevance to intersex narratives on related topics. When accounting for the id and ego, fantasy has been thought to hold a number of purposes such as a defence against harsh or painful truths of reality, as an avoidance or escape of reality, to fulfil wishes, and to live out repressed desires (Greenwald & Harder, 1995; Knox, 2005; Levine, 2005; Rizzuto, 1991; Sandler & Sandler, 1986). Fantasy may also be used to self-soothe, repair feelings of abandonment or rejection, and may (albeit, temporarily) mitigate harm to the self that arose from severe trauma (Friedman & Downey, 2008). Whilst fantasy has many uses, some psychology theories suggest there is a strong relationship between shame and fantasy. Levine (2005) discussed how fantasy is often used in response to experiencing shame. For example, feeling shame and wanting to hide away, but having violent, vengeful fantasies which result in guilt, cycling back to shame. Shame is a feeling of self-evaluation; by feeling undeserving of a particular response from others. One may feel like they are not worthy of love by being themselves, and they may even change themselves to adapt to the ideals of that environment or social scenario. This neglects the needs of the true self to prioritise the expectations of someone else and limits their agency which reinforces the ‘badness’ of the person experiencing shame. Fantasy is then used to cope with this loss of agency and vice versa (Knox, 2005). Shame has also been theorised as an internalised sense of helplessness (Thomaes, Stegge, & Olthof, 2007).

Shame and fantasy are often connected though not always knowingly; pathological shame may also result in unconscious fantasies (Rizzuto, 1991). Those who experience shame will often withdraw (see the aforementioned helplessness) to avoid experiencing the feeling of shame where possible. Where Levine (2005) discussed this amounting to violent fantasies, Rizzuto (1991) noted that this may lead to fantasies where they can be fully embrace being themselves or where they can impress others, or a reality where the shame-occurring incident or experience never took place. Further, these unconscious subject matter of fantasies often happen as a result of not having needs met during childhood (Rizzuto, 1991). Shame may also be experienced by those who are experiencing internalised homophobia. Similar to shame, internalised homophobia may also not be conscious, and may occur as a result of the superego/ego ideals not correlating with one's desire or sexual identity (Downey & Friedman, 1995). Therefore, fears or conflicts about their negative sense of self may be subconscious and therefore, they may not outwardly experience self-hatred or shame.

Empowerment and sexual fantasy

There is much debate in feminist literature as to whether sexual empowerment, particularly for adolescent girls, is conceptualised as an internal feeling of agency and subjective power (power-to) or whether it should be a more objective, quantifiable amount of control and power (power-over) (Peterson, 2010; Riger, 1993). By viewing sexual empowerment as a subjective concept, it may pair agency with institutional or cultural power, however it does legitimise girls' individual perceptions and experiences. There are arguments for protecting young women from objectification and misogyny, and other arguments for encouraging young women to have the freedom to express and experience sexual pleasures, desires and self-efficacy. Lamb (2010) critiqued some models of adolescent sexuality and debated whether *being* empowered and *feeling* empowered are synonymous. They also mused if empowerment is simply a feeling or if should be connected to autonomy and power in other avenues; is it a subjective feeling, or is it an objectively measurable notion? If it is something to be externally measured, this means that someone has the authority to measure and subsequently 'grant' the status of being empowered. Lamb (2010) refuted the idea of subjective empowerment and discussed how some girls may mistake empowerment for a self-sexualised or 'pornified' commercial version of empowerment which in actuality, is just an imitation of male voyeurism and is oppressive to women. Peterson (2010) counters this thought by stating that this is dismissive of girls' own desires and perceptions of empowerment or enjoyable sexuality. Further, Tolman (2000) discussed how the ability to experience or be granted sexual desire and pleasure in a culture that minimises the sexuality of girls can be viewed as an expression of empowerment which also supports this concept of empowerment.

Sexual empowerment can be multi-dimensional. Rissel (1994) discussed the differences between psychological empowerment and community empowerment. Psychological empowerment is one's own sense of control over their life, similar to power-to. Whereas community empowerment involves members of a community who are psychologically empowered are involved in political movements or actions to initiate change or push for resources. Similarly, Chavis & Wandersman (1990) found a reciprocal relationship between participation, or a sense of belonging to a community and a sense of personal control or personal power. This reflected the empowerment theory that involvement in decision making may improve personal empowerment and how in turn, empowered individuals are often involved in community groups or activities (Zimmerman, 1990). Whilst this theory may not be the best to understand sexual empowerment, it may be useful in understanding empowerment through peer-led organisations. Zimmerman (1990) explored the importance choice makes in psychological empowerment, whilst one may not hold political power, they have an understanding of what choices can be made in different scenarios. They also discussed how empowerment is not an absolute threshold, where one slowly reaches the tick box of empowered; it is the relationship between individuals and their environments and may change contextually, a sentiment also expressed by Peterson (2010). This may be applied to this thesis by exploring the levels in which a participant has been empowered or disempowered at various institutional levels, or self-empowerment levels they have achieved through their own identity exploration. These theories of empowerment and sexual fantasy assist in developing a framework to examine how one's sense of empowerment may have effects on their sexual fantasies or desires.

Sadomasochism, desire, and internalised homophobia

Sullivan (2003) critiqued theories on how some sexual behaviours such as sadomasochism are an expression of the inner self. Sullivan reflected on the narratives in the documentary episode 'Pleasure and Pain' of the two part series, 'Wimps to Warriors' (Watson, Munden, & Woolcock, 1991). One man in the documentary was bullied and humiliated to extreme emotional exhaustion during school years and reflected that it might be a way of punishing himself; the documentary also suggested this history of bullying is a cause for his current sexual submissiveness. Similarly, another man in the documentary expresses a desire for control and did not enjoy being touched by women. The documentary suggested this stemmed from being abandoned by his mother as a child which had since given him trust issues. His desire to control or restrain women is a displaced effort to retrospectively control the first woman in his life who abandoned him. These narratives are similar to the theories in Polhemus & Housk (1994) who identified three causes of submissive desires; a means to escape everyday responsibilities or life, a need for attention, or to expunge a deep guilt or self-loathing.

Older literature suggested other reflections of the inner self, such as how gay sadomasochistic (SM) practices are a result of internalised homophobia as the sadist projects (or, delivers transference) these feelings onto the submissive masochist (Rechy, 1979). Similar sentiments are expressed by radical feminists such as Russell (1982) when exploring lesbian SM practices who stated that these practices were therefore anti-lesbian, anti-feminist, and anti-woman. Additionally, Jeffreys (1994) discussed how practices like piercings are a form of self-abuse SM practices, a ‘corporeal confession’; how this is an internalisation of abuse to turn on one's self and a perpetuation of patriarchal violence. These reflections of the inner self are not expressed across all theorists. Hart (1998) suggested otherwise, that there is neither no constant or completely disjunctive distinction between fantasy and reality in SM. That is to say, that there is no cause and effect relationship between history or trauma and sexual desires. Other theories surround the concept of acts. Hopkins (1994) theorised that SM practices are simulations under a different context. For example, SM participants do rape scenes, not commit rape. These thoughts are similar to Foucault's (1997) suggestions that SM practices are a recontextualisation of acting out power structures.

Whilst some of these theories are anti-SM practices, the researcher acknowledges that there are a number of different attitudes towards SM practices expressed by theorists and to explore them all would be beyond the scope of this thesis. The theories that suggest SM practices reflect the inner self or indeed, a reflection of internalised homophobia may be a useful framework in understanding the purpose or origins of fantasy (or sexual acts) in marginalised populations, such as the intersex and LGBTI community in this study. These concepts of whether shame or reflections of the impacting sexual fantasy or desire are used to explore the differences between sexual practices and sexual desires in this study. Exploring this level of subjectivity is one of the goals of navigating the narratives of lived experiences.

3.4 Theory Challenging the Compliance View of Engagement with Institutions

3.4.1 Institutions

Institutions rely on people to do gender in order to comply (such as biological citizenship), and rebelling against this may instigate change (Risman, 2004). However, Berger & Luckmann (1967) theorise that institutions emphasise both control and historicity. Therefore, institutions both always have a history and in turn, are products of that history. Berger & Luckmann (1967) go on to argue that institutions do not develop spontaneously to societal goals or needs, and that they have controlling attributes, ‘to say that a segment of human activity has been institutionalized is ... to say that this segment of human activity has been subsumed under social control’ (Berger & Luckmann, 1967. pp.55). The material body also has a part to play in the dynamics of institutions and should be studied without inducting biological reductionism or other aspects of gender essentialism (Connell, 1987; Giddens, 1984). However, the institutional aspect of this theory dictates that these gendered policies, including organisational practices, are a powerful conceptualisation connected to bodies. All the dimensions of gender structure theory are intertwined, each informing the other. In the context of intersex, the internalisation of gender identity develops because of how the law defines intersex at an institutional level. Further, this institutional social control trickles into how intersex people do gender; how they are expected to behave and present themselves and how they are perceived by others on an interactional level (Davis, 2015a).

3.4.2 Bio-politics

Governing entities often use their power in an effort to control their populations. Foucault (2003) discussed how the sovereign, or powerful institutions decide who gets to live or die; to ‘take life and make live’ and ‘make live and let die’ in the 19th century (Foucault, 2003. p.240). This may speak to the sovereign actively taking a role in both taking life and choosing not to protect the lives of their citizens. By failing to protect some citizens, this illustrated that those lives were not as valued if they did not fit the constraints of a healthy ‘normal’ population. This started to be debated in the 17th and 18th century, how can one protect life but also take it? This power play shift was accompanied by a change in perspective from individual bodies (man-as-body) to man-as-species (Foucault, 2003). Disciplinary acts of power such as surveillance transformed to a regulatory power which called for newer strategies of population surveillance, catering for the now and future populations. The governance of a whole population was being controlled through bio-power; examining the population through a lens of healthy and not healthy or productive and not productive. This bio-political framework illustrated how the state has moved from focusing on the individual to the population. However, the individual must still be scrutinised to normalisation to evaluate their worth to the state, therefore, their individualised body becomes bodies of the state and government. These bodies are scrutinised and are subject to marginalisation and discrimination should they fall outside these parameters of ‘normalcy’ with lesser rights. Using the bio-political lens, it is clear that the intersex population are no exception when it comes to being exposed to scrutiny by institutions of power. The intersex population is subject to medicalisation including not just surgical intervention, but the categorisation of ‘intersex’ itself as they do not fit the standards of a typical body (Das, 2014). Intersex/ DSD is deemed a ‘condition’ that requires treatment to be ‘fixed’. Disabled bodies are placed under the same scrutiny and share adversities. Further, there are some laws and policies which allow for some complex intersectionality between these two populations. This in itself highlighted the manoeuvres of a bio-political state and how it aims to categorise certain populations (Das, 2014). Puckett (2000) applied this Foucauldian ideal to intersex people aptly; ‘The matrix of discourse on sexuality, since the end of the Sixteenth Century, gradually put the liberty of naming one's own sex out of the hands of the person and into the hands of the institution’ (p.1).

3.4.2 Challenging power in institutions

Foucault examined the relationship between power, discourse and knowledge and used the example of the classification of different sexual perversions. He stated that using powers of analysis at the same time as gaining new knowledge creates new power. Relating this to discourse, what is known about something and how that knowledge was obtained directly influences the way in which the subject is spoken about. Foucault recognises the ‘repressive hypothesis’ and discussed how the nature of the relationship between power and sex is born out of repression. That power (or ‘insistence of rule’) is exercised to mask sexuality; to keep conversations about sex behind closed doors and is something to not be discussed nor even thought of, as illustrated by taboo and legislations. Any discourse on sexuality was restricted to marriage, between man and wife. Foucault refuted this hypothesis, stating how instead, power is used to introduce sex into discourse rather than exclude it in order to explore it in a more analytical focus. Therefore, the power introduces sex into the discourse to create knowledge (Foucault, 1981). Further, Foucault describes how sexualities are a technology of power; a way to organise people as a whole, similar to the earlier discussed concept of biopower. For example, social norms enforced the act of crimes and sodomy as a temporary disorder rather than the person or 'self' committing the crimes. Foucault discussed how modern power creates people who 'carry' identities such as the criminal or homosexual (Foucault, 1976). However, the more visible the identity, the more likely it may be a trap leading to increased surveillance, regulation and self-regulation, leading to more power-knowledge of the newly understood sexual groups (Foucault, 1979).

This may be applied to the policing of intersex bodies; as a visible body, an intersex person is subject to more scrutiny by doctors, parents, institutions and peers than those who are not born with an intersex variation. They have increased surveillance (repeated examinations, a subject for medical school students), they are more heavily regulated with surgical and medical interventions and strict rules surrounding the adhesion to gender roles and norms and are required to self-regulate by self-reporting this adherence back to medical professionals.

3.4.3 Gender structure theory – Pressure from above

Gender structure theory examined gender as an institutionalised and governed social structure; a foundation for stratification in culture, personalities and institutions in a complex manner (Risman, 2004). This theory discussed how those may only see the options they feel are made available to them, as a certain gender. For example, women who are parents may ‘pick up the slack’ because they feel the father may not contribute an equal level of responsibility and see no alternative. This is a prime example of acting on a perceived constraining choice (Risman, 2004). Therefore, if men and women continue to view themselves as different kinds of people (not ‘similarly situated others’), women are less likely to compare their available options to those available to men. This example illustrated the power that gender can have and highlighted how deeply embedded this notion is. Other structuralist theories (Epstein, 1988; Kanter, 1977) have previously examined gender, conceptualising that if gender-related identical structural conditions and expectations were eradicated, observable gender differences would vanish. However, this ignores internalised gender on an individual level as well as cultural interactional expectations of gender for men and women (Risman, 2004). Giddens (1984 cited in Risman, 2004) added to this by considering the cyclical nature of actions and reflexivity; individuals shaping social structure which, in turn, shapes individuals. This difference highlighted the variances in these theories, as well as reiterated the importance of acknowledging the deeply ingrained sense of gender at an individual, cultural and institutional level. Further, this individual reaction may come from habit rather than questioning their own action – this forms the cultural component of social structure within this theory. In contrast, post-structuralists and post-modernists tend to view sex as a group with many possible outcomes; a spectrum between the two extremes of female and male, or even a combination. Further, these may then sometimes be falsely socially categorised (Fausto-Sterling, 2012).

With this approach, gender structure theory can be used to examine when gendered behaviour is habitual and what is done with intent or rebellion. Further, it can be used to analyse the differences in opportunity and constraints experienced by different sexes and genders; at an individual level when developing a sense of gendered self (individual), during interactions with other sexes and genders (cultural), and institutions where policies, resource distribution, and regulations are gender specific (structural) (Risman, 2004). The individual dimension of this theory consists of the development of the gendered self, stemming from the internalisation of gendered personality traits and a female or male identity. These masculine or feminine traits and behaviours may arise without thought, unchanging, or nonreflexive. This may be what is presented when exploring the interactional dimension of gender structure, and how people may represent themselves to illustrate this, such as through gendered clothes, mannerisms or hairstyles; this is how people ‘do gender’ (Davis, 2015a). Doing gender is not only self-presentation, but a kind of social psychology that categorises sex and gender, a foundation for stereotypes and gender expectations which influences how one is treated or expected to behave in society (West & Zimmerman, 1987). Gender is therefore performative in nature, developed on the basis of repetition, exhibiting the same certain behaviours or words both by people and towards people (Butler, 1990).

3.4.4 Structural functionalism – conforming to roles within the family and society

There are multiple theories about what may influence or illicit behaviours in individuals. Whilst behaviourism explored how behaviour is learned through conditioning (such as the classic example of Pavlov's dogs), functionalism examined how individual behaviours are prompted by the idea of social control (Repo, 2013). With influence from early systems theory, society could be seen as an amalgamation of structures and institutions including laws, religion, education, and family to develop and maintain a social order. Structural functionalism explored these structures, processes, relationships and acts that ensure the preservation of social conformity. This conformity or 'social norm' is said to be clear, therefore, any violation of these norms can be defined and controlled separately. Thus, this theory holds the assumption that societies require a level of social control in order to function (Repo, 2013). Parsons & Bales (1956) describe how these processes of social control and socialisation were essential to ensure conformity to individual roles that could perpetuate the status quo. This included having a 'nuclear family', an ideal family model that perpetuated successful socialisation. Further, the role of this family was to ensure that children were socialised into 'sex roles' to ensure they grew to be reproducing adults within society. Parsons & Bales (1956) stated this was a precursor to 'normal psychological development' and subsequently, the continuation of the cycle of social order. Rose (1999) noted that Parsons' work made clinical psychology and other positions of expertise essential to this maintenance of social order which allowed further influences of government control into the family unit.

The 'roles' aspect of Parsons' work was applied to some of John Money's research which had a more behaviourist approach, stating that gender was socialised and imprinted during infancy; a behavioural response to certain stimuli such as gender performative attitudes and experiences (Repo, 2013). Further, he believed that this imprinted state could contradict other biological sex indicators in the body, and was permanent once established, which became the premise for much of his future work (see the John/Joan case in chapter 1). Money used this theory to ‘correct’ the genitalia (‘stimulus’) of intersex infants to the gender role they could be best socialised into to avoid ‘misprinting’ into a permanent, ambiguous or incorrect gender role (Repo, 2013). An intersex child then becomes a subject of biopolitical potentiality; by creating these ‘normal’ genitals, the child may grow to have a ‘normal’, heteronormative nuclear family, and fit neatly into their designated sex (and gender) roles to perpetuate the cycle of social order. This imposition of gender on a child’s body is literally a ‘…machinery of power that explore[d] it, br[oke] it down and rearrange[d] it.’ (Foucault, 1991, p.138). Parents also became a part of this process as both part of the experiment and as an enforcer of discipline towards the child’s assigned gender (Repo, 2013). Money reasoned that the gender should be reaffirmed by parents, peers and siblings, which in turn, gave them a disciplinary power over the child; the family becomes responsible for the management of the imposed gender. As imprinting occurred during infancy, these crises were presented under a discourse of urgency, being guided by unquestioned authoritative voices to ensure their compliance. This functionalist rationality utilised family and parental figures as access point to control the individual behaviours of the child. Thus, institutional structures can enforce social norms through the distribution of power. When applied to the subject of this thesis, people with intersex variations are subject to the imposition of sex and gender roles by authoritative figures such as doctors and parents to adhere to the status quo of the social order of the essentialist gender expectations of men and women.

3.4.5 ‘Protecting’ the innocence of children in institutions

There are several theories when it comes to the constructions of ‘the child’ in institutions, many of which come from an authoritarian perspective. Whilst some of the following constructions come from an education context, they may be applicable in both a broader application and specifically, in health. Children are often framed as innocent or pure; fragile beings in need of protection. Jones (2011) explored child constructs from conservative to liberal constructions in the context of education. One of the more conservative constructions is ‘the romantic child’; the ideal that children are devoid of any sexuality, naturally asexual, protected from knowledge; an empty vessel not yet filled from outside sources (Jones, 2011). Such outside sources are the gatekeepers of information from positions of authority such as adults and institutions (schools, medicine, government, etc.) who may give or deny knowledge or information. Controlling this information means that children are unable to pursue or possess knowledge on their own accord, it may only be given to them. Particularly, withholding sexuality information ensures the protection of the innocence of the child (Egan & Hawkes, 2010). The romantic child is a precursor to ‘the knowing child’. The knowing child is still required to have their purity protected, however they possess a sensual body with complex emotions and are not ignorant to desires (Irvine, 2002). This child is at risk of misinformation or corruption from outside sources. Protection is given by directing behavioural guidance when it comes to matters of morality, gendered behaviours and sexuality.

Moving away from conservative constructions, there are four more liberal constructions of ‘the child’ including the Informed Decision-Maker, the Sexual Decision-Maker, the Developing Sexual Decision-Maker, and the Gendered Decision-Maker (Blair &

Monk, 2009). Whilst parents or concerned communities are still identified as protectors, there is a lesser emphasis on the need for protection. The Informed Decision-Maker is viewed as child + sex = abuse (governance is referred to external sources such as the law); and child + sex = adult (treated as a decision-making adult guided by authoritative institutions like parents or school). For the latter, information is given to them to aid in their informed decision making and primarily addresses sexual risk such as pregnancy and sexually transmitted infections, or social risks including dating. The Sexual Decision-Maker is similar, but the sexual nature of the person is considered, acknowledging that some knowledge will come from their own practice experiences beyond received education. Information given may include an assortment of sexual acts, freedoms and responsibilities. Building upon this further is the Developing Sexual Decision-Maker, who is seen as one who requires particular information but only some, as they are at a particular stage of being able to process information (Egan & Hawkes, 2010). Therefore, they are given ‘age-appropriate’ information to make their decisions at various stages of development. Finally, the Gendered Decision-Maker is similar to the aforementioned models, but with a greater emphasis on the effect of gender in decision-making, such as women being equal to men and having choice over her own occupations and body (Jones, 2011).

Robinson (2005) discussed how many of these constructions of ‘the child’ occur within the more conservative constructions when it comes to sexuality and young people who identify as lesbian, gay, bisexual, transgender, intersex or queer/questioning (LGBTIQ). Further, information given to young people by institutions operates under the notion that this group is non-existent; the focus of information given is around heterosexual reproduction, meaning any sexual acts outside this do not exist. Therefore, knowledge given is largely heteronormative, isolating a number of young people. There are also child constructs that look to the future, such as the construction of the Sexual Citizen. For example, a gay liberationist places emphasis on combating homophobia via identification and eradication of direct and indirect sources. Further, there is a focus on acknowledging, supporting and protecting the marginalised LGBTIQ community with an effort to make LGBTIQ issues more visible in society (Jones, 2011). Whilst these constructions of 'the child' are discussed in an education context, these constructions may be applicable in a healthcare context. This thesis considers the constructions of 'the child' when discussing authoritative powers such as parents or healthcare professionals when it comes to what knowledge intersex children receive about their own bodies and treatments. The voices of children are often ignored when it comes to sexuality research. As Casper & Moore (2009) discussed, this is due to an Institutional Review Board (IRB) process that is both inadequate and heavy-handed, developed in a culture where children are perceived as pertaining 'innocence', despite this not necessarily being reflective of their reality. Whilst this work has discussed children in a broader context, Davis (2015a) has shown children's voices are rarely heard in both decisions regarding their own bodies, or even in the broader debates about intersex care and management, even though they are the most acutely affected by medical management (Davis, 2015a). The voices of children are framed via a retrospective voice from intersex adults reflecting on their childhood experiences and the way institutions responded to them when they were children.

3.5 Conclusion

Critical and postmodern frames suggest the importance of focussing studies on marginalised groups' own perspectives on their experiences in institutions (Davis, 2015a; Jones, 2017, Liao & Simmonds, 2014; Morland, 2008). However, rather than focusing on the leaders of marginalised groups, Morland (2008) emphasised the importance of non-authoritative voices and narratives on the lived experiences of being intersex. The study this thesis focuses on, therefore, explores the key problem of intersex peoples' sociocultural experiences of healthcare from the perspective of people from the general international intersex community without a focus on intersex authority, specifically through surveys bringing their voices forth. The theory around sexuality and gender norms and the social stigma attached to being outside of them further underline the importance of offering people opportunities to talk about these issues with anonymity, such as via an anonymous online survey.

The study by Davis (2015a) propositioned that healthcare around intersex people currently occurs in the later stages of Conrad and Schneider's (1992) five-stage model of deviance. Specifically, much of Western healthcare around the world (though not all) reinforces the legitimacy of medical ownership of intersex variations and institutionally recognises a medicalised deviance despite the resistance by intersex groups. The nature and extent of the resistance varies country to country despite the existence of organisations such as OII Australia and must be considered in the internationally focused study that this thesis reports on. Therefore, while this study draws on the five-stage model, it does not assume that all participants exist in a context that has reached the fifth stage. Theoretical writing around medicine and intersex people emphasises the problem of the positivist paradigm for doctors and the lack of recognition of bodily autonomy. These were the key areas to consider in analysing the data. By having an understanding of the essentialist framework that health professionals often operate in gives context to the grounds as to why they are delivering certain treatments and sex assignments to people with intersex variations; to fit them into a 'normal' binary body (Davis, 2015a). Using the critical framework to analyse these data challenges this essentialist or biological lens of looking at bodies. The essentialist ‘essence’ also affects citizenship, blocking some rights or treatments to people with intersex variations as they are viewed as ‘troublesome and impossible citizens’ outside of the two-sex binary (Rose & Novas, 2005). Given the complications to access this may initiate, it became vital for this study to explore experiences in healthcare from intersex voices, as participants are asked to reflect on their experiences in healthcare, mental healthcare and how they think healthcare could be improved for themselves and their families in the future.

Morland’s (2001) critique surrounded the of notion of genitals = gender used by health professionals in conjunction with the concept of ‘cultural genitals’ has directly been applied to the intersex population. The need for ‘phantasmal genitalia’ is idealised from health professionals towards patients. This theory has been applied to this study to further illustrate why and how doctors are assigning sex and gender, and further highlights the essentialist claims of health professionals when treating intersex patients. It is therefore appropriate to explore the differences between current gender identities and assigned sex and genders at birth, and surgical intervention in this study. Butler’s (1990) theories on gender being a performative action is applied to this study to justify asking participants if they found their reared gender and subsequent gender roles inappropriate as well as determine if they were treated the same as their siblings. This will allow them to reflect on their feelings about gender performances which may have been enforced and if their siblings were held to the same high expectations in this area.

The number of theories explored here in relation to non-heteronormative sexual identities illustrated how the othering of sexual identities stem from institutions of power by outlawing ‘deviant’ (i.e. non-heteronormative) acts and are therefore, a result of sociocultural influences (Traub, 1995; Sullivan, 2003; Weeks, 1977; D'Emilio, 1992). This can be applied to the lived experiences of the intersex population, and the othering they have experienced as a direct result of institutional powers. This study uses these theories to justify exploring participants' experiences of sexual identity; what that experience is, and if it is fluid. This includes exploring how they were treated by others, particularly those in positions of power (parents, institutions such as healthcare and schools) as a result of a non-heteronormative sexual identity. Whilst symbolic interactionism has not been directly used for intersex populations, it has been used to explore adolescent experiences of dating. This study will use this theory to understand how the dating and sexual experiences of the intersex population may differ to those who are cis-sexed and cis-gendered as well as how the subjective experience of surgical intervention has coloured their future sexual experiences. This lens can also be used to understand why they may not choose to access healthcare from previous traumatic experiences. Further, this reinforces the need to hear intersex voices to gain a deeper understanding of how they respond to things based on the meanings they have attributed to them. The psychological theories on fantasy give grounds for a base understanding of why fantasy may occur. As these theories indicate, it may stem from avoiding reality, escapism and to live out repressed desires. These theories suggest that fantasy may occur from feelings of shame or internalised homophobia, or on a more positive note, even used as a form of sexual empowerment. As the literature dictates that the intersex population frequently experiences shame (Beh & Diamond, 2005; Herdt, 1990; Jones et al., 2016), this study uses these theories to justify exploring sexual fantasy to see whether this bears any influence. Further, exploring sexual fantasy allows for analysis between sexual identity, sexual experience, and sexual fantasy to see if these are correlated or if fantasy differs from experience and why.

Finally, having an understanding on the theories of power used by institutions to enforce gender roles, sexual identity, and the two-sex binary assists in understanding why intersex populations are exposed to more scrutiny by, and why they may be more reactionary towards institutions of power. This idea is furthered by the structural functionalist theories of how behaviours are influenced by social control (Repo, 2013; Parsons & Bales, 1956). This study proposes that people with intersex variations are subjected to conforming to strict gender roles and expectations imposed by institutions of power including healthcare, schools, and the family unit. Thus, it would be appropriate to explore experiences at school, and relationships with their family members to determine the extent of which they were treated differently to their peers regarding the imposition of sex and gender roles from authoritative figures.

Chapter Four: Methodology

4.0 Introduction

The previous chapter highlighted significant gaps in literature that surrounded longitudinal studies of intersex individuals which emphasised gaps in literature surrounding long term studies, school experiences, family relationships, lived experiences in gender, and sexual experiences and desires. This provided the needs analysis for the basis for this research project. This also highlighted the lack of qualitative research which informs the methodology of this study. This chapter describes the methodology and research approach of the research project. It will explore the mixed method research approach and rationale followed by the research design and method. This informs the sampling strategy and development of the mixed method survey. The survey development and implementation is explored further. The outcomes of the survey are introduced in the research sample section. The information needed for the study will be explored, leading into research procedure, the ethics approval process, and recruitment. The data collection methods will be explored followed by how the data were analysed. Ethical considerations were pivotal for this study, and as such, are then explored in detail. This chapter then concludes with the validity and reliability of this study.

4.1 Qualitative and quantitative research rationale and approach

This study was developed utilising both qualitative and quantitative methods, resulting in a mixed methods approach. There is no one approach to conduct qualitative research, as it is a an ever expanding field of inquiry (Denzin & Lincoln, 2011). Some qualitative research approaches consist of exploring a topic matter via the participant themselves, rather than dictating a particular response. By ‘entering the world’ of participants and allowing them to speak freely about their experiences, valuable information may be revealed including their social framework, interactions, values and circumstances (Bloomberg & Volpe, 2008; Denzin & Lincoln, 2011). The purpose of this approach is to gain an investigatory broad insight via participants’ descriptions and may even become a foundation for theory from the data (Woods, 2006). One particular qualitative method that was applied to this study was a ‘grounded’ approach.

The grounded approach or ‘grounded theory’ in qualitative research allows a further exploration of a topic matter, particularly in areas which have little research (Grbich, 2009). It provides a platform for the participants to tell the research story. This method utilises data collection and analysis to inform each other through an ever-developing process (Charmaz, 2011). This approach contrasts greatly with quantitative research methods which rely heavily on statistics to test a previous theory or hypothesis. Using a grounded approach is particularly useful for establishing the needs of a population or group. This is highly applicable for this study, as it requires sensitivity to the participant’s contexts and meticulous, descriptive data (Huberman & Miles, 2002).

As there is limited qualitative research in intersex studies, utilising grounded theory is essential to analysing data by allowing the participants to tell their stories to fully encapsulate the context of the lived experience of the intersex community. These recollections form rich or ‘thick’ descriptive data which form a basis for developing its own theory from the ground up via exploring lived experiences, as opposed to applying an existing theoretical application to the dataset prior to analysis (Charmaz, 2008).

Whilst there are different components of grounded theory, this study will largely utilise the line-by-line initial grounded theory coding, as it brings the researcher into the data and allows them to interact with each piece of it (Charmaz, 2011). This method also helps to find meanings and comparisons between data points and may even reveal a narrative from the character of the data.

4.1.1 Research design and method

Utilising the internet for data collection allows for a faster administration of surveys, further flexibility in design, and is more cost effective than traditional methods (Best, Krueger, & Smith, 2001). Furthermore, it is more easily accessible to hard-to-reach groups (Bernard, 2012). It additionally allows marginalised groups to utilise the disinhibiting nature of the online world such as having the advantage of the invisibility and anonymity as well as being able to delay responses that involve disclosing information they may ordinarily keep to themselves (Barak et al., 2008).

As the literature review previously stated, most studies regarding the intersex population are clinical based. Surveys are underutilised for this target group which has the potential for collecting diverse and rich data. Face to face (or Skype) interviews are valuable and it allows for instant further elaboration and clarification, but these can be both costly and time consuming, in addition to often requiring numerous phone calls to secure just one participant (Bernard, 2012). In contrast, surveys allow multiple people to be interviewed at the one time are more cost effective. Additionally, all participants receive exactly the same questions which may eliminate bias from the researcher or response effects and allows for more complex questions (Bernard, 2012). As such, this study utilised a mixed methods survey for the majority of data collection.

As mentioned in the literature review, there is a lack of long term follow up studies for intersex people who have had surgical interventions (Lev, 2006; Schober et al., 2012; Jones, Hart, Carpenter, Ansara, Leonard, Lucke, 2016). Jones et al. (2016) reiterated the absence of large scale mixed method surveys in intersex research, and noted that surveys allow for a more sociological approach rather than the historic pathologising method of clinical studies which additionally, may be physically invasive. This information informs the use of this data collection method for this study.

With the data collection method selected, this study utilised SurveyMonkey, an online survey system, to formulate and deliver the exploratory questionnaire. The aim of the study was to collect demographic data about the participants as well as provide a platform for participants to tell their stories under various categories. The participants chosen for this study were adults (over 18 years of age) who were intersex. The survey was open to intersex individuals who had and had not had surgical intervention in infancy and childhood.

The internet was a vital component to the study for both delivery and participant recruitment. As there is no current worldwide (or even Australian) register for individuals diagnosed with an intersex variation, locating individuals in this target group would prove difficult and therefore, would limit the study’s potential reach.

Closed questions were utilised at the beginning of the study to gather demographic data. Following this, there study largely consisted of open-ended questions but still utilised some closed questions throughout. Utilising open ended questions allows participants to discuss as much or as little as they choose when articulating their experiences, feelings, opinions and behaviours. This method allows the researcher to fully appreciate the depth and range of experiences and emotions of the participant (Huberman & Miles, 2002; Patton, 2002). Text boxes were allocated unlimited text to allow participants to provide fuller responses where they could expand and reflect on their prior experiences.

The researcher of this study acknowledges that the intersex community may experience feelings of secrecy and shame and that it may even be the first time sharing these experiences and stories for some intersex participants. Therefore, the use of anonymity via a computer allowed for a confidential, naturalistic, and safe environment for participants to describe their personal histories, feelings and experiences (Bernard, 2012; Dohrenwend, 1965; Fricher & Schonlau, 2002). This anonymity may allow for participants to be more forthcoming with their experiences surrounding sensitive topics.

Questions were formulated in a chronological order using predominantly open-ended questions surrounding life experiences from infancy to adulthood in an effort to reduce recall bias and improve the validity of the retrospective method. This ordering was deliberate in order to aid memory retrieval (Brewin, Andrews, & Gotlib, 1993).

This study additionally involves an action research approach as it investigates a comparison on the conditions and effects of varying forms of existing social actions (reconnaissance), developing an understanding of these social actions, and finally, resulting in the research outcomes leading to developing the steps towards social change (Lewin, 1946; Elliot, 1965). For this study, the social actions in question are the experiences of intersex children in order to improve their circumstances and care in the future. Some of these areas may be investigating social action between doctors and parents, doctors and intersex people, access to healthcare services, intersex people and their family relationships, intersex people and school policies and experiences, and intersex people and romantic and sexual relationships through a retrospective lens.

4.1.2 Sampling Strategy

To ensure the research questions would instigate relevant and rich data, it was vital to locate participants who had lived experience of the needs of intersex individuals. As this survey was investigating this from a client-centred approach, the recruitment of intersex individuals was the sole target group for this questionnaire. Rich data is more likely to be obtained if the participants feel the questions are important to them and have a personal interest in the subject matter (Charmaz, 2006). Therefore, individuals with an intersex variation were selected as the most appropriate population for the survey regarding the needs of the intersex community. Intersex adults were selected for their intimate and subjective understanding of life as an intersex child, adolescent and adult.

Strategic and purposeful sampling was utilised in order to focus on the knowledge and experience of this population. The snowball technique was also used for recruitment, allowing for participants to suggest the survey to other individuals in the targeted community.

Participants were sourced from Australia and internationally in order to provide a broader range of views and experiences as well as to obtain a sufficient number of participants. A population sample was not used given the broad range in figures surrounding prevalence of intersex variations. Additionally, the nature of having an intersex variation is a sensitive subject, therefore, not all intersex individuals may be comfortable openly discussing their experiences. Furthermore, many intersex variations go undiagnosed so finding a definitive number for a population sample of intersex individuals based on prevalence and population sizes of each country would not be an accurate figure to aim for recruitment for this study.

Participants for this study were initially recruited via targeted advertising in intersex support groups and online support forums. Intersex support groups who approved of the study sent the survey description and website address out to their members via emails, newsletters or advertising on their website (*AIS Support Group Australia, OII Australia, Genders in X, Beyond XY, LGBTI Health, AIS Support Group UK, AIS-DSD Support Group for Women and Families*). Online community forums allowed for direct advertising of the study (*Bodies Like Ours, FetLife*). As the snowball technique was utilised for recruitment, it is possible that qualifying participants may have come from outside of these support groups.

Eligibility requirements for the survey included access to the internet, and the ability to speak English, in order to avoid any translation issues. The survey was designed so it could be completed by intersex individuals who had and who had not had surgical intervention at some point in their lives. A forced-choice question allowed participants to select if they had or had not had surgical intervention as a child or infant and participants could enter their ages of surgical intervention and diagnosis. Participants were also given numerous opportunities throughout other questions to comment about surgical intervention during later stages of life, such as adolescence, adulthood or not at all. These questions surrounding surgical intervention and diagnoses allowed the researcher to remove any participants who were not diagnosed with an intersex variation and whom were therefore, not eligible for the study.

The survey was uploaded into SurveyMonkey and formatted to incorporate ‘skip logic’ as well as being formatted to include quantitative data from drop down boxes. The survey was launched 13th July 2014 where the link was distributed to the relevant parties and was later closed on the 10th July, 2015 when an appropriate sample had been collected.

4.2 Development of the Survey

The survey development was enriched by the inclusion of academics and intersex individuals. The individuals involved in this development were consulted for input and feedback. Input and feedback on the study proposal was received from a member of an intersex support organisation particularly surrounding terminology and accuracy which was of great value. Further utilisation of reference groups is highly recommended for future research.

Upon completion of the development of the survey, it was distributed to eligible intersex participants (n=2) for a pilot study to ensure that the questions would elicit relevant responses that reflected the needs of the intersex community, in addition to being sufficiently sensitive to the target group.

The survey included open- and closed-ended questions to collect rich and meaningful responses from participants as well as demographic data. The open-ended questions were written in chronological order, beginning with demographics and interventions during childhood (including infancy). The purpose of this order was to elicit contextual responses in the relevant period of their lives as well as allow time for participants to reflect on their personal history and experiences. Placing these questions on a chronological timeline was designed to prompt recollections of participants and to prepare them for further comprehensive participation in later questions surrounding puberty and adulthood. The survey completed with an open-ended debriefing question for participants to add any further comments.

‘Skip logic’ or skip-patterns are common in web-survey design and are a popular choice for removing errors of omission (participants not responding to an applicable question) and unnecessary burden (participants responding to non-applicable questions) with ease (Peytchev, Couper, McCabe, & Crawford, 2006). Skip logic was used throughout the survey to ensure that all responses were voluntary, and to allow participants to skip questions that were not relevant to them. One example of this was the series of questions regarding changing genders. Upon the initial release of the survey, these questions were mandatory to answer. Some complaints (n=4) were raised regarding the necessity of these questions as they did not apply to every participant. Skip logic was introduced shortly afterwards as a solution to ensure that they became voluntary. This was essential to ensure that sufficient data was requested whilst allowing participants to skip questions that were not applicable. This also allowed for more agency and control from the participants so they could answer only questions they felt comfortable answering and give them more ownership over the research, which was a vital component to the study to ensure its adherence to a sociological framework rather than a clinical frame. Following this decision, the only questions that remained mandatory were in the initial demographics section.

4.2.1 Mixed methods survey questions

Effective probing questions play a pivotal role in quality research. Questions were phrased as neutrally as possible to minimise any bias or deference effect that may come about as a result of question phrasing (Bernard, Wutich, & Ryan, 2017). For example, ‘describe your sexual experience’ was a question aimed to probe participants to discuss sexual activity, sexuality, as well as share any positive and negative experiences. If the question was phrased ‘have you had any negative sexual experiences’, a deference effect may occur, creating bias data.

Adults with an intersex variation were asked 11 demographic questions followed by 37 questions surrounding childhood, adolescence and adulthood. The survey explored the impact of being intersex on their friendships, their relationships with family members, their experiences at school, and experiences throughout their life as well as exploring experiences with dating, relationships and sex. The latter questions regarding adolescence and adulthood were designed to contextualise their current insights and recognising their experiences and views after childhood. Allowing participants to discuss their adulthood experiences may assist them with personal comprehension, allowing them to debrief after their lengthy recollections of childhood experiences. This, in a way, forms a journal which may also be therapeutic to the participant (L’Abate, 2011).

The survey also investigated participants’ views of services and existing healthcare management of intersex variations. The survey requested that they identify services that were useful to them during childhood, adolescence, and adulthood and asked what services they think may have been beneficial to either themselves or their families. The survey concluded with the last question inviting further comments from participants. A list of support services including websites, support groups and mental health helplines were given at the completion of the survey, should the participant need to debrief about recalling potentially traumatic memories and discussing personal information of a sensitive topic matter.

4.3 The Research Sample

Participants were included in analysis if they completed a minimum of one open-ended question. This ensured that the analysed data reflected the represented participants in the demographics. From a total of 101 participants who responded to the survey, 86 were included in the analysis. Some participants completed the survey twice (n=5). These participants were only analysed once in the dataset. This is represented in Table 4.1.

Table 4.1

Number of Participants who responded to the Survey

Survey Participants	(n)
Responded to the survey	101
Responded only to demographics	10
Responded twice to the survey	5
Total	86

4.4 Information needed to conduct the study

The aim of this study was to identify the needs of people with intersex variations via exploring intersex peoples' experiences of healthcare, their gender, sexuality and sexual satisfaction, and their relationships in social settings (for example, school experiences, developing friendships, and family relationships). Therefore, the study explores the sociocultural experience of healthcare for intersex people. When seeking answers to the research questions, it was vital to obtain demographic, perceptual, theoretical and contextual information (Bloomberg & Volpe, 2008).

Demographics were obtained from each participant from the mixed method survey. The demographics addressed the participants' age, education level, occupation, relationship status, their assigned sex at birth (if known), country of birth and residence, chromosomal status (if known), and whether they received an intersex diagnosis and when. Further contextual information was sought about diagnoses regarding who the diagnosis was from, and how that diagnosis was performed (for example, DNA test, physical examination, etc).

Perceptual information from participants was a vital component of this study. This consisted of allowing the participant to explore their concerns, attitudes, approaches, emotions and reactions regarding the experience they were describing.

A literature review (see chapter 2) was conducted to form the basis of a needs analysis regarding the issues that face the intersex community. Many of these studies stated that existing literature was limited, and it was clear that there were few qualitative studies aiming to identify the needs and experiences of the intersex community, with the exception of Jones et al. (2016), and Davis (2015a; Davis et al. (2016); Davis & Wakefield (2017). The needs of the community were identified from existing literature; thus, became the basis for the development of the target areas needed for the survey questions.

4.5 Research Procedure

Prior to the development of the surveys, the key researcher conducted the literature review and conferred with two intersex individuals to identify key concerns for the intersex community and subsequently, pilot the study.

4.5.1 Ethics Approval

The approval from the Human Research Ethics Committee on 7th August 2014 (project number 2014/225) at the University of Sydney. This approval was inclusive of all advertising (Appendix C) and survey documents (including questions), in addition to the participant information sheets for the survey (Appendix A).

4.5.2 Recruitment

Participants were recruited via newsletters of support organisations, website forums for intersex people, and further spread via word of mouth and social media. Recruitment was later amended to include recruitment from public social media profiles who publicly associated themselves with an intersex support organisation.

4.6 Data Collection

4.6.1 Data collection methods

Data were collected utilising the internet. The survey was administered via SurveyMonkey, which allowed for a direct download of data upon completion of the study. The internet is highly effective for surveys and has illustrated significant benefits in terms of recruiting international participants and allowing for a greater range of responses (Pequegnat et al. 2007). It also provided greater flexibility in the research design, such as utilising skip logic to make the survey easier to navigate for participants. Whilst some may see the internet as a survey tool that is problematic in terms of concerns such as generalisability (Best, et al., 2001) and coverage (Hoonakker & Carayon, 2009), this may not be so problematic when targeting minority or stigmatised groups.

The internet is highly valuable for accessing minority or stigmatised populations, such as the intersex community. Many previous studies are based in clinical environments or from clinical referrals, or individual stories. Given the small population of the intersex community, the internet is also a valuable tool for connectivity amongst the intersex community on a global scale.

Data obtained via the internet has been shown to be just as reliable and high quality as data collected via telephone or paper surveys (Denscombe, 2006; Rankin et al., 2008; Touvier et al., 2010). Participants responding via the internet are shown to provide further information with more frequent responses to open-ended questions compared to postal surveys (Gunter, Nicholas, Huntington, & Williams, 2002; Hoonakker & Carayon, 2009).Therefore, it is more suitable for participants who are required to disclose confidential or sensitive, more vulnerable information (Pealer, Weiler, Pigg, Miller, & Dorman, 2001).

In order to minimise potential inaccuracy in participant responses, there was some overlap in questioning throughout the open-ended surveys as well as asking multiple questions surrounding the same event.

A high response rate was valuable but not required as it was a largely qualitative study. As this did not need to be transcribed, the length of answers was not a concern and therefore, there was no need for a limit on open-ended questions or the number of participants. Whilst this may be a limitation of the study, the exploratory approach required targeted participants and the internet provided a sufficient amount of input was required.

4.6.2 Data Collected

Information was collected from the online survey to create the final reports for this study. Data collection began in August 2014 and was open until June 2015 for participant recruitment. Whilst 101 participants began the survey, only 86 were included in the analysis as some participants completed the survey twice (n=5) or only completed the demographics section and did not respond to the open-ended questions in the survey (n=10). The overall coverage of responses to open-ended questions was very high (see Table 4.1). At times, participants felt the questions were repetitive but often would further elaborate on their previous responses or redirect attention to a prior response. This aided to triangulate important issues raised by participants.

To keep the data anonymous, all participants were assigned a computer-generated participant identification number (PID). Given the intersex community is small, PIDs were only shown to the researcher during analysis and have been withheld for reporting to increase the privacy of participants, as some details may make a participant recognisable to others.

The ‘other comments’ question at the end of study allowed for participants to share further comments on their experiences. In this field, some participants commented their praise or gratitude towards the study, others used this opportunity to be critical of the study and its contents, and some simply provided more comments on their life or attitudes towards intersex treatments and research.

Overall, the responses obtained via the survey were rich recollections of the lived experience of being intersex. These responses provided sufficient data for content analysis in addition to allowing the researcher to gain further insight and sensitivity to the intersex experience. This progress of awareness via contextual sensitivity encouraged a deepened insight and holistic perspective of participants’ experiences.

There was insufficient interview data captured for a thorough analysis. Whilst 61 participants stated they would be interested in being contacted for further interviews, 13 email addresses bounced, 10 participants did not give enough information for further interview, and 31 did not respond to the interview request or follow up attempt. Of the remaining 15, some could not find a time that suited them (different time zone scheduling conflicts) and opted out or did not attend the interview time. Only one interview was recorded, thus, analysis was not conducted as more were needed for sufficient analysis. It is possible that too much time had passed since survey recruitment and participants had lost interest in any further participation.

4.7 Data Analysis

The qualitative data in this study was analysed utilising grounded theory as a part of content/thematic analysis (Charmaz, 2008; Grbich, 2007). To accurately analyse the content, the data were investigated via each participant as well as through responses for each question, followed by a final, holistic summary. Responses were coded under the guidelines by

Buckingham & Saunders (2007) using ‘discrete categories’, where a code was assigned for each category of response.

4.7.1 Coding the data

Coding most of the open-ended responses for quantitative analysis was done via a manual method in Excel that required a logical way of thinking using a numbering system. This was an intuitive method of implementing the Buckingham and Saunders (2007) categorisation. This method made it easier to track previous steps and analysis as well as making the data more visible and accessible for review. An example of the initial coding of the open-ended questions is presented in Table 4.2.

Table 4.2

Sample of coding performed on the intersex mixed methods survey

Theme	Cat no.	Item
Full disclosure about my variation	1	Why I was getting treatment, why my expressed desired were overruled, why my agency was ignored. I don't give a damn that I'm infertile, I care that I was forced through a puberty that I didn't want and nearly killed me. [sic]
That I was okay/not abnormal	2	That it was okay to be me
That I was informed at a younger age	3	Yes. I would've preferred to have known this at age 12.
That I had options	4	What other options for treatment were available.
That I was not alone	5	That they were lots of people like me all over the world. My parents and I were left isolated. [sic]

Each question was analysed and coded separately to ensure that each process of analysis and subsequently, the production of the ‘needs’ for the target group, were as clean or as removed as possible to the following question to ensure it was not determining the future themes and categories.

There was constant re-evaluation of the data and codes throughout the analysis process to ensure saturation and to improve accuracy. Each classification or key was reduced or expanded to best accommodate as much of the response data as possible for that question. Responses that were stand alone or not quantifiable as a code in a question were flagged for qualitative investigation.

All manual, open coding was done in an Excel spreadsheet which could be viewed by question or by participant on a one-page matrix. This allowed for the researcher to view all responses from each participant in addition to cross checking responses across one question. The coding process involved a number of logically sound decisions regarding significance and meaning to ensure that responses were placed in the appropriate and sometimes multiple categories. Each section of this data was analysed holistically to identify the ranges of feelings and experiences for each theme. Responses were then moved into themes and categories. This process was repeated three times to ensure accuracy and integrity in the analysis. Any discrepancies identified in the quantitative codes were discussed by the primary supervisor and their two supervisors to find the most appropriate category and were identified by the inter-rater reliability assessment. Each participant’s response was read as a whole to identify any overall themes or missed categories. This also allowed for further immersion and familiarity with the dataset.

4.7.2 SPSS qualitative analysis

Once manual coding was completed, the numbered responses were placed into a statistical analysis program (SPSS version 21) to check for any correlations in the data. Some categories for questions were collapsed into overarching themes or broader themes in order to gain greater, quantifiable saturation. Demographical statistics were analysed, as well as an investigation into the relationships between data points and testing for trends and significance. Some t-tests were conducted, though often the same size was too small to identify significance. As a result, mostly chi-square tests and ANOVAs were used to analyse the data as it was categorical and not continuous. Chi-square tests aided in being able to determine whether the distributions of the categorical variables are the same. Expected count tests were additionally useful in analysis.

4.7.3 NVivo qualitative analysis

Qualitative data was cleaned of any existing quantitative codes and placed into the program NVivo for text analysis and coding. This program is useful in textual interrogation, identifying word-based repetitions or querying word frequencies, concept maps, word clouds, text queries, and other relevant features for qualitative analysis. Using programs such as NVivo or Leximancer aid in preventing the researcher from pre-empting or ‘faking’ themes as it allows the researcher to both map how themes were extracted and simultaneously provide evidence, such as word frequency queries. Given that NVivo only shows the data and coding that is physically there in-text as well as its internal coding system (nodes), this program is crucial to providing stability and reproducibility (if used correctly).

This program is not without limitation, it does not offer insight on the social meaning of words, take into account visual grammar or spelling errors from the original data, identify silences or negations or examine a broader context. Furthermore, some word text queries include all verbs which may not be of use or relevance to the analysis unless you are coding gerunds. Gerunds are used to analyse action and how these actions are related (Charmaz, 2011). These were not actively investigated as this is a retrospective study and gerunds did not provide the same insight as investigating nouns such as emotions, experiences or relationships in the data.

Primarily, this program was utilised in this study for word frequencies and text for further context. The data were too small to create adequate concept maps, so this approach was not exercised.

Some word frequencies were either not included or shortened in reporting to remove irrelevant words to the data or words that were identified in the question phrasing and therefore, offered no valuable input to the analysis. Most word frequency queries were run on automatic settings, including grouping synonyms which were individually checked by hand, any irrelevant synonyms were removed, though these instances were rare.

The data itself was read manually by the lead researcher in NVivo and was then coded (open-coding/line-by-line coding) into ‘nodes’ or themes. Some nodes were grouped into bigger concept categories to gain a more comprehensive, ‘big picture’ overview of the data for each qualitative question. These nodes were then reported on by node theme, for example, participants discussed school experiences for one question, one theme identified in the responses was ‘sexuality and gender identity’ (n=12). Within this group were other sub-themes, for example, not dating in high school (n=4), and further again, feeling too self-conscious to date (n=4). These were coded into nodes and concept categories such as *sexuality and gender identity > not dating in high school > too self-conscious to date in high school*. This allowed for specific grouping and seeing how themes related to bigger themes.

4.8 Ethical Considerations

The ethical considerations for this study primarily relate to informed consent for participation, anonymity and confidentiality, and sensitivity in addition to the validity of the research. However, there are other ethical considerations that must be taken into account for marginalised populations.

4.8.1 Ethical considerations for intersex research

Whilst there are deliberations to be had for sensitive groups, there are further considerations required when investigating the intersex population. It is vital to ensure a sense of ownership by the intersex community for intersex research (Jones, et, al. 2016). The researcher sought this by contacting leaders of intersex support groups and individuals to form a reference group. Some members of this reference group were able to provide invaluable feedback on the initial project proposal and pilot the survey.

Another important ethical consideration for intersex research is the degree of freedom and control participants would have interacting with the study (Jones, et, al. 2016). Participants were able to opt out of the survey at any time, did not have to answer questions they did not want to, and had the ability to give any suggestions or additional comments at the end of the survey. This was communicated in the participant information sheet at the commencement of the survey which read ‘Submitting a completed questionnaire/survey is an indication of your consent to participate in the study. You can withdraw any time prior to submitting your completed questionnaire/survey. Once you have submitted your questionnaire/survey anonymously, your responses cannot be withdrawn' (Appendix B). As well as informing participants of their opportunities to opt out, it also ensures that they acknowledge that their submission of their responses would contribute to evidence of their consent to take part in the research.

It is vital to consider the difficult nature of reflecting on certain life periods for intersex people (Jones, et, al. 2016). Wording of questions should be both politically correct and respectful and support service contact information should be offered at the start and commencement of the survey. As the intersex population is relatively small, it is essential to be mindful and considerate of 'research fatigue' which may be experienced by this group as they are repeatedly disclosing personal information to researchers (OII Australia, 2012a). Anonymity should be insured for the intersex participant's protection at both the input and output stages of the study. Randomised participant identification numbers were issued to each completed survey with an optional section for an email address should they wished to be contacted for follow up stages of the study. Confidentiality and anonymity were furthered by limiting the researcher (and their three supervisors) who had direct access to the data as well as removing any identifying information in all quotations form participants' responses in any manuscripts and reporting. IP addresses were collected by default from SurveyMonkey, however this data was not needed and removed prior to analysis.

Sensitivity is a vital component of this study. Given that this study calls for participants to recall traumatic memories and experiences, it is essential that the questions and delivery of this investigation are approached in a sensitive manner. Whilst it is a delicate balance, given there is often tension between researchers and vulnerable or stigmatised target groups, it is necessary to conduct research with these kinds of target groups in order to improve the lack of resources and improve future care (James & Platzer, 1999).

4.8.2 Ethical considerations for sensitive groups

Approaching sensitive target groups can be aided by self-disclosure of some of the researcher’s own stories or experiences to ‘level the playing field’ and ensure there is no hierarchy or power play between researcher and participant (Dickson-Swift, James, Kippen, & Liamputtong, 2007). Additionally, building a rapport to establish trust with the participant is also beneficial. This can also help to humanise the researcher to the participant. It is essential in qualitative research to remember that participants are not a number, they are a person. As participants are revealing private, sensitive details about themselves, it is encouraged to return this sentiment by being honest and caring towards this person (Dickson-Swift, et al. 2007).

Conducting research with sensitive groups may also have effects on the researcher. Guilt may be common when investigating qualitative research with participants, and researchers may hold onto feelings of guilt regarding the impact the research may have had on the participant or feeling that they have ‘used’ their participants as a means to an end (Dickson-Swift, et al. 2007). Conflicts of excitement and guilt about obtaining the data are also common. This in turn, may also lead to emotional exhaustion, or even vicarious trauma for the researcher. At times, the researcher found this to be overwhelming and experienced compassion fatigue during analysis; in hindsight, the researcher should have pre-emptively considered vicarious trauma training. This is recommended for future researchers to consider when conducting research in populations who have experienced trauma; this assists in developing compassion fatigue resiliency which can minimise stress and prevent emotional burnout (Potter, Pion & Gentry, 2015).

4.8.3 Community reception

Existing intersex research is largely dominated by a medical or clinical discourse. Comparatively, there is limited (but emerging) existing social research identified that investigated the needs of the intersex community from a psychosocial perspective in the literature review process. Any relevant material close to this theme had very limited participants or individual stories, highlighting the need for large scale mixed method studies in intersex research. Therefore, this is an area worthy of further investigation, making this study valuable. The interest from intersex participants has, at times, been apprehensive, but overall the study was met with enthusiasm, further illustrating the need for further research in this area. Some participants were appreciative of the researcher's efforts *'Thank you for interest [sic] and your work and advocacy is appreciated!'.*

4.9 Validity and Reliability

The validity and reliability of qualitative research is based upon its trustworthiness; evaluated by its transferability, dependability, confirmability and credibility (Lincoln & Guba, 1985). Bochner (2001) stated that it is the quality of listening to the voices of the silenced in an attempt to empower and destigmatise people, to open up a dialogue to create a 'better social world'. Listening to these unheard voices allows for greater immersion into the 'real world', meaning that the data attained holds ecological validity.

The debriefing, scrutiny and persistent immersion in the data and field may all contribute to the credibility of a research project (Lincoln & Guba, 1985). Debriefing with a number of supervisors, both experts and multidisciplinary peers was ongoing throughout the entire study; from conception of the research proposal to the final submission of the thesis. All aspects of this thesis and research project were scrutinised under peer review in efforts to consistently improve and refine the final components of the work. Immersion in the field of the intersex community was obtained by continuing to follow intersex advocacy groups and relevant news to stay updated on the needs of the community. Datapoints in the survey were compared for differences and similarities to ensure consistency and reliability.

4.10 Inter-rater reliability assessment

Furthermore, inter-rater reliability assessment was completed on the quantitative data. Inter-rater reliability testing may be beneficial where results are being coded by hand, other research designs, or by an in-experienced coder (Hallgren, 2012). Additionally, it adds further validity to the data eliminating some potential bias. This test was performed on the data by three academics who had not seen the original open-coding performed by the lead researcher. These academics followed a set list of coding rules developed by the lead researcher in order to determine the reliability of the coding. Each 'codeable' question was given a random number assignment in Excel using the command '=RAND()*100'. The values were then set by copying and pasting the value rather than the formula. The questions were then sorted from smallest to largest and the first five questions were selected.

The initial coding ranged from 100% concordance to 50% for Question 23B. After some deliberation, the researcher and their supervisors discussed preliminary inter-rater reliability results and further clarified the coding rules about blank codes for question 23B and the priority of consultation over and above happiness. The rules were then updated, and the other assessors went from a 55% to an acceptable level of 80% overall. Whilst question 23B question had the lowest rate, it was later analysed via qualitative rather than quantitative analysis.

Steps were also taken to ensure consistency and reliability for the qualitative data. Data was coded in the program NVivo utilising nodes. Word frequency queries also highlight crossover with extracted themes, making this analysis reliable and replicable for transferability by other researchers.

Transferability consists of external validity via ‘thick descriptions’ that allow the reader to determine if the conclusions of the presented research are applicable to their own circumstances (Lincoln & Guba, 1985). The real-life contexts and experiences were demonstrated via utilising participants’ individual responses, which additionally contributed to the ‘vividness’ of the study, allowing readers to connect with their experiences (Polkinghorne, 1983).

The dependability of this research stems from the researchers who were not involved in the development of the study but evaluate whether the interpretations and findings of the study are supported by the data (Lincoln & Gupa, 1085). This contributes to the reliability of the study. Further, the confirmability of this study comes from the objective nature of the project that exposes how the findings are impacted by such things as bias, interest or researcher motivation. This objectivity is demonstrated via audits, peer review, and triangulation processes (Lincoln & Guba, 1985).

Triangulation is achieved by investigating the data by participant and cross checking the themes with viewing the data by question responses. Additionally, triangulation was reached by comparing the qualitative data with the quantitative data; using the two methods together rather than treated as separate approaches, allowing for a more holistic view of the study (Jick, 1979).

The ‘better social world’ (Bochner, 2001. p.152) is something to strive towards that is elaborated best in the projects aims and outcomes, and the potential to contribute towards further research to inform a healthier and safer management of intersex children to develop into emotionally healthy people.

4.11 Conclusion

This chapter has explored the qualitative and quantitative research methods rationale including the research design and method used, and how the surveys were developed from the needs analysis from the literature review. This informed the questions developed for the survey to obtain data to ideally bridge the gaps in existing intersex studies. The ethics process was discussed followed by how participants were recruited from intersex support organisations and via a snowball effect. Both qualitative and quantitative data analyses were discussed regarding their respective programs (SPSS and NVivo). The chapter then explored the ethical considerations for sensitive groups including intersex groups, and concluded with discussing how the study was tested for validity and reliability.

As the methods and methodologies have been established, the following chapter will report on the findings regarding the first of three results chapters; intersex people’s attitudes and experiences in healthcare management.

Chapter Five: Intersex People’s Concerns and Desires in Healthcare Management

5.0 Introduction

The literature review identified a need to further explore the needs and experiences in healthcare management. This chapter explores the quantitative and qualitative findings from the mixed method questionnaire that was delivered online to participants. To begin, this chapter will first explore the demographics of the participants with intersex variations in order to give greater insight to this sample of the intersex population. This chapter will secondly discuss the intersex status of participants and their age of diagnosis. It thirdly reports the qualitative and quantitative findings regarding the participants’ experiences and attitudes around physical healthcare, experiences and attitudes around mental healthcare. Finally, the chapter outlines the participants’ ideals for intersex healthcare management and draws conclusions on the main findings in this area.

5.1 Survey Participant Demographics

5.1.1 Age

The mixed method survey reached a total of 86 participants who completed the survey. Only two participants did not answer the age question. Of those who did (n=79), the ages ranged from 22 to 71 years of age, with the mean age being 43 years. This range provided an expansive, historical view of intersex management over the decades.

5.1.2 Location

Data were collected from individuals born in 19 different countries across the globe. Of the 80 who completed the question, the majority of participants were born in the USA (n=38), closely followed by the UK (n=10), and then Europe (n=10). The UK was separated from Europe in analysis as some participants specified the UK rather than Europe, thus, this differentiation was used. Additionally, European participants may have experienced different cultural experiences which was important to investigate. Whilst America, Europe and the UK have much denser general population sizes than New Zealand and Australia for example, the higher numbers of participants that were from USA were perhaps linked to the high numbers of support groups available in these regions.

Table 5.1

Participants' countries of birth and residence (n=80)

Region of Birth	Total	Region of Residence	Total
Africa	1		0
Asia	3		1
Australia	8		12
Canada	9		8
Europe	10		11
New Zealand	1		2
United Kingdom	10		6
United States of America	38		40

Some participants did move internationally at some stage during their lives. Participants moved from the UK to Australia (n=2), from Asia to the USA (n=2), from the

UK to New Zealand (NZ) (n=2), from Canada to the US (n=2). Further, one participant moved from the UK to the US, one moved from NZ to Australia, one moved from the US to the UK, and one moved from Africa to Australia.

A qualitative investigation into the participants that moved countries showed minimal differences, however the participant who moved from Japan to USA received no diagnosis until adulthood and was gender neutral until they were adopted at age seven.

5.1.3 Education

Participants had an array of educational backgrounds, with 34.6% (n=27) completing tertiary education and 26.9% (n=21) completing postgraduate studies. A further 13.8% (n=11) stated they had completed some tertiary education and another 13.8% (n=11) completing a trade certificate. Only 10.3% (n=8) had halted their education after high school, however; it is unclear as to whether they *completed* high school. Two participants did not answer the question, which perhaps may indicate that they did not finish high school, as this was not an option on the drop-down box to select from. As such, this appears to be a more highly educated group of intersex participants compared to a recent Australian study which found 18% of 272 people with intersex variations had not completed high school (Jones, 2016), which may relate to particular contextual health and education experiences being different from country to country, or may simply reflect a lack of choices for lower rates of education in the questionnaire.

5.1.4 Sex and Gender

Participants were able to write in an open text box to enable a range of responses for their assigned sex at birth. Most participants (n=43) were assigned female at birth (54%) and 31 stated they were assigned as male (39%). One participant stated they were assigned male, then female at birth. Another participant noted they were assigned female, then reassigned male at three months of age. The two participants who were not assigned at birth were aged 28 years and 44 years, suggesting no major change in intersex management over the time period corresponding to the ages of birth, in this sample. An important finding showed these participants are in the younger half of the sample, however these numbers are too small to make any conclusions. Only three participants chose not to disclose their sex at birth and indicated this question was too personal.

Table 5.2

Participants' sex assignment at birth (n=80)

Sex assigned at birth	Total
Female	43
Male	31
Ambiguous	1
Not assigned	2
Did not disclose	3

To compare any changes in rearing or ill-fitting gender identities since birth, participants were asked to state their current gender identity in an open-ended question. This question design was aimed at ensuring the data could encapsulate the range of subjective gender identities of each participant. A total of 60 participants responded to the question, with 31 participants (51.5%) currently identified as women, 10 identified as men (16.5%), three stated they were gender fluid (5%), two identified as genderless (3.5%) and the remaining seven identified as having a combination of identities (11.5%). Some of the subjective terms used or collapsed into the aforementioned combination of identities included the following:

- Agender
- Transsexual
- Soft butch
- Androgynous
- Pangender
- Genderfull
- Masculine intersex
- Drag queen out of drag
- Gender neutral
- Herma

In total, this means that 31.5% of participants had identities that challenge the two gender binary norms and identify as either fluid or their own subjective interpretation of gender. When looking at binary and non-binary identities with age, there was no significance found, with the average binary identity age being 44 and the average non-binary identifying age being 42. A qualitative investigation of the data illustrated that some participants actively state their rejection of existing gender norms, *'If I could become third gender, a hermaphrodite I would. I was born to be both an I want my body to be both'.*

When looking at sex at birth and current gender identity, there are some changes over time. Those who were assigned female at birth (n=43) currently identify with a range of genders, with 44.2% (n=19) of females identifying as women. A total of 18.6% (n=8) of assigned females did not disclose their current gender, and 13.9% (n=6) identified as men. Additionally, 9.3% stated that intersex was their identity, with the remaining 13.9% (n=6) stating they were either gender fluid, genderless, or a combination of identities.

There was a total of 31 participants who were assigned as male at birth. These participants also currently identify with a range of genders, with 32.3% (n=10) currently identifying as women and only 12.9% (n=4) identifying as men. A total of 9.7% (n=3) stated that intersex was their identity, and the remaining 9.7% (n=3) identified as a combination of identities. Of the remaining two participants, one was not assigned a sex at birth and described themselves as gender fluid, and one chose not to disclose. This reflected findings in an Australian study that those assigned male at birth were particularly likely to have a different gender identity later in life, compared to those assigned female (Jones, et al. 2016).

5.2 Intersex Status

5.2.1 Intersex Variation

Understanding the range of intersex variations was paramount to understanding the diversity experienced within the intersex umbrella. A total of 74 participants stated they did receive a diagnosis of some kind, with only six saying they received no intersex diagnosis. Fewer participants answered this question clearly with 65 of the 74 who were given a diagnosis at some time were able to give us an initial, ‘recognised’ diagnosis. Some intersex variations were collapsed into categories in order to get a clearer snapshot of the range of variations. For example, complete Androgen Insensitivity Syndrome (cAIS) and partial Androgen Insensitivity Syndrome (pAIS) were collapsed into simply AIS. Additionally, some intersex variation names have changed over time. The current terminology was used to envelop prior terms to avoid confusion and unnecessary categories. For example, those who listed their variation as ‘male pseudohermaphrodite’ became categorised under the current terminology, 46XY (Kaneshiro, 2015). Of those who did know their diagnosis at birth, AIS (n=16) and Congenital Adrenal Hyperplasia (CAH) (n=8) were the most common intersex variations diagnosed which aligns with the relative proportions of these conditions among intersex populations (Jones et al., 2016). Progestin Induced Viralisation (PIV), Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome, and Swyer Syndrome were the least common variations stated by participants, with only one participant in each respective category.

Table 5.3

Frequency of intersex variation diagnoses (n=65)

Intersex variation	Total
CAH	8
AIS	16
Klinefelter Syndrome	7
46XY	3
46XX	2
MRKH	1
Swyer Syndrome	1
Mosaicism	4
Ambiguous genitalia	10
Hypospadias	3
Gonadal dysgenesis	2
Ovotesticular	4
PIV	1
Unknown	3

5.2.2 International ranges of intersex variations in this sample

In terms of which regions had the highest amount of specific intersex variations, Canada had the highest number of participants with Klinefelter syndrome, and USA contained the highest number of participants with AIS, followed by Europe (see Table 5.4). These numbers may not necessarily reflect an increase in diagnoses in their corresponding regions but may be more of a reflection on the specific support groups available in those regions.

Table 5.4

Crosstabulation of intersex variation by country of residence (n=73)

	USA	Canada	Australia	Asia	Europe	UK	NZ	Africa	Total
CAH	4	1	2	0	1	1	0	0	9
AIS	7	0	4	1	5	2	0	0	19
Klinefelter Syndrome	2	4	1	0	0	2	1	1	11
46XY	2	0	0	0	1	0	0	0	3
46XX	1	1	0	0	0	0	0	0	2
MKRH	1	0	0	0	0	0	0	0	1
Swyer Syndrome	0	0	0	0	1	0	0	0	1
Mosaicism	3	0	0	1	1	0	0	0	5
Ambiguous genitalia	6	1	1	1	0	2	0	0	11
Hypospadias	2	0	0	0	0	0	0	0	2
Gonadal dysgenesis	0	0	0	0	0	1	0	0	1
Ovotesticular	4	0	0	0	0	0	0	0	4
PIV	0	0	0	0	0	1	0	0	1
Unknown	1	1	0	0	0	1	0	0	3
Total	33	8	8	3	9	10	1	1	73

5.2.3 Age of Diagnosis

Diagnosis occurred at several different ages throughout the survey participants' lifespan. Specifically, 34.2% (n=26) were diagnosed from pre-natal to three years of age, with only six participants being diagnosed between the ages of 4-10. As some variations go undiagnosed until puberty, another spike in numbers occurs with 13.2% (n=10) being diagnosed from ages 11-17 and another 13.2% (n=10) between ages 18-25. As the diagnoses were then scattered over the age span at 31.6% (n=24), the last age grouping was 25+. The six who stated they did not receive a diagnosis at birth, two were diagnosed later in life, one stated they were diagnosed later in infancy, and two remained undiagnosed. A qualitative investigation revealed that their stories suggest they have an intersex variation (for example, genital scarring, delayed puberty, etc.) despite never receiving documentation on the nature of their intersex status.

Disabilities

Disabilities were concurrent with intersex status for 12.5% (n=10) participants. A qualitative investigation found that seven of these participants were diagnosed with an unclassified disability (three of whom received a disability pension), one had a learning disability, and another participant described a 'developmental disability' but did not describe whether this was a physical or learning disability. This is a lower percentage than the Australian study by Jones et al. (2016) who found 27% of intersex participants also had disabilities. However, the incidences of disability for this sample may not be accurate as participants in this study were not directly asked about concurrent disabilities and thus, may not have offered this information voluntarily.

5.3 Physical Healthcare Experiences and Attitudes

5.3.1 Experiences of Surgical Intervention

The question ‘*did you receive surgical intervention in infancy and/or childhood*’ was a mandatory question in the questionnaire. A total of 49 participants stated they did receive surgery during this time, and 30 participants stated they did *not* receive surgery during this life stage. This does not necessarily mean that the remaining participants did not receive any surgical intervention, as they may have been exposed to surgery later in adolescence or early adulthood as seen in the qualitative analysis. To gain better insights into differences by age of respondent, the ages were divided into under and over 40 years of age. As 64.3% (n=21) under the age of 40 had received surgical intervention in infancy or childhood, this may suggest that this has not been a declining practice in the last half century.

A percentage of participants had repeat surgeries throughout their childhood and adolescence. Of the 49 participants who stated they did have surgical intervention in infancy or childhood, 42.8% (n=21) went on to have further surgical interventions prior to adulthood.

5.3.2 Global rates of surgical intervention

Investigating surgical intervention around the globe showed that six out of the seven (85.7%) born in Australia had received surgical intervention in infancy or childhood, and 20 out of 25 (80%) participants born in the USA received surgical intervention. Six out of 10 (60%) participants born in the UK had received surgical intervention, whilst five out of nine (55.5%) of European participants received surgical intervention during these years. Lastly, three out of eight participants (37.5%) born in Canada had received surgical intervention. Whilst it is likely that those born in Canada may result in less rates of surgical intervention, there is insufficient numbers to determine any conclusive statements; further cross-country investigations may be worth exploration.

Table 5.5

International frequency of surgical intervention (n=74)

		Yes	No	Total
Country of Birth	USA	20	15	35
	Canada	3	5	8
	Australia	6	1	7
	Asia	2	1	3
	Europe	5	4	9
	UK	6	4	10
	NZ	1	0	1
	Africa	1	0	1
	Total	44	30	74

When participants were asked how they felt about the status of their surgical intervention, a total of 95.5% of participants (n=64) stated they felt the surgery was inappropriate with three stating they felt that the surgery was appropriate. Participants were given the opportunity to discuss this further in an open-ended question, and 40 participants expanded. Responses were diverse and as such, difficult to quantify. A qualitative analysis showed that the lack of consent was the most common theme expressed (n=11) followed by six participants who disclosed being given a gonadectomy, six discussed psychological trauma, five discussed being given a clitorectomy, clitoromegaly, or clitoroplasty, four reflected being coerced to take or are now dependent on hormone replacement therapy

(HRT), and three mentioned damaged genital sensitivity or reduced sexual pleasure, and a final three mentioned feeling shame about their surgery or surgically altered bodies.

Two participants discussed feeling 'forced' into a transition, *'I felt like I was transitioned against my will, and [sic] treated according to medical ethics paradigms that I would not have consented to as an adult'*, the other feeling forced to transition from female to male as a mid to late teenager. These statements further highlight the lack of consent and bodily autonomy.

A later question asked, '*if no, reflecting on this as an adult, do you wish you had received surgical intervention as an infant? Why?* (see Figure 5.1). This question was answered by 46 participants, despite it being targeted only towards those who had not had surgery in infancy or childhood (n=30). This indicates that many participants felt they had more to say on the issue. A total of 76% of participants (n=35) stated no, they did not wish they had received surgical intervention in their early years. Furthermore, one participant stated they wished they had it later in life, and 7.5% (n=6) said it was not applicable which may be due to an intersex variation that has no physical 'atypical' external differences such as cAIS.

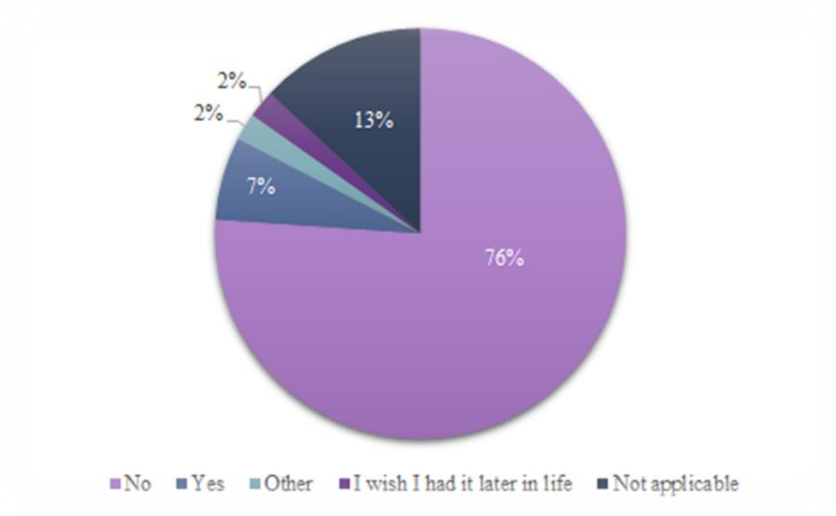

Figure 5.1. Participants’ responses to if they retrospectively wished they had received surgical intervention during infancy.

A qualitative analysis of this question highlighted some of the reasons behind these responses. Most gave minimum detail and the majority had just said ‘no’. A qualitative analysis showed eight participants that described how they could not provide their own consent to such a procedure as they were too young and how they felt about this, ‘*The fact I was a child undergoing such treatment created a real sense of difference and was completely dis-empowering to me because I could not consent to it’.* The importance of consent over surgical intervention itself was highlighted by another participant, ‘*Some of the surgery could have waited until I was old enough to understand and consent. I may have agreed to the surgery, but I would have preferred it to happen with my consent*’.

Six participants chose to voice their regret at receiving surgical intervention, despite this question targeting those who had not received it. Whilst only one participant stated that they wished they did receive this surgery earlier to better prepare them for adulthood, one other participant stated, ‘*For health purposes I wish reconstructive surgery would have* *occurred*' which indicates that a health issue was involved rather than just a cosmetic correction.

5.3.3 Interventions and support

As this study primarily focuses on surgical intervention, it is also important to acknowledge other methods of treatment to gain a more comprehensive insight into the management of intersex variations. Participants were able to tick all treatments that applied, illustrating a broader overview of their treatments. Many participants (n=43) received hormone treatments, while 15 received non-specified other medications. Besides further surgical intervention, some participants received further physically invasive treatments such as dilation therapy (n=10) and 11 participants received counselling.

Participants were asked '*what kind of ongoing support did you receive from health services during childhood and adolescence?*' and were able to tick all the services or support staff they were given access to. Endocrinologists were the most common (n=25 followed by general practitioners (GP) (n=24), Support from surgeons was also reported by 13 participants whilst counsellors (n=7) and psychiatrists (n=9) were the least common. A further 14 stated they had continuing support from gynaecologists, and seven participants received ongoing care and support from urologists. A total of 37 participants stated 'other'; 31 of which disclosed they felt they did not receive any support.

There was little discrepancy when asked if they knew if their parents were fully informed by health professionals about their intersex variation. A total of 23 participants said yes, 29 said no and 28 stated they were unsure.

5.3.4 Attitudes Towards Healthcare Management

A total of 66 participants responded to the question '*Do you feel you currently have sufficient healthcare management regarding your intersex variation? (e.g. sufficient specialists, ongoing support, ease of access to information, etc.). How has this level of care changed since childhood?.* A total of 16 participants discussed receiving insufficient healthcare management, though a further 15 mentioned they had better healthcare now than when they were a child. Following this, 13 stated they currently had sufficient healthcare. A total of 10 participants discussed having issues with healthcare professionals' education, and another eight disclosed they did not want further healthcare management. Following from this, eight participants mentioned a form of self-directed care, a further five participants discussed mental health access, and four mention a lack of intersex-specific services as a child. Three participants discussed not having autonomy as a child, though that may be the subtext implied by the aforementioned 15 participants who stated healthcare had improved since childhood. Finally, three participants mentioned they concealed their intersex status from their healthcare professionals.

Sufficient healthcare management

There were 13 participants that stated they currently receive sufficient healthcare. Whilst some just stated 'yes' to receiving adequate healthcare management, others provided further insight about why they have a positive experience with their current healthcare plans. These involved having a doctor who was able to manage an array of their medical complications, and health professionals who are educated in intersex health concerns. A further three participants discussed being able to access to mental health services:

> I have a very good reproductive endocrinologist who takes care of my physical issues. And I am working closely with an excellent therapist about facing my cAIS diagnosis and revealing it to a partner when the time comes.

This statement also illustrated the benefits of a multidisciplinary approach when it comes to intersex healthcare management.

Insufficient healthcare management

This was the most common emerging theme, expressed by 16 participants. Comments on this theme were broadly not receiving proper care or support, not feeling comfortable with the health professional, not validating their intersex status, limited handover from adolescence to adulthood health professionals, and limited ongoing support. Only two of these participants mentioned this being limited to their area of residence, indicating that whilst rural and remote areas are a factor, they are not the key issue in lack of support or sufficient services.

Access to mental healthcare services

Whilst five participants discussed mental health, only two of these participants were currently receiving adequate support in this area, one of whom stated that it was difficult finding support. The remaining three participants discussed wanting further mental health support; two specifically mention requiring counselling to cope with trauma from previous surgical interventions, as well as part of preparing for surgery, '*I needed counselling and better understanding of what the surgical outcomes could be*'.

Adolescent to adult healthcare

Three participants discussed the lack of autonomy they were granted over their bodies as children, '*I do like that I have doctors that are supportive of my decision to live the way I want to live, when I didn't have any level of care as a child'*. A further four participants used this question to reflect on the difficulties of healthcare management from adolescence to adulthood. This often involved the fallout that occurred from child and adolescent management to adult management. One participant expressed concern about having no support once they reached adulthood and existing childhood support ended '*no - there was a big plan to remove my testies [sic] and give me HRT - then your [sic] an adult an NO care - a freak for every new dr [sic] since'*. Handovers as an adult had also been a concern by another participant, '*I have no access to specialists, and no ongoing support from previous medical care practitioners. There is no help available'*. This is supported by another participant, '*I have never had proper care for this since I discharged myself at 17/18'*. One other participant mentioned that it is harder to find care as an adult.

Lack of intersex specific services

A total of four participants mention there being a lack of intersex-specific or related services throughout childhood. Further, one additional participant remarks not being able to get specialised help as an adult; it is unclear if this relates to the lack of handover from childhood physicians to adult physicians, lack of services itself, or the autonomy required to seek such services.

Issues with healthcare professionals and education

Educating health professionals was experienced by 10 participants who noted that the health professionals they had encountered had no experience or knowledge about intersex variations. Some participants expressed concern with doctors or health professionals who are not interested in learning about intersex issues, '*I am very careful when I choose a primary care physician making sure to locate one that will take the time to learn updated medical information*'. Participants (n=3) noted that they often end up educating doctors on their intersex variations. One participant noted that the doctor they were seeing used mixed, gendered terminology when referring to her:

> My physician often contradicts herself using 'clitoris' in one sentence and 'phallus' in the next, which becomes offensive and invalidating. She often doesn't want to make a decision to use gendered terminology and sometimes won't describe me as completely a woman.

Confusion with Transgender

There has been some confusion or crossover with transgender care plans by health professionals, which has been limiting in terms of being able to offer services to intersex people, '*I have attended a GIC [Gender Identity Centre], but as I am not transsexual [sic], this has tended to be a hindrance*'. This approach has been deemed offensive by some participants as they are not transgender, one commented:

> I have little to no access to endocrinologists willing to work with me, I have seen a few and they either insist on treating me along Trans treatment plans with absolutely no access to HRT for the opposite gender to my passport… I am to be treated as if I am a mtf transsexual [sic].

Another participant sought help from an LGBT clinic in 2014, *'…They had never worked with intersex and did not give me very good healthcare, they could only treat me as biological male and therefore were unable to give me a well-rounded view*'. These participants are aged in their twenties and early thirties (at the time of collection) and are discussing this as a current issue in healthcare they are facing; this indicates that this is a current rather than historic issue in healthcare management.

Patient-centred care

There was an emergence for the need for patient-centred care. '*if I don't focus them on needing a better experience, then they just hand out the same pills and never even bother to ask 'how is this going? ... is this working? ... How do you feel?*'. Another participant shared similar sentiments, '*She also doesn't want to get into the details of my intersex variation and would rather just write me a prescription and be done with me'*. This showed a lack of patient-centred care in healthcare approaches.

Self-directed care

Several participants (n=8) expressed how they needed to self-direct their care and felt that health professionals were either under-educated or allowed little room for self-determination when it came to healthcare, '*It has taken far too long to shape that [healthcare management] to my needs, rather than what clinicians feel appropriate. The two are not synonymous*'. Other concerns mentioned for self-directed care were the difficulty finding doctors who made them feel safe, were willing to work with them for healthcare management, or who were prepared to educate themselves on intersex variations. These participants talk about self-directed care by taking ownership over their own bodies (self-determination) and educating themselves on their own variations and finding doctors that suited them. Taking ownership of their own bodies may also be a powerful experience, '*I am in charge and empowered in my* *healthcare. Big difference: I am educated about my CAIS. I ask lots of questions, unlike my parents'.*

Furthermore, three participants mention seeking out intersex support groups as part of their care, '*Knew nothing as a child but AISSG group has enlightened me*'. The two other participants discussed joining these groups for support or as an alternative source for information.

Concealing their intersex status

Only three participants disclosed hiding their intersex status from their health professionals, '*My doctor is unaware of my history and I like it that way. Previous doc treated me like a freak once he found out'*. This indicates that this concealment may stem from a place of fear, shame and stigma.

5.3.5 Concerns for the future

Participants were asked in an open-ended question, '*If you were fully informed about your intersex variations, did you have concerns for your future?*'; they expressed several views which were categorised into 'yes', 'no', and 'I do not feel like I was fully informed about my intersex variation'. Most participants (60%) shared that they did not feel like they were fully informed about their intersex variation (n=48). Some of the remaining participants stated they did have concerns for their future (n=12), and eight expressed no concerns. It is noteworthy that one participant had commented in another related question that they did express a desire for an earlier diagnosis, '*I wish I had been diagnosed as a child,it [sic] would have allowed me to be at one with the person I now am'.*

A qualitative investigation offered further insight into these data. These themes included not being fully informed, concerns for relationships, general concerns for the future. Some participants found out later in life and therefore stated they did not have any concerns during childhood or adolescence.

Most participants discussed a form of not feeling fully informed about their intersex variation. Of these, three participants mentioned feeling lied to. Some participants who discussed this theme were unclear as to whom the lack of information was coming from and others cited specifically either their parents or doctors. Some participants mentioned parents or doctors concealing aspects of their variation or avoiding the truth about what had happened to them, one stated:

> I was always kept in the dark and felt like I was being treated differently to my brothers. Any time I asked about it, I was told birth defect over and over until I got so fed up, I didn't ask any more.

Statements like these illustrate the infantilisation of people with intersex variations as details about their own bodies are concealed from them. As a result, some participants felt misinformed and even had to go to great lengths to get a complete understanding of their intersex variation or medical history, one mentioned:

> I received the same lies…I learned the diagnosis of 'male pseudohermaphrodite' at age 33, by STEALING my medical records from my doctor's office. I demanded, and finally got, a full genetic sequencing done at age 50.

Relationships

Participants also expressed concern for romantic relationships in their future (n=6). Two sub-themes emerged from this, being concerns with having biological children, '*I was very* *depressed… nobody would want me because I couldn't have children*'. Furthermore, participants were concerned about finding a life partner and concerns for their future sex life *'My condition was never discussed with me as a child…as a young adult I assumed I would never have a sexual component to my life'.*

Unspecified general concerns for their future was identified by eight participants, and a further five mentioned feelings of depression, experiencing thoughts of suicide and suicidal attempts '*…definitely had concerns about my future. at the age of 15 I tried to kill myself, that was the point where my parents found me and we first talked*'. Other comments included not seeing a future for themselves, and feeling self-conscious or unhappy with their body, *'I was suicidal throughout my childhood, youth and young adulthood. I had concerns about not having a future, not wanting to live in my body as it was made'.*

One participant's comment highlighted the infantilising nature of concealing medical details as well as health professionals allowing little room for consent, '*I felt completely left out nobody ever cared to ask me what I wanted'.*

Enforced gender roles

Whilst not a direct answer to the question, some participants noted being forced to live under strict, almost fearmongering gender roles, *'I wasn't told anything except 'take your hormones and your medication or you'll turn into a man'. This was posited as a fate worse than death*'. These strict roles of masculinity and femininity left some participants feeling limited in their life choices, one reflected:

> I experienced extreme gender reinforcement as a male, so for many years was unable to question either my sexual orientation nor my gender assignment. Had I been properly informed… I could have been in a position to make different and better decisions about

> how to live my life within the limits I had, rather than attempting to live a life I was biologically incapable of.

5.4 Mental Healthcare Experiences and Attitudes

5.4.1 Experiences of Mental Health Support

Participants were asked if they chose to seek mental health support as an adult and if so, to describe this experience. Based on hand-coded theme extraction for statistical analysis, responses were categorised into five categories: ‘Yes’ (undetermined); ‘Yes – it was positive’; ‘Yes – it was not helpful’; ‘No’; and ‘No – I was not offered this service’. Whilst 65 participants responded to this question, not all their responses could be quantified for statistical analysis, however responses were examined during the qualitative analysis. When looking at the frequency of mental health support uptake, most participants did seek support. A total of 75% (n=48) participants stated they sought support with 16 stating they did not seek (n=12) this service. Of the 48 who did seek mental health support, 25% (n=12) said it was a positive experience and 23% (n=12) stated it was not helpful. 8% (n=4) of participants were not offered mental health support.

When investigating participants who sought mental health support on a cross-country scale, there were no statistically significant results found. However, it appears that participants in the USA are marginally more likely to seek mental health support. Furthermore, participants from Australia were most likely to not disclose whether they sought mental health support when looking at the expected figures (see Table 5.6).

Table 5.6

Expected count test of participants' country of birth against whether or not they sought mental health support (n=76)

		USA	Canada	Australia	Asia	Europe	UK	NZ	Total
Sought MH support	Count	25	3	5	0	7	3	2	45
	Expected Count	23.1	3.6	7.1	0.6	5.9	3.6	1.2	45
Did not seek MH support	Count	9	2	2	0	0	3	0	16
	Expected Count	8.2	1.3	2.5	0.2	2.1	1.3	0.4	16
Did not disclose	Count	5	1	5	1	3	0	0	15
	Expected Count	7.7	1.2	2.4	0.2	2	1.2	0.4	15
Total	Count	39	6	12	1	10	6	2	76
	Expected Count	39	6	12	1	10	6	2	76

Support Seeking and Intervention

A t-test was conducted to determine the differences between further surgeries during infancy and childhood and seeking ongoing mental health support as an adult. Whilst not statistically significant, it is of note that those who received further surgeries during these life stages were more likely to seek more support services in adulthood (n=21) compared to those who did not receive further surgeries. Furthermore, responses to the question surrounding seeking mental health support services as an adult were collapsed to three categories: 'sought help as an adult', 'did not seek help as an adult', and 'did not disclose'. There was little difference between those raised as boys (n=15) and those raised as girls (n=14) in terms of seeking support as adults, however there were three more participants raised as boys than those raised as girls who did not seek (or were not offered) mental health support as an adult. There is an overall trend of participants seeking mental health support as adults compared with not, but no statistical significance in this instance (see Table 5.7).

Table 5.7

Participants' mental health support seeking by gender of rearing (n=67)

Seeking mental health support	Raised as a boy	Raised as a girl	Raised gender neutral
Sought help as an adult	15	14	1
Did not seek help as an adult	5	2	1
Did not disclose	7	20	3

When considering their seeking of mental health support, it was interesting to examine for differences by participants' consideration of the appropriateness of their gender rearing. It was found that 29 participants (out of 67) who found their reared gender inappropriate sought mental health support as an adult, while only eight participants who found their gender inappropriate chose to not seek help or were not offered the service. Whilst not statistically significant, it is noticeable that of those who did not disclose whether they sought help (n=30), all identified as being assigned an appropriate gender.

Given that 29 participants found their reared gender inappropriate, further investigation was conducted examining those who sought help as an adult and what more they would have liked to have known growing up (see Table 5.8). There was no statistical difference found between those who reported seeking help and wanting full disclosure (n=21) about their variation and other responses. Following this, the next most common response for those who sought help are often concerned with wanting to know that they were okay/not abnormal (n=9). There were a further six participants who wanted to know that they were okay/not abnormal, however they did not disclose whether they sought help as an adult.

Table 5.8

Participants' Seeking mental health support and the what they wished to know growing up (n=67)

	Full disclosure	That I was okay/not abnormal	That I was informed at a younger age	That I had options	That I was not alone	That I had rights	Risks of my surgery	That sex is a spectrum	Total
Sought MH support	21	9	0	4	6	1	1	0	42
Did not seek MH support	6	0	1	2	1	3	0	0	13
Did not disclose	5	6	0	0	0	0	0	1	12
Total	32	15	1	6	7	4	1	1	67

Table 5.9

Chi-Square Test of participants' Seeking mental health support and the what they wished to know growing up (n=67)

	Value	*df*	Asymp. Sig. (2-sided)
Pearson Chi-Square	28.116[a]	14	.014
Likelihood Ratio	28.728	14	.011
Linear-by-Linear Association	.000	1	.999
N of Valid Cases	67		

a. 20 cells (83.3%) have expected count less than 5. The minimum expected count is .18.

Looking at responses to this original question about experiences with mental healthcare support through a quantitative analysis offered further insights. Positive experiences were expressed by 20 participants, followed by 15 participants who stated they found mental health services unhelpful. A further 18 participants discussed difficulties in finding appropriate mental health services for their needs, and nine participants experienced difficulties with mental health professionals. A total of eight expressed either no interest in seeking these kinds of services or were not offered them by any other health professionals. Another 14 participants discussed a specific form of counselling, being for trauma or PTSD (n=7), gender issues (n=3), and other mental health issues (n=4) respectively.

Those who did not seek/were not offered mental health support

Eight participants stated 'no' or similar for this question. One participant wrote that they actively avoided seeking mental health support, though offered no further insight as to why they may not have been interested in these services.

Positive experiences seeking mental health services

Twenty participants who sought the support of a mental health service or mental healthcare professional reported a positive experience, finding the experience helpful. These responses ranged from it being adequate to statements such as, '*Yes, God yes. I would not have survived suicidal depression without mental health support'*. A total of five participants mentioned seeking this support more than once, which may indicate difficulties in finding this support, or that they have required support at multiple times throughout their lives.

Negative experiences seeking mental health services

Whilst 18 participants discussed the difficulties finding appropriate mental health support, 15 participants also discussed how the services they accessed were not helpful, and both of these categories shared 11 participants. The remaining four discussed general reasons, or gave no reasons as to why mental health support was not helpful, '*did go to therapy for a while but then that therapist moved to another place to work.it didnt [sic] help me much anyway'*.

5.4.2 Attitudes Towards Mental Health Services

Difficulties finding appropriate support services

It was notable that difficulty finding appropriate mental health support services was reported by 18 participants. Some participants express that it took a long time to find someone who could help them with their mental health (n=4). Mental health professionals not being educated about intersex was found to be a frustrating experience from many participants (n=6), '*The therapists I have encountered have heard the word intersex, but that is about it. I end up having to educate my own therapists'*.

Some participants expressed concern about mental health professionals not listening to their needs and focusing on other issues (n=6). The majority (n=5) of these were mental health professionals confusing intersex with transgender, or attempting to 'blame gender issues' rather than addressing traumatic childhood, intersex issues, depression or other factors, '*14 years of having both psychiatrists and social workers ignore my intersex issues and continue only acknowledging transgender issues has broken any faith I have in counselling'.* This sentiment was also expressed by two participants who specifically noted the lack of intersex specialists for mental health, '*Very difficult to access. I was assumed to be trans*. There are next to no specialist psychologist [sic] working in the field of intersex'*.

Inappropriate mental health support

Nine participants mention receiving inappropriate mental health support. This ranged from dismissing their intersex status (n=6) to not being supportive of their gender or sexuality (n=2). For example, one participant commented, '*The experience was terrible and the Therapist refused to acknowledge my bisexuality. He also hinted that I should be more manly. I quit going*'. Another stated, '*They [mental health professionals] ignored my childhood medical history, and would not let me talk about the gender assignment issues'*.

Reasons for seeking mental health support

The reasons for seeking mental health support were not necessarily directly related participants' intersex status. There were three clear themes of mental health support expressed by participants; gender counselling, counselling for mental health issues (depression, suicidal thoughts), and counselling for post-traumatic stress disorder (PTSD). Of the three who sought gender counselling, two were the aforementioned transgender participants who required this as part of their transition, and one was referred to gender counselling as a result of having no other specific intersex services.

Two of the four participants seeking support for depression found solace in this support, '*relied on support from a local counsellor for psychological support in dealing with the anger, depression...etc, which was hugely helpful but did not discuss interest/gender issues'*. The remaining two did not state whether this was helpful for their mental illnesses.

PTSD and trauma were the most common, specific cause for seeking mental health support (n=7). Sexual abuse was reported as the cause for this trauma as they reflected:

> it was helpful only after mental health experts stopped pestering me about gender and what gender I should be and supposing gender must be a dreadful problem for me and treated the PTSD i was experiencing as a consequence of prolonged childhood sexual abuse.

This illustrated how mental health professionals are often overlooking trauma and PTSD as a root cause for seeking treatment, further, this can result in symptoms worsening, *'...most had absolutely no experience of my situation. Told [them] I have PTSD, etc etc some just gave me meds for deep depression which didn't help, I ended up twice cramming myself full of pills hoping I wouldn't wake up'*.

An additional participant stated experiencing PTSD due to 'childhood trauma' with no further detail. Trauma from surgeries specifically is expressed by one participant, *'I needed to seek* *mental health support after developing reactive depression following the surgeries I mentioned in an earlier question'.*

5.5 Participants' Ideals for Intersex Healthcare Management

5.5.1 Improving Support for Intersex People

The question '*How do you feel the management and support of both adults and children with intersex variations could be improved?*' elicited responses from 66 participants. The most recommended areas for improvement were better education of healthcare professionals, and delaying all medical and surgical intervention until an age of consent, both themes were expressed by 23 participants respectively. A total of 13 participants discussed a need for greater mental health support and access, and another 13 participants desired more resources about intersex. Seven participants discussed a need for peer support groups for intersex individuals or parents, and five suggested better long-term support and follow ups with intersex adults. A further five wanted greater access to treatments, records and identification changes.

Education for healthcare professionals

This theme embodied several concerns expressed by 21.3% of participants. Some comments were broad and expressed a need for doctors and other healthcare professionals to have more education regarding intersex variations and potential health concerns.

Heteronormative approaches

Some participants (n=7) discussed the need for health professionals to move away from heteronormative approaches as it is not inclusive, limiting, and may cause offence. Participants mentioned how doctors need to move away from a two-sex binary approach to treatment, and not assume their patients' gender or sexuality, '*Acknowledgment that some intersex people are not male or female, do not want to be male or female, and need support living as intersex people rather than as men or women'*. This approach was also found to be dismissive of their identities, *'[we need] validation of gender and use of properly gendered words and terminology that affirms the person's identity'.*

This was also used as an opportunity for participants (n=2) to express how this approach meant they were viewed throughout a corrective lens by health professionals*, 'Recognize that variation in biologic sex is normal and not a problem that needs to be fixed'.*

Treatment pathways

Some participants (n=4) expressed a desire for multiple or tailored treatment pathway options, as intersex is diverse and cannot be treated in a two-sex binary system. Participants found this limiting and not tailored to their individual needs, '*Educating Health Care workers about intersex and that we don't have to choose one or the other in a binary gender system'*

Three participants specifically discussed the need for patient-centred care, *'treatments that do not seek to normalize or are driven by social imperatives...medicine should deliver client centered medicine'.*

Hormone treatments

Three participants particularly commented on the misuse of hormones in their treatment. One stated they were given incorrect hormones, and the other felt boxed into a transgender HRT plan, '*Physicians need better training to understand that we are not Transgender and because of our sexual variations that the model they use to chart hormones are irrelevant. They need create a new model of care specifically for intersex'*. Another participant noted that hormone treatment should be an option, rather than mandatory, *'Exogenous hormones should be viewed as an option as opposed to the present holy grail'.*

The illness experience and the corrective lens

Some participants discussed not requiring or wanting treatment as they are not sick and do not to be 'fixed', *'stop presuming that everything that comes with us must be sick [cancer risk]'*. This ties into the aforementioned corrective lens often used by health professionals. Rejection of illness was expressed by another participant, '*We don't need medical care because we are not sick!*'.

Attitudes

There was concern expressed over the attitudes of some health professionals towards intersex individuals. Participants discussed how they feel health professionals need more empathy, need to be more honest, and to not be condescending towards their patients, and to create an open dialogue for patient education, '*More empathy more compassion. Drs should not condescend to parents. They should encourage parents to ask lots of questions'*. These sentiments are shared by Liao (2015) who discussed the stonewalling of doctors towards intersex people. One participant was even ridiculed by a health professional, '*Be honest with* *children, they are not stupid. I was put down by a doctor who made fun of my hypogonadism and penis size when I was in my mid 20s'*. Being engaged and present with intersex individuals and not just their parents was also discussed, *'listen to the person no matter how old they are. Don't give meds or do surgery unless the person has agreed its a good idea'*.

Delaying medical and surgical intervention

Many participants expressed concern regarding surgical intervention on infants (n=23). Most of these participants (n=15) specifically mentioned the lack of consent for surgical intervention; that no one had consulted them regarding surgical or medical intervention on their own body. This indicates that consent or waiting until someone is of an age where they can give informed consent is more of the specific area of concern than the surgery itself, *'No surgery on infants, children or minors as long as there is no current real physical health problem. Adults shall decide on their own behalf'*. This highlighted the explicit need for bodily autonomy, *'[we need] bodily autonomy. We should never be denied treatments we want and need and should never have any forced on us or [be] coerced'*.

Mental health support

Some participants (n=13) stated the need for further access to mental health support. The reasons they wanted to seek mental health support were varied, and included requesting mental health support at the time of diagnosis, *prior* to taking any hormonal or surgical interventions, '*an individual needs to be evaluated by a mental health profession so as to ascertain they will be able to adhere to mind altering life long treatment'*; and *after* surgical interventions for trauma, *'There NEEDS to be a focus on mental health! There is no point doing surgery on the body if you break the person'*.

One participant discussed why this was important in a multidisciplinary context and stated:

> …would hope that children born intersexed would be followed by medical practitioners through their childhood so that when they reach an appropriate age they would be counseled in conversations with parents and clinicians regarding their feelings and desires regarding who they are and who they want to be.

Another participant highlighted the difference in support between the transgender community and intersex community:

> There is absolutely no counselling or support here. Nothing. It's very secretive, regular trans folk g[et] great support, next to nothing if you have a dsd [Difference of Sex Development]. After all it's just a birth defect say the stupid doctors.

Resources about intersex variations

A total of 13 participants discussed a need for resources for intersex people and their families as an area for improvement for healthcare management. This included ensuring there was greater information or educational resources available for intersex individuals and their families, suggestions of online courses about intersex variations, and a database for intersex specialist health professionals. Participants also mention that being informed is empowering and may help them make their own informed decisions, *'Information. Get it to the parents. Get it to the kids. Make them feel as if their condition doesn't make them weird and let them choose what gender they feel most comfortable as'*.

Greater awareness

Awareness about intersex for the general public was also an area of interest (n=3), *'information about intersex should be provided to the general public, so that everybody knows about the possibilities, what could happen if a child is born'*. These sentiments were extended to how this may be implemented and what benefits it may have, *'There needs to be* *more positive representations in media, to lessen the growing suicide rate among those with intersex variations'*.

Peer support

Seven participants expressed the desire to be connected to peer-support groups which may be beneficial for intersex individuals and their families. *'All individuals to be directed to support groups where they can meet others'*. Finding peers and gaining a support network may assist in eliminating other barriers such as secrecy and shame.

Barriers to medical records, treatments and legal documents

Participants discussed the issue of barriers, or 'red tape' that makes basic access difficult. This included access to obtaining their own medical records (n=2), changing legal identification documents (n=1), and obstructions to getting treatment (n=2), *'Make it easy to get hormones and other medical needs without all the red tape to get them and allow us to change our bodies as we see fit to so we can feel normal'*.

Follow up support for intersex adults

The lack of long term or ongoing support for intersex adults was an area of concern raised by five participants. This was important to participants as it allowed for a retrospective look into the healthcare management of intersex children, *'Professionals should see both adults and children; they can't learn what the long-term outlook is for child patients unless they see adults'*. It also illustrated how some intersex variations may have health complications that require lifelong care, *'NEED to have a life time plan in place for care and treatment'*. These comments also highlighted the general lack of concern for intersex adult care, '*How about* *someone caring about adult intersexuals? The activist pressure is all for little kids and no one gives a damn that we can't get intelligent medical care as adults'.*

Research

Research was a conflicting topic amongst participants. One participant identified the need for further research, *'More research would greatly improve the management of intersex variations in adults and children'*. However, being the subject of observational research was found to be distressing, *'Stop displaying us to students'*; particularly as children, *'Don't make the child a spectacle'*.

A word frequency query was conducted in NVivo for this question (see Table 5.10). The most common words of 'need', 'intersex' was part of the question, and as such, do not offer any additional insight. The question asks about children and adults – here we see that 'children' is mentioned a further seven times than adults, indicating that participants are either reflecting more on childhood experiences, or are placing a great emphasis on the needs of children rather than adults.

'Informed' along with often used synonym 'information' are also frequently used at 17 times throughout these responses, indicating that information and being well-informed is an area of priority.

'Support' is also of great significance at being mentioned 17 times. Looking at this in context showed it related to peer support, mental health support, a lack of support, and support groups.

A query into the context of 'surgery' which also appears 17 times showed that this was used in a negative context ('stop surgeries', etc.) in 100% of its use by participants.

‘Parents’ were discussed in a bit more variation, but the context of this use was regarding more education, resources and counselling for parents, except for two participants who discussed how surgical intervention should not be the decision of parents.

Table 5.10

Word Frequency query for the question “How do you feel the management and support of both adults and children with intersex variations could be improved?’

Word	Length	Count	%	Similar Words
need	4	26	2.31	need, needed, needs
intersex	8	24	2.13	intersex, intersexed
children	8	19	1.69	children
informed	8	17	1.51	inform, information, informative, informed
support	7	17	1.51	support
surgery	7	17	1.51	surgeries, surgery
parents	7	14	1.24	parents, parents'
doctors	7	13	1.15	doctor, doctors
medical	7	13	1.15	medical, medically, medics

5.5.2 Improving to Support for Parents/ Family

There were 66 participants who responded to the question, ‘*Reflecting as an adult, what support do you think would have helped your parents/family when you were a child?*’. Five common themes emerged from this data. There was a strong theme of wanting honesty and transparency from doctors, with participants wanting non-bias or non-binary information for their parents, all of which was collapsed into the theme of ‘non-bias or non-binary information to parents’. This theme was extracted from 23 different participants, who stated that they felt information given was biased or that their parents did not receive accurate or enough education regarding their variation. One participant stated, *‘More information on the variations, and the emphasis on the variations being just as normal as if it were binary* *conditions'*.

Counselling for parents (n=4) or family counselling was collapsed into the theme of 'family counselling' and was an area of concern for 13 participants. A strong theme emerged of wanting to know that being intersex is 'okay' (n=32). Some participants discussed this in the context of body positivity, or 'not being freaks', while others wanted their parents' anxieties relieved, '*Someone telling them that I didn't have a birth defect. That there wasn't anything wrong with me*'.

'Peer support' was another theme extracted from these data. This was mentioned as just 'peer support' or some participants were more specific in recommending peer support from other parents of intersex children (n=4) or peer support from other intersex people (n=2) *'…in general I think also meeting some adult intersex people. Not just the gender variants but also the ones that identify as men and women'*. Some participants suggested that doctors should offer more rearing options (n=2) *'More options for how to raise me, including non-surgical intervention before I was old enough to speak for myself'*.

Family attitudes

The question allowed participants to discuss conflicting family attitudes towards their intersex variation. One participant stated, *'Nothing would have helped my father, he was to [sic] prejudiced'*. There were some instances where just one parent was educated on the intersex variation or 'dealt with' the intersex status, *'My mom was kept in ignorance. My dad, as a trained nurse (RGN) and army medic, did all the 'dealing''*. Two participants mentioned religious themes underpinning their parents' attitudes, *'Since they were Christians, I don't think much would have helped. They once had the Bishop perform a 'blessing' on me… He prayed over me to have the demons caste out'*.

Another two participants mention shame or stigma, one of whom suggested this is due to their mother's social background. Social background as an issue for parents is mentioned by another participant, however it is unclear what specifically the participant was referring to.

Word frequency query

A word frequency query was conducted for this question (see Table 5.11). The most frequent word was 'counselling' (including synonyms 'counseling', 'counselor', 'guidance') with 11 appearances throughout participant responses. 'Doctors', 'helped' and 'information' all appear eight times. Examining the context of these references, 'doctors' was mentioned by five different people (at times, twice in one sentence). Contextually, this indicates that this is the health professional that intersex people are seeking more support form for their families, in conjunction with counselling. Similarly, 'information' and 'education' are other high frequency words that appear in this word count, highlighting this as a priority area for support for parents of intersex children. Other words of interest include 'normal' and 'accepting', which may indicate a need for parents to be reassured by physicians or other support staff that their children are not 'abnormal'. The word (and synonyms) for 'chose' also appeared. An exploration of the context showed that this reiterated the need for choice and options for parents when it comes to decision making about rearing and surgical intervention in infants.

Table 5.11

Word Frequency Query for responses to the question 'Reflecting as an adult, what support do you think would have helped your parents/family when you were a child?'

Word	Length	Count	%	Similar Words
counselling	11	11	2.91	counseling, counselling, counselor, guidance
doctors	7	8	2.12	doctors, physicians
helped	6	8	2.12	help, helped, helpful
information	11	8	2.12	information
needed	6	6	1.36	asked, need, needed, take
variations	10	6	1.59	variants, variation, variations
children	8	6	1.59	children
educated	8	5	1.19	development, educated, education, trained
intersex	8	5	1.32	intersex
surgery	7	5	1.32	surgery
accepting	9	4	0.83	accept, accepting, take
feel	4	4	1.06	feel, feeling, feelings, notions
making	6	4	0.83	make, making, take
normal	6	4	1.06	normal, normality

5.6 Conclusion

The findings from these data provide vast insights into many facets of the lived experiences of people with intersex variations. Firstly, the demographics showed most participants were from Western countries, predominantly the USA, UK, Canada, and Australia. Most participants were assigned female at birth; however this was not reflected in current gender identity demographics as a range of gender identities emerged with nearly a third of participants identifying along the gender spectrum.

Concurrent with other research, the findings from these data show that the most common intersex variations are AIS and CAH (Jones et al., 2016). A third of participants were diagnosed in infancy or early childhood, whilst another third was diagnosed after the age of 25. More than half of the participants received surgical intervention in infancy or childhood, with the highest rates in Australia and USA, with Canada reporting the lowest incidences of surgical intervention; however, there are insufficient numbers in this sample to make any conclusive statements, thus, further cross-country research should be explored.

Surgical intervention was frowned upon by participants as 95% stated that surgery felt inappropriate. The biggest cause being a lack of consent and involvement in decision-making about their own bodies. This emphasises the problem of the positivist paradigm for doctors and the lack of recognition of bodily autonomy in Western countries.

Secondly, participants had mixed experiences in healthcare settings but were mostly negative. Insufficient healthcare experiences involved a lack of access to appropriate support including a lack of transitional care from adolescence to adulthood, this concern was also raised by Crouch, Minto, Laio, Woodhouse, & Creighton (2004) who noted there are minimal studies exploring evidence-based models of transitional care when it comes to intersex healthcare management.

Having to educate health professionals on their variations was a common complaint among these participants, as well as being mislabelled as transgender by health professionals, which was also an issue identified in other studies (Jones, 2015). The findings identified a lack of patient-centred care when it comes to managing intersex variations in healthcare. The themes in all these stories highlight the need for consent and the clear lack of bodily autonomy experienced in their lives; surgeries and other interventions were happening to (power-over) them rather than with (power-to) them. These experiences fit with Davis's

(2015a) suggestion that much of Western healthcare around intersex people currently occurs in the later stages of Conrad and Schneider's (1992) five-stage model of deviance.

Three quarters of participants sought mental healthcare services at some point in their lives, with only a quarter of them finding it to be a positive experience. The need for greater mental health support has been identified by numerous previous studies (Diamond and Watson, 2004; Jones et al., 2015;Leidolf, Curran, Scout, & Bradford, 2008; Liao, 2015). Jones et. al (2015) found that 19% of Australian intersex people were not offered mental health services; though more participants answer this question compared to the sample in this study so it is unclear if this impacts the saturation of answers being smaller in this sample, or if this difference is due to the international scale of this study. If it is the latter, this could point to a much higher deficit of offering mental health support in Australia compared to other countries. Those who had multiple surgeries throughout their lives were more likely to seek mental health support which indicates greater levels of trauma with repeat surgeries. Further, those who found their reared gender inappropriate were more likely to seek mental health support. The most common reason for seeking mental health support was to get full disclosure on their intersex variation or to just know that they were okay and not 'abnormal', and others sought help for trauma and PTSD from surgical intervention. Wanting to know they are 'normal' is an illustration of the imposition of the essentialist two sex binary that is used to pathologise those who sit outside of it.

These data showed that intersex people want more education for healthcare professionals, diversity in treatment options, a cessation of heteronormative practices, greater mental health support, a ceasing of surgical intervention without consent, less 'red tape' to changing and obtaining legal documents, better follow up support for intersex adults, access to peer support groups, greater awareness for the general public about intersex variations, and greater resources for intersex people and their families. Attitudes towards future research was mixed, an understandable attitude given the history between researchers and this community.

Whilst this chapter provided a thorough exploration of the experiences and attitudes on healthcare management for people with intersex variations, the demographics offered some insights into gender identity, assigned sex, and gender identity. The following chapter will explore these themes in greater depth.

Chapter Six: Intersex Peoples’ Gender, Sexuality and Sexual Satisfaction

6.0 Introduction

The literature review highlighted the small amount of country-specific literature surrounding sexual experiences and satisfaction in intersex individuals who received non-consensual surgical intervention (Jones et al., 2016; Lux et al., 2009; Warne et al., 2005); and the lack of literature on intersex people’s sexual desires and fantasies. This chapter will explore the quantitative and qualitative findings on gender, sexuality and sexual satisfaction of the mixed method questionnaire that was completed by intersex participants. To begin, this chapter will first explore gender; investigating genders reared from birth, followed by whether participants found their reared gender appropriate. Following this, these results will investigate who made these gender rearing decisions and attitudes towards these authority figures. Changes in gender identity are examined, followed by a comparison of reared and current gender identity to distinguish if there were any changes in this over time. This chapter will then inspect the nuances of sexuality and satisfaction, beginning with the exploration of dating anxiety in both high school and adulthood. It will then investigate the sexual satisfaction and sexual encounters experienced by this sample, the relationship between surgical intervention and sexual satisfaction and whether the sexual fantasies of this sample differ from their sexual experiences to better understand the relationship between the body and the mind. The chapter will conclude by reflecting on the potential meaning of this data.

6.1 Gender

6.1.1 Rearing and gender identity

Participants were asked about their gender of rearing, and whether they found their reared gender appropriate. A total of 36 participants were raised as girls, 20 found this to be an appropriate gender. Whilst 26 participants stated they were raised as boys, only five found this to be appropriate. Five participants were raised gender neutral, with four finding it to be an appropriate gender rearing choice.

Most participants responded to the question (n=62) about gender rearing as well as the question about their assigned sex at birth. The majority of participants were assigned female at birth (n=36). Of these, 86.1% (n=31) were raised as girls, 8.3% (n=3) were raised as gender neutral, and 5.6% (n=2) were raised as boys (see Figure 6.1). There were 26 participants who responded to both questions who were assigned male at birth. Of this number, 88.5% (n=23) were raised as boys, whilst 11.5% were raised as girls. No participants assigned as males at birth were raised gender neutral.

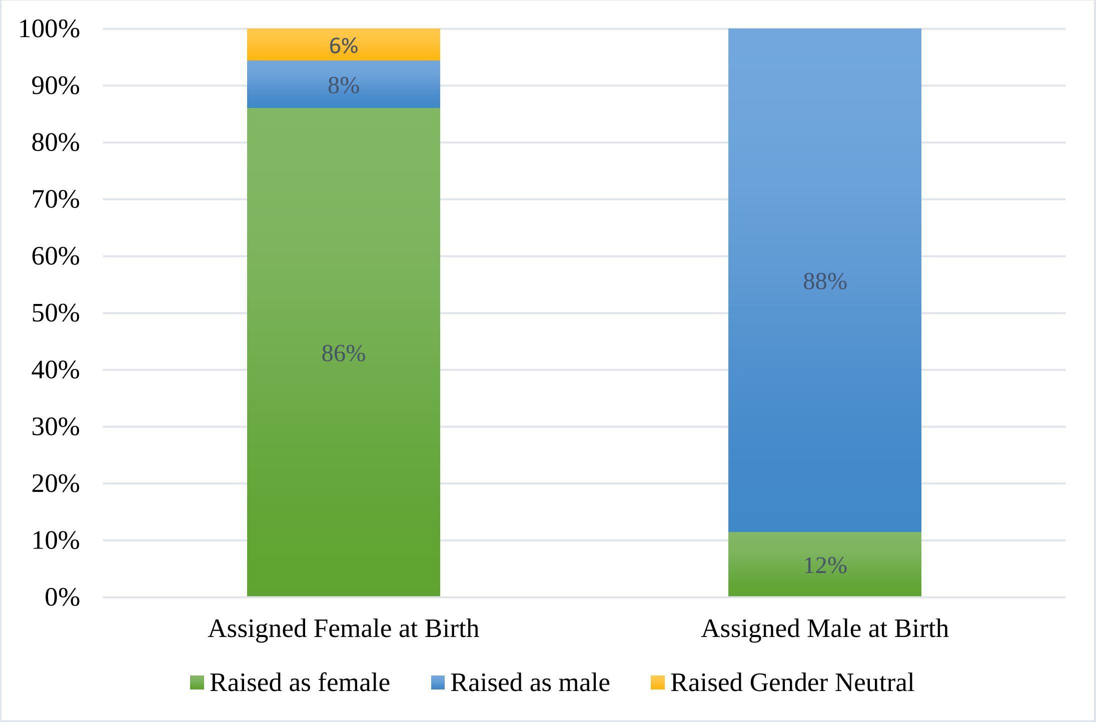

Figure 6.1 Participants' sex assignment at birth and reared gender (n=62).

When asked if participants had siblings, and if they were treated similarly with gender rearing, 83% of participants stated that their siblings were treated similarly with gender rearing all or most of the time, whereas 17% (n=8) stated that they were only treated similarly some of the time, or were rarely treated similarly. Whilst there are no other studies in this area to compare these data, Karkazis (2008) stated that parents may read more into gendered behaviours for their intersex children compared to their non-intersex siblings.

6.1.2 Gender Appropriateness

Some participants did not agree with the gender they were reared as and subsequently, found their imposed gender inappropriate. Comparing 'gender appropriateness' yielded a plethora of surprising data. It is meaningful that when investigating the age of intersex diagnosis and appropriateness of reared gender, it was found that 75% (n=15) of those over the age 26 felt that their reared gender was inappropriate. Whilst these numbers are too small to make any conclusive statements, this may indicate that older generations of people with intersex variations experienced more severe gender imposition in their youth, or less choice regarding their gendered experiences growing up. This is where qualitative data may be able to bridge gaps in quantitative research.

Globally, there were no major differences in gender appropriateness. An expected count was conducted in SPSS and found that those in the UK were less likely to feel they were raised with an appropriate gender compared to those born in Europe (see Table 6.1). However, numbers are too small for conclusive statements; this may be worth further exploration.

Table 6.1

Expected count test of country of birth against whether they found their reared gender to be appropriate

		USA	Canada	Australia	Europe	UK	New Zealand	
Gender Appropriate	Count	16	1	4	6	2	0	29
	Expected Count	15.9	2.3	3.6	3.6	2.7	0.9	29
Gender Inappropriate	Count	19	4	4	2	4	2	35
	Expected Count	19.1	2.7	4.4	4.4	3.3	1.1	35
Total	Count	35	5	8	8	6	2	64
	Expected Count	35	5	8	8	6	2	64

Gender appropriateness and assigned sex at birth

There were 62 participants who answered both questions regarding assigned sex at birth and whether the felt the gender they were raised as was appropriate (gender appropriateness). Of those who were assigned female, 58.3% felt the gender they were raised as was appropriate. Adversely, only 23.1% of males assigned at birth felt that the gender they were raised as was appropriate, meaning that 76.9% found their gender to be inappropriate. With very minimal numbers answering the other categories (n=5), results were re-examined, investigating only those who were assigned male and female.

Table 6.2

Participants' views on gender appropriateness against their assigned sex at birth (n=62)

Assigned sex at birth	Gender appropriate	Gender not appropriate	Pearson Chi-square	*df*
Female	21	15		
Male*	6	20	7.633	1
Ambiguous	0	1		
Not assigned	1	1		
Did not disclose	2	1		

Note. * p < 0.006

Examining only participants who were assigned as female or male at birth, a chi-square test indicated that it is statistically significant (p < 0.006) that those who were assigned as males at birth and raised as boys were more likely to feel that their gender was inappropriate (see Table 6.2). Similar results were reflected in Jones et al. (2016) which found male sex allocations were more likely to be experienced as inappropriate by intersex individuals.

A qualitative investigation of this topic yielded further insights. Participants were asked '*how do you feel about the gender you were raised'*, an open-ended question that allowed participants to further discuss their thoughts and feelings on their gender rearing. The most common themes to emerge from this question were participants feeling they should have been raised gender neutral, feeling they did not fit into traditional gender roles, those who were satisfied with their rearing, and those who exhibited some non-conforming gendered behaviour. The latter presented with two sub-themes; those who grew up in an environment where this was either accepted or encouraged, and those who grew up in an environment where it was discouraged, even punished.

Rejection and acceptance of gender roles

Some participants (n=12) discussed feeling they did not belong in their assigned traditional gender role. Some spoke of struggling to fit in with other members of their sex and gender, or feeling like another gender altogether. Others expressed feeling like an outsider, '*I thought I was an 'it''*. Some participants (n=3) wished they were reared gender neutral.

Whilst many participants rejected their imposed gender and subsequent gender roles, three participants mentioned feeling happy with their gender rearing, all expressing different justifications for their satisfaction. One participant stated that being assigned to be a boy meant he could more easily identify with the gay male community. Another was raised gender neutral, one participant stated:

> I picked my clothes from a certain age on, I picked if I wanted a haircut, I asked for my preferred toys. I just had to be a 'girl' in public at school and there I was more one of the boyish girls which was fine, I was not the only one.

Note that this participant discussed being involved in the decision-making process for their gender and was given agency, which led to a positive experience.

Rigid gender roles

Some participants were raised under strict gender roles whereas some were raised under more lenient gender roles. Many participants expressed that they were accepted for not being completely binary in terms of their activities and interests, '*I tended to be somewhat of a tom boy growing up but that was treated as a normal and acceptable variation of being a girl'*. However, not all participants found this to be an accepting experience, *'I was hit and beat a lot for not acting 'more feminine' I was punished for being a tomboy'*. Whilst these two participants come from different generations (in their thirties and fifties respectively), it is important to note that self-acceptance of gender fluidity or flexibility has not become more lenient with younger generations, as mentioned in the previous chapter.

Word frequency query

Words related to the themes extracted have been highlighted in Table 6.3. The most frequent words in the query were words directly related to the question. Following this, the word ‘neutral’ is a common word. A text query was run to examine the context. This is used in the term ‘gender neutral’ and is used to either describe the upbringing a participant did have or wanted to have, growing up. Another frequent word of note is ‘forced’. This was always used in the context of having to engage in gendered activities against their will. Interestingly, three of these instances were feminine activities and behaviour with only one feeling forced into masculine activities and behaviours. The word ‘play’ was just as frequent, indicating that this is a strong area when it comes to where gendered activities and behaviours may be instigated. This is further supported by the frequency of ‘toys’. Complimenting this notion is the frequency of ‘clothing’ when investigating gendered activities and behaviours.

Table 6.3

Word frequency query for the question 'how do you feel about the gender you were raised?'

Word	Length	Count	%	Similar Words
raised	6	21	3.07	raised
girls	5	20	2.92	girl, 'girl', girls
boys	4	19	2.77	boy, boys
gender	6	18	2.63	gender, gendered
female	6	14	2.04	female, females
felt	4	9	1.31	felt
male	4	9	1.31	male
like	4	8	1.17	like, liked
neutral	7	8	1.17	neutral
parents	7	8	1.17	parents
age	3	7	1.02	age
forced	6	7	1.02	forced
feel	4	6	0.88	feel
playing	7	6	0.88	play, played, playing
feminine	8	5	0.73	feminine
little	6	5	0.73	little
now	3	5	0.73	now
one	3	5	0.73	one
toys	4	5	0.73	toys
trying	6	5	0.73	tried, trying
always	6	4	0.58	always
clothes	7	4	0.58	clothes, clothing

6.1.3 Authority over reared gender

Participants were asked *'Who made the decision [to decide their gender]? Was this satisfactory?'* to investigate the origins of their reared gender. The most frequently occurring themes in this question were feelings of wanting to be raised outside of the gender binary, feeling they were raised as the wrong gender, feeling satisfied with their sex and gender assignments and subsequent rearing, dissatisfaction that they were not involved in the decision, and lastly, stating they were dissatisfied without further detail. However, this is not necessarily an intersex-specific issue as there are broader pressures on youth to be gender conforming. Yet, these experiences do differ for intersex children as their parents have a heightened sensitivity to gendered behaviours (Karkazis, 2008).

Some found their sex and gender assignment unsatisfactory and wished to be raised outside of the binary (n=8), and others did not mind being assigned but desired to have more choice, *'I think it is helpful to assign a gender at birth, but the 'door should be left open' allowing the child to develop naturally, rather than be 'rail roaded' down a particular path'*. Furthermore, some participants expressed dissatisfaction with their sex and gender assignment and rearing, feeling that they were assigned an incorrect gender (n=4).

Not all participants were dissatisfied with their sex and gender assignments, and stated they were happy with this decision, '*Yes, because my sense of myself was always female. It still is'*.

Consent was raised in responses to this question, with four participants stating they were dissatisfied with who made the decision as they were not at all involved in the process, *'…I should have been consulted prior to the initial operations'*.

Gender reinforcement at school

Some participants used this as an opportunity to discuss gender experiences or reinforcements at school. One participant stated that most gender roles were enforced by the school rather than parents. Another participant felt unsatisfied with their doctor and parents' decision and stated:

> …I was banned from doing things like working out and if I tried out for girls sports I dominated them in a very masculine way, I was called a freak and cousin it..it was very obvious to many people that something was different.

Word frequency query

Words related to the question had the highest frequency (for example, ‘female’, ‘gender’, ‘girl’, ‘parents’, ‘raised’ were the most frequent). The word ‘choice’ was the most frequently word used of note that informed the most frequently occurring themes in this question. A text search query was run on ‘satisfactory’ to gain further insights into the context of this word use. 75% of the time, this word was written in the phrase ‘not satisfactory’, which informs the strong theme of not being satisfied with sex and gender assignments. Words related to the themes extracted have been highlighted (see Table 6.4).

Table 6.4

Word frequency query for the question 'Who made the decision [to decide their gender]? Was this satisfactory?'

Word	Length	Count	%	Similar Words
female	6	13	2.50	female, 'female', femaleness
gender	6	12	2.30	gender, genders
girl	4	11	2.11	girl, girls
parents	7	8	1.54	parents
raised	6	8	1.54	raise, raised
know	4	7	1.34	know, knowing
like	4	7	1.34	like
male	4	7	1.34	male, maleness
never	5	7	1.34	never
boy	3	5	0.96	boy
child	5	5	0.96	child
choice	6	5	0.96	choice, choices
decision	8	5	0.96	decision
doctors	7	5	0.96	doctor, doctors
looked	6	5	0.96	looked
see	3	5	0.96	see
yes	3	5	0.96	yes
age	3	4	0.77	age
allowed	7	4	0.77	allowed, allowing
differences	11	4	0.77	differences, different
feel	4	4	0.77	feel
intersex	8	4	0.77	intersex
left	4	4	0.77	left
make	4	4	0.77	make
satisfactory	12	4	0.77	satisfactory

6.1.4 Attitudes towards parents' decision-making

Participants were asked to elaborate on their feelings surrounding their parents influence regarding their intersex variation for the question, *'How do you feel about your parents' decisions regarding your intersex variation? (e.g. the gender they raised you as, what they* *did and did not disclose to you regarding your intersex variation, etc.)'.* This question revealed multiple themes; diverse, and strong in presence. Participants discussed feeling angry at their parents, how they were not involved in the process/not given consent, feeling betrayed, feeling their parents were heavily influenced by physicians, being forced to act under strict gender roles, and experienced shame and feelings of secrecy. This reflected a similar trend towards negative feelings about parents' and physicians' choices seen in other studies of groups or individuals from intersex populations (Baratz & Karkazis, 2015; Davis, 2015a; Inter, 2015; Jones et al., 2016; Pagonis, 2015). Yet, some participants stated they were happy with how they were raised, and others said that their parents had done the best they could. Some participants were diagnosed later in life and therefore had little input for this question.

Anger

Anger was the third most prominent theme (n=9) experienced by participants. These were often described in conjunction with feeling sad, even betrayed, which was flagged by three participants. This anger was largely directed at parents, often surrounding issues of disclosure, *'It is hard. Sometimes I am very sad or angry. I don't love them anymore since they betrayed me'.*

Consent

Being involved in the decision-making process proved to be a vital theme for this question. Not being consulted or asked for their consent when it came to intersex related matters was mentioned by three participants, *'the issue was me but everybody spoke about this except me. it was my body but i couldn't choose anything'*. Expanding upon this, seven participants mentioned feeling that physicians may have heavily influenced their parents' decisions. Some participants felt their parents were misguided by doctors, others felt that the physicians were misinformed, and another felt the truth was omitted to their parents by their physicians, *'As far as I know they where [sic] in the dark as much as myself…Its as if my parents and doctor where speaking from the same script'*.

Enforced gender roles

Enforced, strict gender roles were discussed by two participants. *'in my teens I had no interest in make-up and dressing-up, but my Parents would often not let me out the house unless I was presented this way'*. Strong gendered behaviour and activities instigated by parents or the participant themselves are a common emerging theme throughout these questions. Another participant spoke about being forced into feminine sports and the impact this had on their relationship, *'My mother was tyrannical about making me a girl. Ballet, dance classes, girl's gymnastics etc. It was horrible. It made it impossible for us to have a close, bonded parent child relationship.'*

Secrecy and shame

Secrecy (n=12) and shame (n=6) were discussed heavily by participants for this question. Delving into the context of these terms, secrecy came in the form of parents either not telling their child about their intersex variation or encouraging their child not to tell anyone else about it. Shame was also experienced by participants, and was often discussed in the same breath as secrecy. Shame was discussed as being felt by their parents, but also themselves as a result, *'They opted to keep my body a secret. I was taught that my body was scary, unacceptable, unloveable, [sic] shameful, and that it was better to lie about it than to be honest about my body'*. These instances of secrecy and shame between parents and child sometimes resulted in a falling out of their relationship.

Word frequency query

The word frequency query (see Table 6.5) highlighted some of the prominent themes for this question. Words related to the themes extracted have been highlighted. Phrases like 'information' were common. When examining a text query, the context of these showed participants often discussed this in the context of not having enough information from either parents or doctors. 'Angry' is the next most common, relevant word to the extracted themes. 'Gender' was mentioned six times, and 'shame' and 'shameful' were mentioned four times, though 'ashamed' was mentioned a further two times, which made it the next most common word associated to the extracted themes. Words related to the themes extracted have been highlighted.

Table 6.5

Word frequency query for the question 'How do you feel about your parents' decisions regarding your intersex variation?

Word	Length	Count	%	Similar Words
parents	7	17	2.38	parent, parents
feel	4	12	1.68	feel
wish	4	10	1.40	wish, wished
much	4	9	1.26	much
information	11	8	1.12	information, informed
know	4	8	1.12	know
raised	6	8	1.12	raise, raised, raising
angry	5	7	0.98	angry
best	4	7	0.98	best
doctor	6	6	0.84	doctor, doctors, doctors'
gender	6	6	0.84	gender
knew	4	6	0.84	knew
little	6	6	0.84	little
never	5	6	0.84	never
told	4	6	0.84	told
age	3	5	0.70	age, ages
body	4	5	0.70	bodies, body
condition	9	5	0.70	condition
given	5	5	0.70	given
physicians	10	5	0.70	physicians
surgery	7	5	0.70	surgery
anything	8	4	0.56	anything
betrayed	8	4	0.56	betrayed
different	9	4	0.56	differences, different
father	6	4	0.56	father
full	4	4	0.56	full
girl	4	4	0.56	girl
ignorant	8	4	0.56	ignorance, ignorant
left	4	4	0.56	Left
lied	4	4	0.56	Lie, lied, lies
made	4	4	0.56	made
mother	6	4	0.56	mother
nothing	7	5	0.56	nothing
shame	5	4	0.56	shame, shameful

6.1.5 Changes in gender identity

Birth sex versus current gender identity

When looking at sex at birth and current gender, there were some changes over time (see Figure 6.1). Those who were assigned female at birth (n=43) currently identify with a range of genders, with 44.2% (n=19) of assigned females identifying as women. A total of 18.6% (n=8) of assigned females did not disclose their current gender, and 13.9% (n=6) identified as men. Interestingly, 9.3% (n=4) stated that intersex was their identity, with the remaining 13.9% (n=6) stating they were either gender fluid, genderless, or a combination of identities.

There was a total of 31 participants who were assigned as male at birth. These participants also currently identify with a range of genders, with 32.3% (n=10) currently identifying as women and 12.9% (n=4) identifying as men. A total of 9.7% (n=3) stated that intersex was their identity, and the remaining 9.7% (n=3) identified as a combination of identities. This is similar to findings by Jones et al. (2016) who found that those assigned as male at birth were more likely to have a different gender identity later in life. The remaining 11 assigned males did not disclose their current gender identity. Of the remaining two participants, one was not assigned a sex at birth and described themselves as gender fluid, and one chose not to disclose. Therefore, of the 53 participants who answered both questions, 62% of participants were either transgender or gender non-confirming in some way.

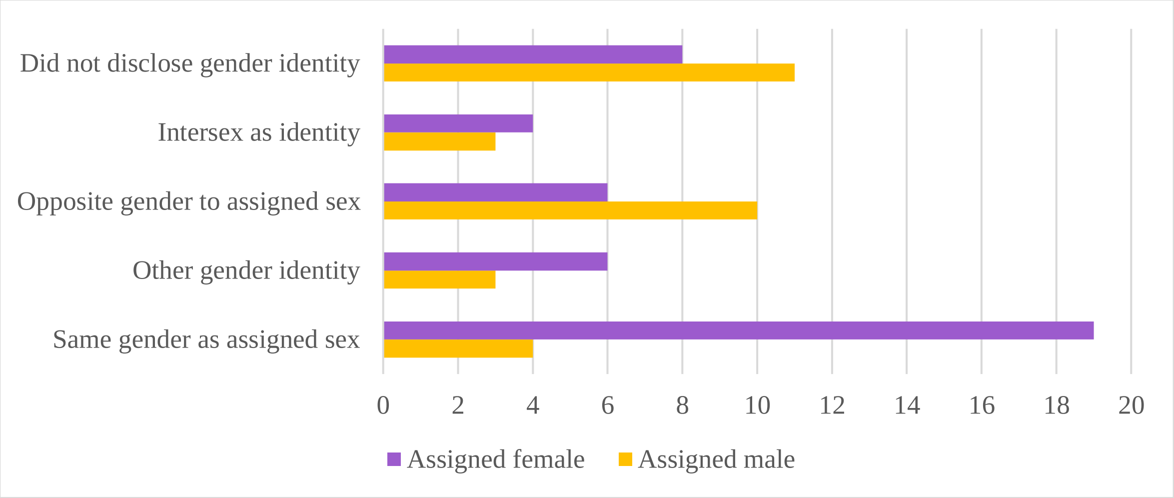

Figure 6.2 Assigned sex at birth versus current gender identity (n=74)

Ages of first desires to change gender identity

It is evident that not all participants accepted or embraced their reared gender. Therefore, it is key to identify when participants began to identify or reject these genders. When asked the question, '*at what age did you begin to think that instead of being the gender you were raised, you should have been another gender?*' participants (n=38) gave a range of ages. Responses were grouped into age brackets to gain a greater understanding of gender self-awareness across childhood, adolescence and adulthood.

Whilst not statistically significant, there is a meaningful trend showing the most common age group for wanting to be raised a different gender begins at ages 3-5 years old, with 22.5% (n=18) falling within this age group. Following this, 11.3% (n=9) of participants stated they came to this realisation at 6-10 years of age, making a cumulative 71% (n=27) wanting to be raised a different gender under the ages of 11. A total of 3.8% (n=3) acknowledged this at 11-15 years of age, with only 2.5% (n=2) wanting to be raised a different gender at 16-20 years old. Interestingly, the percentage of participants spikes at the 20+ range, totalling 7.5% (n=6) in this age group who wanted to be a different gender.

Table 6.6

Participants' age of identifying a want for a different gender identity, against whether they found their gender rearing appropriate (n=37)

Age group identifying a want for a different gender identity	Reared gender appropriate	Reared gender inappropriate
Ages 3-5	3	15
Ages 6-10	1	8
Ages 11-15	0	3
Ages 16-20	0	2
Ages 20+	1	5

Interestingly, there were five participants who stated their reared gender was appropriate who also identified wanting to change genders (see Table 6.6). Most of these participants identified wanting to be a different gender under the ages of 10 (n=4) with just one participant being over 10.

Firmly deciding to change gender

The responses for the question, *'At what age did you firmly decide you wanted to transition to another gender?'* yielded such diverse answers that 14 of the 41 responses could not be coded for quantifiable analysis. This question was only shown to participants who stated they were currently a different gender identity than their reared gender. This was to ensure that only relevant data was captured as well as not wasting the time of participants who found this question not applicable.

Of the data that was coded in this question, 36.6% (n=15) of participants firmly knew they wanted to change gender at 20+ years of age, followed by 12.2% (n=5) firmly wanting to change at 16-19. Two participants firmly wanted to change gender identity at 11-15 years of age, a further two firmly wanted to change genders at 3-5, and one participant between ages 6-10. When comparing this to the ages of first identifying a need to be a different gender other than the one reared, most firm decisions were made later in life, despite signals of this at an early age.

A more qualitative investigation of the data showed further insights into this process. A number of participants found the phrase 'transition' to be upsetting, '*Your question has a binary bias. I cannot transition to herma… Besides, I do not wish to undergo sugery [sic] or bodily transformation. I only wish I could get my bod back. But that is impossible'*. Another participant echoed these sentiments, *'I don't believe 'transition' is an appropriate word'*. These statements illustrate the need for careful consideration, knowledge, and sensitivity when planning a questionnaire for a sensitive population such as intersex.

Three participants stated that they waited to transition or embrace their true gender identity out of fear or self-deliberation, *'I fought with myself over it throughout my twenties, transitioned at 30'*. One participant discussed the journey of their gender identity, *'[at the age of] 4. But I didn't know how. I didn't understand why everyone thought I was a girl. I didn't start living as male until I was 16. But I didn't start physical transition until I was 43'*. Gender was not always about a physical transition, but about gender expression for some participants, *'In my mid to late teens I found the word androgynous and knew that is what I* *am'*. Another participant mentioned trying another gender for a period of time, but decided they preferred their previous gender.

Current gender identity

The previous chapter noted the demographics on the current gender identity of participants in this study. To get more insight into the journeys of gender identity (if any) in participants, the question *'describe your gender you are currently living as'* was an open-ended question designed to allow participants to write their own gender identities. A quantitative analysis revealed that 60 participants responded to the question. Responses could be categorised into five categories: women; men; gender fluid; genderless; combination of identities. There were 31 participants (51.5%) who currently identified as women, 10 identified as men (16.5%), three stated they were gender fluid (5%), only two identified as genderless (3.5%) and the remaining seven identified as having a combination of identities (11.5%).

As this was an open-ended question, it is difficult to encapsulate the full spectrum of gender identities via quantitative analysis. Subsequently, a qualitative analysis was conducted on the responses which found similar results, however this method allowed for more gender identities to be identified, at times, even in a single participant. These results showed 37 participants who identified as women, another 10 identified as a variation of genderfluid or androgynous, and 10 identified as men. Eight mentioned intersex as a form of gender identity, two were hostile or defensive towards the notion of gender, one was genderless, one voiced how they lived as a combination of identities (though this figure increased in the following question, when asked to compare their current and reared gender), and one identified as agender.

Of the 37 self-identified women, nine expanded with further detail or also stated something else about their gender identity. These included ‘female probably’, ‘soft butch slacker (too lazy to shave)’, ‘intersex female’ (also counted as intersex as an identity), ‘ambiguous female’, ‘neuter/female’, ‘butch female’, ‘female identified, non-binary at times’ (also counted as variation of genderfluid), ‘agender/female’ (also counted as agender), and ‘transsexual female’. Interestingly, of the 10 identifying men, none added further ambiguity to their gender, except for one participant who stated, *‘Male of centre, but I prefer to opt out of gender descriptors’* indicating they would rather be outside of the gender spectrum.

Intersex as an identity

A total of eight participants wrote ‘intersex’ as an identity, sometimes with other descriptors. These included ‘a masculine intersex person’, ‘herma’, and ‘intersex female’, remaining participants simply wrote ‘intersex’. Intersex being expressed an identity rather than simply a biological variance has been expressed by some participants throughout several of their responses in the questionnaire.

Genderfluid and rejection of gender

A further 10 participants discussed being a variation of genderfluid including being androgynous (n=4), genderfluid (n=2) or gender neutral (n=1). Other terms were used such as genderfull and pangender (n=1); *‘dress in an androgynous attire and love having all the wrong sticky out body parts. I dress as i imagine a hermaphrodite should dress, to represent my true gender’.* Not all participants were willing to discuss their current gender identity, with two participants being hostile or defensive at the notion of gender, *'No you describe it. Gender might be something someone identifies as but real gender in our society is what others think of us. I live as myself and always have'.*

6.1.6 Comparing reared and current gender identity

To gather more information about the changes in gender identity, participants were then asked *'does this differ to the gender you were raised? How?'.* Many participants who answered this question in detail discussed how their current gender does differ from the gender they were raised as (n=17). Those who discussed being another gender (or it being different to their reared gender), were coded under 'does differ' for quantitative analysis.

A qualitative analysis of participant responses gave further insights into these statistics. Some participants note that it is a relieving experience to live as a different gender identity*, 'It is totally easy and natural, very comfortable, no longer a freak'.* Others express the ownership they now get to have over their own gender, *'...Forced to wear girly clothes. Now I get to pick my own clothes'*. One participant who initially identified as transgender later found out their intersex status (turner syndrome) had been concealed from them:

> started finding out about what was done to me from meeting intersex people in the trans support groups. When they talked about their experiences, it was exactly the same as mine, I was quite shocked and confused, then angry, depressed felt stupid like I'd been tricked.

Consistent gender identity

Some participants noted that their current gender identity had not wavered from their reared gender (n=8). This does not necessarily correlate with strict gender roles, as two of these participants state that whilst their gender is congruent with their assigned sex, they do prefer gender neutral clothing. Two participants were raised as one sex and gender until 18-24 months and then another gender thereafter (one girl to boy, one boy to girl), however as this decision may have been made by parents and physicians at this age, they have been marked as ‘not differing’ from their reared gender.

Other gender variances

A total of 22 participants discussed something other than their gender differing, or not differing from the gender they were raised. They mostly stated how their current gender differed slightly, or identified as something else on the gender spectrum. Two participants discussed being consistently raised gender neutral, and one other discussed currently identifying as gender neutral after a consensual sex reassignment surgery did not satisfy their gender identity,

> I transitioned to Male to reflect my genetic sex, I have been unhappy about this as well, and hence I have now determined to live legally and physically as Gender Neutral / Indeterminate which I currently feel reflects my physical part female/part male Intersex body and mind.

Six participants expressed a combination of identities, and a further five participants mention being either androgynous or gender fluid, *‘gender to me is fluid and playful. I don't really feel comfortable saying I'm gender queer or gender fluid, but at the same time I'm not offended if I am labelled that way’*. There was an emergent theme of rejecting labels and expressing themselves as who they are*, ‘I don't feel male or female and I don't think of myself in those terms. I don't have a name for what gender I am, it just feels like me’*.

The construct of gender itself was completely rejected by three participants, *'The whole philosophy of gender is a nonsense to my mind it has never held any feelings of connection or identity'*. One participant discussed being agender but appears as a woman to others. Another discussed being genderfluid around their extended family but takes on a more feminine appearance in public. Some participants (n=3) discussed being 'out' and state that their gender identity *is* intersex *'I now identify and dress as my true gender within my social circles and am out as an Intersex individual'*.

A further two participants used this as an opportunity to express concern about expressing their gender identity. This included wishing it was easier to change official documents (n=1), concerns about expressing their gender at work (n=1), *'Different at work, but I don't want to make others feel uncomfortable. I let them see me whichever way they like. I value my career'*.

6.2. Sexuality and sexual satisfaction

6.2.1 Sexual activity in adolescence

Dating

Courtship proved to be difficult for participants, as 83% (n=54) of participants stated they did not feel comfortable dating during their teens. Given the subjective nature of dating and courtship, it is difficult finding consensus data in other studies. However, other heteronormative studies such as Boyle & O'Sullivan (2013) found that Canadian adolescent girls had more dating anxiety than boys (particularly surrounding being negative evaluated by a partner), however 82.8% of participants had a boyfriend or girlfriend at some time during high school. Glickman & La Greca (2004) conducted a study of American youth and found the opposite findings; that boys experienced more dating anxiety than girls, but both studies identified that dating anxiety was more common in the younger years of adolescence.

Intersex variations were collapsed into two categories of physical variations and chromosomal variations. Table 6.7 shows some differences in comfort levels of dating between participants who have physical intersex traits and participants who have chromosomal intersex differences (but not physiological traits), but no statistical significance was found.

Table 6.7

Participants' comfort with dating during adolescence (n=65)

Intersex variation type	Did feel comfortable dating during teens	Did *not* feel comfortable dating during teens	Pearson Chi-square	*df*
Physical	9	39		
Chromosomal	2	15	0.436	1

It is difficult to assess whether this dating anxiety frequency is limited to the intersex population, or if it is reflective of the broader adolescent population, even when looking at the qualitative data (however this does offer more insights). For example, one study suggested that younger adolescents (10th graders) experience higher rates of dating anxiety than older adolescents (11th and 12th graders), most likely due to their fewer dating experiences (Glickman & La Greca, 2004). The same study also stated that boys experience more distress and dating anxiety than girls, potentially due to the increased pressure for boys to initiate courtship.

Participants were then asked if they were sexually active in their teens. There were 41 participants (61.2%) stated they *were not* sexually active with 38.8% (n=26) stating that they *were* sexually active during this time. A national self-reporting study in the USA found that 46.8% (n=13,583) of high school students were sexually active (Kann, Kinchen, Shanklin, Flint, Hawkins, Harris, Lowry, Olsen, McManu, Chyen, Whittle, 2014). Therefore, there is a 12% difference when compared to the general adolescent population.

A qualitative investigation of the data revealed several themes when exploring the occurrence of sexual activity in high school, highlighted the subjective experiences of intersex adolescents. These themes included; avoiding sex because they were ‘different’, not dating in high school, experimenting sexually with different genders, having sex to reaffirm their gender identity, displaying no interest in sex (asexual), being sexually active with no concerns, feeling uncertain about their sexuality, reflecting how surgery had made sex uncomfortable, or disclosing that they were victims of sexual abuse. While there are several themes extracted from this question, the highest number of participants discussing any one theme was eight, or 16.33% respectively.

Not dating or engaging in sexual activity in high school

This was the most common theme amongst participants was those who did not date in high school (n=8). Some participants did not elaborate or give much further detail on this, though some discussed having interests other than sex, *'I had no dates in my teens. I threw myself into sport, and had no sexual awareness'*. Adversely, some participants actively avoided romantic or sexual encounters, *'There was no way I was going to be open to a boyfriend or to be sexually active. I was also attracted to girls which confused me more about my sex of rearing and sexual orientation'*. Questioning sexuality and subsequently avoiding sexual experiences was expressed by three participants.

No interest in sex was experienced by six participants; they explained they had no sexual interest, awareness or curiosity in high school. One participant discussed being ridiculed by a sibling as a result, *'When I was a teenager I had no interest in sex… my sister insisted that I was a homosexual because I showed no interest in sex'*.

Body image and avoiding sex

Building upon this, a further five participants stated they avoided sex because they felt their bodies were 'different'. This was due to concerns about sexual partners discovering their intersex status, knowing they were physically different to most of their other peers, or feeling unsure of themselves as a result, *'Had one girlfriend in high school, dated a couple of times, kissed and cuddled, but nothing sexual, I was too scared she would find out I wasn't really a boy'*. Not only does this statement indicate fear of being 'outed', it additionally highlighted the heteronormative expectation of 'typical' genitals dictating gender, a concept that may be psychologically harmful for intersex adolescents.

Using sex to affirm gender identity

While some participants avoided sex out of fear of looking physically different to their peers, other participants (n=3) used sex as a means to affirm their gender identity or gain a sense of control, one stated:

> I had heard a certain guy was fairly small in size and knew I had a small vagina. Even though I had no interest in him what so ever and he actually repulsed me I felt I had to get this milestone over with to be considered a real girl and not a fake being.

Further commentary from this participant may additionally exhibit low self-esteem or, that they do not feel worthy of a relationship, *'I started sleeping with anyone who would have me, certain that no one would ever want a relationship with me and that one night stands were the best I could hope for'*.

Another participant also used sex to affirm her femininity, *'started having sex at 15 in order TO TRY TO feel comfortable as a girl, and to prove to them and to me that I REALLY was a girl'*. The final participant to emerge in this theme discussed how sex was not only to validate their gender, but as a method of control over people, *'Sex was validation and control over others. I didn't actually have sex that was good and non-dissociative until decades later, after I transitioned and got new partners who wanted me the way that I actually was'*. The latter section of this quotation illustrated a desire to be accepted the way they are. It is notable that all three participants were born female, one identifies as a woman, one is genderfluid, and the other transitioned to identifying as a man. No participants raised as boys discussed using sex to affirm their gender. This concept of women using sex to affirm their identity is similar to other results in LGBTI studies; a large Australian study by Hillier et al. (2010) which found 15% of same-sex attracted young women who reported being pregnant, and similar results for same sex attracted women and pregnancy rates were found in by Smith, Agius, Mitchell, Barrett, & Pitts (2009).

Outcomes of surgical intervention and sex in adolescence

A total of seven participants mentioned that surgical intervention had made sex either uncomfortable or not pleasurable, making it the second most common theme that emerged from this question. This supported findings in other research that sexual function can be harmed by intervention (e.g., Jones et al, 2016; Lux et al, 3009; Warne, 2005; Lev, 2006). Two of these participants discussed surgical intervention outcomes in relation to masturbation, *'My genital surgeries destroyed or removed all my sexual organs and nerves. I couldn't masturbate and practice like other kids'.* A further two discussed this in the context of their clitorectomies, and another two specifically mentioned vaginoplasties which made penetrative sex painful, *'I was sexually active after vaginoplasty, but didn't tell my male partners. It was very painful'.* This participant also noted that they did disclose this to their female partners. When discussing sex, it is often heteronormative sex that participants feel they are 'failing' at, *'Sex was never satisfactory, because the equipment was damaged by surgery etc, and I could never relate to the sex-role expected as a male'.*

Whilst these participants clearly discussed physical components (surgical intervention) that made sex uncomfortable or pleasurable, some participants reflected on a psychological component. For example, one participant described a positive experience, *'The one that was a positive experience told me often I was 'gorgeous' and did not seem to be caught up on gender norms…'.* Conversely, another participant discussed a negative psychological thought process, *'I did wonder if I would be accepted with my body intact. But* *as the doctors had instilled the doubt that I could not be loved as I was, I felt it was a risk'*. Both experiences discussed matters relating to body positivity which may also play a role in body acceptance and sexual satisfaction.

Neutral sexual experiences

A total of four participants mentioned being sexually active with no elaborated concerns. This was either exploring sexual abilities, having a stable relationship, having a high libido or just feeling comfortable with their body. A further six participants discussed sexual encounters with different genders during adolescence. None of these six reported negative experiences associated with exploring their bisexuality.

Sexual abuse

Instances of sexual abuse during adolescence and childhood were discussed by two participants. In both cases, sexual abuse was perpetrated by family members. This is consistent with other reported data on child sexual abuse perpetrators. For example, one study stated that perpetrators of child sexual abuse (CSA) are either family members or parental figures of 85% women and 72% men CSA victims (Vaillancourt-Morel, Godbout, Labadie, Runtz, Lussier & Sabourin, 2015).

Further, it is common for victims of CSA to experience more sexual compulsivity as well as more sexual avoidance (Vaillancourt-Morel et al., 2015). This is reflected in each of these participants' responses. One of these participants discussed how this experience made them avoid sex and hold a negative attitude towards sex, *'I did not understand the pairing* *and sexualised behavior [sic] going on around me and on account of abuse I was being subjected at home didn't want to know about it. It made me feel sick'*. Whilst this participant clearly demonstrates behaviours of sex avoidance, the other participant who discussed instances of CSA demonstrated elements of sexual compulsivity behaviours,

> I started having sex with boys at 11. I was hoping my second step father would find out and stop molesting me. He didn't find out until I was 14. But he did stop physically molesting me, and I stopped having sex with neighbourhood boys.

Word Frequency Query

Given the diversity in themes, the most frequent words are relating only to the question. Words such as 'felt' (n=10) indicate that this was an emotional question, and so participants mainly focussed on emotions in their responses overall.

6.2.2 Sexual satisfaction in adulthood

The first question to explore sexuality was a demographics question asking participants if they currently had a partner. There were 51 participants who responded with 'yes' while 29 participants said 'no'. The nature of these relationships was explored via other questions later in the questionnaire. These findings are similar to that of Jones et al. (2016) who found that 62% of intersex participants were either in a relationship or dating. This may be slightly higher as this included dating, which was a broader question than this study which specifically asked about partners. Participants were asked to describe their sexual experience rather than list a sexuality or sexual orientation identity. As such, there is no data that clearly describes the sexual orientation of this sample.

However, some data on sexual orientation were extrapolated from the question, *'please describe your sexual experience'* where 24 participants did describe either their sexual orientation or who they were sexually attracted to. Most of these participants were heterosexual or married to the opposite sex at 33% (n=8), whilst five participants identified either as pansexual or having sex with 'all kinds of bodies'. A further five participants discussed being bisexual with one now preferring men overall and another preferring women. Four participants identified as being a lesbian or only being interested in women, and two participants stated having no interest in sex or being asexual. These results differ to Jones et al. (2016) who found that 48% of intersex participants were heterosexual. However, the low numbers in this study may reflect the insufficient data to reflect an accurate representation of sexualities in this dataset.

Dating and sex in adulthood

Participants were asked if they felt comfortable dating in adulthood. This question was also asked regarding the adolescent life stage to evaluate changes over the lifespan.

When looking at comfort levels and dating over time, there are some improvements from adolescent to adulthood experiences, but nothing statistically significant to report (see Table 6.8). However, this may be more reflective of the general population rather than those who are specifically intersex. These improvements in comfortability dating may stem from additional experience gained in social dating situations over time, as highlighted by Glickman & La Greca (2004).

Table 6.8

Participants' comfort with dating in adolescence and adulthood (n=66)

Intersex variation type	Did feel comfortable dating during teens	Did *not* feel comfortable dating during teens	Pearson Chi-square	*df*
Comfortable dating in adulthood	8	22	0.095	1
Not comfortable dating in adulthood	4	32		

Participants were given the option to comment on this question (*'As an adult, do you feel comfortable dating?'*) to expand upon their answer. Some participants misunderstood the question, thinking that the question did not relate to them as they were married, or differentiated dating from intimate or serious relationships. Though this question was intended as a hypothetical to assess the comfortability of dating and to identify dating anxiety, this question should be reworded in future studies to be more specific. A qualitative investigation into the data for this question showed that there were four main themes when it came to feeling comfortable dating as an adult. Some participants simply said 'no' (n=6), while others expressed that they were not comfortable dating because of their body or intersex status (n=14). The two remaining themes were those who were comfortable dating (n=16), and those who had not dated in a long time (n=8).

There were 16 participants who felt that they would be comfortable dating as an adult. Some of these participants expressed comfort with dating, but still felt uncomfortable about sex (n=5), *'I still feel a bit awkward about sex and physical relationships. But I'm in a serious* *long-term relationship with a female'*. One participant was very confident with themselves and with dating, *'I love dating and am out and open about being Intersex, bisexual, pagan, and into the kinky lifestyle'*. Some participants (n=3) discussed how they are now comfortable dating, but it has been a process, one reflected:

> It's often difficult and I've experienced abuse and hate due to being intersex but the connection with others is stronger and more fulfilling than the negative experiences are harmful, so I keep trying to make connections with others.

Body image anxiety and intersex identity as a barrier to dating

Avoiding dating due to body image anxiety or their intersex status was expressed by 14 participants. For some (n=2), this was due to previous negative experiences with disclosure, *'The few occasions where I have been upfront about my intersexuality, the person generally distances themselves from me'*. Besides negative experiences, some participants (n=3) felt that it was too complicated and repetitive to explain their variations to people, *'I don't think I would enjoy dating because I would feel a need to explain myself constantly to dates'*.

Feeling self-conscious about their physical bodies was also a concern expressed by participants (n=6), *'It's complicated when your body doesn't represent your gender identity or your sexual orientation'*.

A further two participants discussed cautiously venturing into dating or a relationship, but will actively avoid sex, one stated:

> …most people get frustrated to date without having sex and it often feels like I shouldn't bother. It's also been odd to watch people around me be comfortable with one night [sic] stands, I would love to be able to do that but I don't feel my body allows that. People looking for one night stands want what they expect.

Not feeling comfortable dating for reasons other than body image and concerns around intersex identity disclosure were experienced by six participants. Two of these participants express a disinterest in dating and sex, *'dating, relationships, and marriage never really interested or appealed to me'.*

Some participants (n=8) discussed how it had been a long time since they had dated which made it difficult for them to answer the question. As a result, participants interpreted as not applicable as they were in a relationship, lack of opportunity to date, or forming relationships in other ways besides dating, such as connecting with people over the internet rather than in person. Trust was an issue expressed by four participants when asked about dating, *'I am currently in the longest-term relationship in my life... It took a long time to come to trust this much'.* This was one of few participants who discussed trust being a journey when it came to relationships.

Sexual satisfaction

As the previously mentioned literature dictates, there are existing studies that state how surgical intervention may lead to a decrease in sexual satisfaction (Fagerholm, Mattila, Roine, Sintonen, & Taskinen, 2012; Köhler, Kleinemeier, Lux, Hiort, Grüters & Thyen, 2012). As such, participants were asked to *'describe your sexual experiences'* to gain a greater understanding of their levels sexual satisfaction without bias toward negative or positive subtexts. As this was an open-ended question, an array of responses was coded by theme extraction for quantitative analysis. The existing codes were then collapsed further into two categories of satisfactory and not satisfactory sex.

Appropriateness of reared gender and sexual satisfaction

When looking at the enjoyable and not enjoyable sex categories of the question *'please describe your sexual experience'*, it is important to also investigate the impact of participants' perception of their reared gender. A total of 70.8% (n=17) of those who found their reared gender appropriate were found to also experience enjoyable sex whereas 42.8% (n=12) of those who found their reared gender not appropriate discussed having enjoyable sex (see Table 6.9). Respectively, it is statistically significant (p < 0.04) that individuals who found their reared gender inappropriate were also more likely to experience not enjoyable sex (see Table 6.9).

Table 6.9

Cross-tabulation Chi-square test for whether participants found their reared gender appropriate and whether they experienced enjoyable sex (n=52)

	Enjoyable sex	Not enjoyable sex	Pearson Chi-square
Reared gender appropriate	17	7	
Reared gender inappropriate	12	16	0.043
Total	29	23	

Note.* p < 0.04

Furthermore, considering reared gender itself yielded interesting results. Participants who were raised as girls were the most likely to go on to experience enjoyable sex (n=21) at 63.6% whereas only 33.3% (n=5) of reared boys were likely to go on to experience enjoyable sex. A total of 75% (n=3) of participants raised as gender neutral went on to experience enjoyable sex, however the total participant numbers are too small to determine any statistical significance.

Data for this question were analysed via a qualitative method to gain greater insight into the sexual experiences and attitudes of participants. It was found that participants experienced a diverse range of sexualities, sexual desires, levels of satisfaction, and experiences. The most common themes extracted from this data were experiencing enjoyable sex, enjoying subjective non-heteronormative sex, psychological barriers to sex, unsatisfactory sex (including the sub-themes of experiencing pain or discomfort, and experiencing little to no sensation during sex), and those who were not interested in sex. Sexuality was also discussed by 14 participants.

Sexuality

A total of 14 participants mentioned their sexual orientation. Two women identified as lesbians and one additional participant noted they had been sexually active with men, but now preferred sex with women. Two participants identified as being pansexual and an additional two discussed having sex with ‘all kinds of bodies’. One person identified as bisexual, however two more stated they have sex with men and women. Three people identified as being heterosexual, two of whom mention they had only had heteronormative relationships.

Sexual experimentation

Four participants discussed experimenting sexually with men and women. One experimented sexually with men and women with a preference for women, while another participant noted experimenting with a preference for men. One participant was in a heteronormative relationship but had a prior sexual experience with a heterosexual couple, *'My first sexual relationship was with a married couple, mainly the woman, and it mainly didn't involve PIV sex with me but lots of oral and fingering, which was fine as I am quite orgasmic'*. Lastly, one participant stated they were heterosexual, but had previously had sexual experiences with men and women.

Enjoyable sex

There were 24 participants mentioned experiencing enjoyable sex. Three of these participants mentioned how being comfortable with themselves allowed them to have improved sex lives, *'have had a few partners with varying levels of sexual satisfaction. It has gotten better over time as I have learned more about my own body'*.

Enjoyable non-heteronormative sex

Furthermore, nine participants specifically discussed engaging in enjoyable, non-heteronormative sex. Four of these participants disclosed not having penetrative sex, one found this kind of sex painful, one noted it just not being involved, and the other discussed feeling too small to penetrate but enjoying other forms of sex*, 'Oral and anal sex as im to small to penetrate any thing [sic] but I do in joy sex if you call it that'*.

Kink and BDSM

Two participants discussed engaging in kink and Bondage and Discipline, Sadism and Masochism (BDSM) play. It is evident that both participants stated having very enjoyable sex, *'My sex life is great. I assume several different roles, different genders, dominant/submissive, penetrative/receptive, etc and I enjoy it immensely'*. A third participant mentioned having *'sex in all kinds of ways with all kinds of bodies'*, but there is no further detail to confirm if this included kink or BDSM practices.

Disinterest in sex

Five participants stated having no interest in sex. One participant mentioned that sexual intimacy is difficult and experienced a low sex drive as a result. Another participant talked about only engaging in sex to please their partner, *'I am not interested in sex. I have only been sexually active throughout my life to please my partner'*. Engaging in sex to please partners was expressed by three participants, the other using prosthetics to please their partner, despite having little interest themselves, *'My genitalia is ambiguous and often times, I have to use prosthetics to please my wife..it's a little embarrassing for me and makes me subconscious that I'm abnormal'*.

Unsatisfactory sex

It was found that 11 people experienced unenjoyable sex. Two of these participants stated it was unsatisfactory or they were unable to have sex, whilst most found they either had pain or discomfort during sex or had little to no sensation during sex. Experiencing pain or discomfort during sexual activity was discussed by five participants. Whilst they all mentioned pain, two specified skin tearing (and scar tissue) or bleeding, *'The constant bleeding and haemorrhaging [sic] and pain (horned retroflexed deformed uterus) during my teens and 20s rather traumatized me about anything connected with the female bits'*. One participant discussed avoiding penetrative sex and currently identify as a lesbian, whilst another noted that, *'First year it was really painful, but everything is perfect now'*. It is unclear what this 'first year' relates to; the rest of this participant's data offers no further insight, though it is evident they did not experience surgical intervention during infancy or childhood.

A further four participants described feeling little to no sensation during sex. Two participants discussed being unable to orgasm, *'climaxing has often been difficult, but since I did not know I had lost sensation (never masturbated before the OP), I always presumed I had psychological problems'*. A third participant also noted feeling no sensation. Two of these participants expressed frustration as a result. One participant mentioned feeling desensitised but also noted that current medications interfere with sexual ability, *'I am desensitised, and the medication for my prostrate problem renders me impotent, so sex is not frequent'*. It is noted that only two (both who experienced pain or discomfort during sex) out of the nine participants who either had pain or discomfort, or little to no sensation during sex did *not* receive surgical intervention, meaning that 77.8% of participants who experienced pain, discomfort or little to no sensation during sex were the recipients of surgical intervention during infancy or childhood.

Some participants (n=9) experienced some form of psychological barrier when it came to sex. Two participants discussed how previous negative experiences have impacted their current sex life, *'i am able to great sex and orgasms, but i would love to have my intersex body back and not to feel mutilated. sometimes i'm also negatively affected by my experiences in sexual situations and become sad'*. Two participants mentioned feeling self-conscious about their genitals, one reflected:

> Some times [sic] with those I've gotten closer to they can get me close [to orgasm], but I end up panicking that the longer they interact with my genitals, the more they'll think I'm a freak, and I fake an orgasm so they stop quickly.

One other participant disclosed psychological trauma from uterine haemorrhaging and pain as an adolescent as a psychological barrier to engaging or enjoying in sex, and another participant discussed difficulties with sexual intimacy and vulnerability. Another participant assigned male at birth and currently identifying as *'predominantly a man but with some feminine sides'* struggled with gender identity and sex, *'The phycological issue is I have a very hard time getting past that I am not female and cannot make love like a women [sic]. Nor is my spouse a lesbian like I feel I was born as'*. This highlighted the complexities and inter-relationship between gender identity and sexual orientation and identity.

6.2.3 Surgical intervention and sexual satisfaction

The quantitative analysis found that 33 participants who stated they had surgical intervention responded to the question regarding their sexual experiences. Of this number, 48.5% (n=16) were in the category of ‘enjoyable sex’. Conversely, of those who stated they did *not* receive surgical intervention in infancy or childhood (n=17), 12 participants said they did receive enjoyable sex (70%) while the remaining four stated they did *not* have enjoyable sex. Whilst no statistical significance was found, there is a notable difference regarding whether those who had surgical intervention in infancy or childhood had satisfactory or not satisfactory sex. In comparison to other studies, this is slightly lower than the Australian findings that explored heterosexual relationships which found that 76% of women and 88% of men who were experiencing very or extremely physically pleasurable sex (Richters, et al. 2014).

After participants were able to neutrally describe their sexual experiences, they were then directly asked if they felt that any surgical intervention they had received as an individual with an intersex variation has affected their sex life. Any words associated with positive or negative connotations were left out to keep this question neutral and without bias.

This open-ended question was collapsed into five categories of ‘yes, negatively’; ‘not applicable’; ‘Yes, positively’; ‘Yes (undetermined)’ (no indication given); and ‘No’. A total of 47.7% (n=31) stated that surgical intervention impacted them negatively, and a further 10.4% (n=13) responded with ‘yes’ with no further detail given as to whether they meant positively or negatively. Just one participant stated that surgical intervention impacted them positively (1.5%) (n=1) and 10.8% (n=7) of participants stated that no, it did not affect them. The remaining 10.4% (n=12) stated that this was not applicable, which may indicate they have a chromosomal variation which therefore did not require surgical intervention, or they simply may not have received surgical intervention for any physical variations. Further, the one person who did state that surgical intervention had a positive impact received surgical intervention as part of their gender transition at age 25 and is therefore not reflective of the attitudes or experiences towards surgical intervention during infancy and childhood.

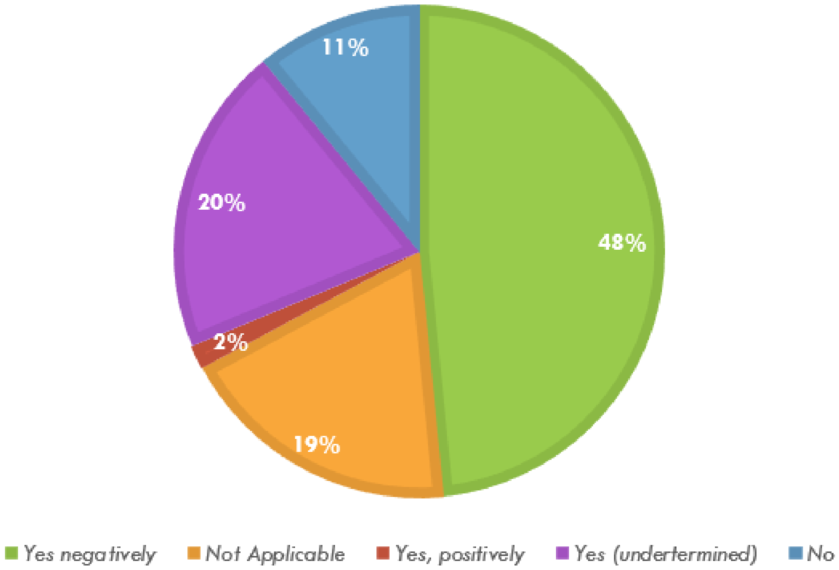

Figure 6.3 Participant responses to the question, 'Do you feel that any surgical intervention you have received as an individual with an intersex variation has affected your sex life?' (n=64).

Besides yes and no, other themes emerged from these data. Some participants highlighted that surgical intervention caused them a range of negative effects, including loss of sensation and pain, loss of sexual function, problems associated with scar tissue, psychological distress, and issues with PIV (penis in vagina) sex. Few participants mentioned positive outcomes. Similar results were reflected in a small UK study (n=14) of young (aged 14-19) intersex women; three expressed concerns that their vaginal surgeries would result in painful sex, however one decided to try dilation therapy again in hopes to improve their believed ability to be a potential sexual partner (Sanders, et al. 2015). This study stated that many participants reflected on a need to have personal control over their own bodies including its limitations and potential performance in intimate scenarios.

Types of surgical intervention experienced

Whilst the previous chapter discussed the types of surgical intervention experienced by this sample, it is important to note the specific surgical interventions mentioned in this question may be more relevant to the negative sexual outcomes experienced by these participants. Seven participants recalled specific surgical interventions that they feel have negatively impacted their sexual satisfaction. These included having a mastectomy (n=1), vaginoplasty (n=2), clitoroplasty/clitorectomy (n=2), and gonadectomy (n=3).

Sexual function

Three participants speak of vaginal dryness due to surgical intervention. One of these participants stated this is from a gonadectomy which has affected their lubrication and libido. Elsewhere, another participant also discussed becoming inorgasmic since their gonadectomy. The two other participants who experienced vaginal dryness mentioned it due to the hormone replacement therapy (HRT) they had to take as a result of surgical intervention, one of whom also noted a lacking sex drive, *'Due to HRT mismanagement I have gone through multiple spell´s where sex has been impossible because of low hormone levels causing vaginal dryness'*.

Loss of sensation and pain

Eight participants experienced loss of sensation due to a range of surgical interventions. Three participants disclosed difficulty or inability to orgasm since surgical intervention. One participant discussed issues with a mastectomy as an adult, *'I was pressured into having a* *mastectomy as an adult without my full informed consent and regret doing so. I had several complications and in addition to pronounced scar tissue also have no nipple sensation'*. Others mentioned the loss of genital sensitivity, *'I've lost much sensation an my [sic] body doesn't feel like my own'*. Further, this participant noted a dissociative feeling, making them feel separate from their genitals.

Pain was described by three participants, *'can only have sex in certain ways and must care for my genitals in unique way and I need medication to orgasm and function sexually'*. Another participant simply wrote that they experienced genital pain, and the third described discomfort from scar tissue.

Psychological effects

Surgical intervention had some psychological impacts on some participants (n=6). Two participants particularly mentioned issues with confidence, *'Scarring has effected [sic] my confidence knowing people will notice a scar across my abdomen'*. Two participants discussed difficulties with relationships, *'It has undermined my ability to form and maintain relationships'*. Another participant stated they had since developed issues with trust and intimacy, while another mentioned anxiety about new partners, *'I am initially self conscious [sic] with a new sexual partners, so I do tend to resort to alcohol to loose [sic] my inhibitions'*. Another participant discussed how they are perceived:

> …doctors who don't have a sexual investment in me can be so cruel and mean, and it feels echoed by those who scoff at having a one night stand with a 'freak', how can I be expected to lead anything resembling an 'normal' sex life?

Scar tissue

Surgical intervention resulted in problematic scar tissue for five participants. Three participants mentioned that scar tissue or nerve damage they have from surgical intervention has resulted in decreased sensitivity, '*I am certain that the sexual insensitivity I experience is due to nerve damage to the glans during genital surgery'*. Body confidence was also affected by resulting scar tissue in two participants. One participant described tightness and irritation from surgical intervention, *'the tissue sample they took left my left side labia short and tight and gets irritated because of scar tissue'*. This highlighted that even minimally invasive surgical intervention may have negative repercussions.

PIV sex

Two participants specified issues with penis in vagina (PIV) sex. One participant lamented their genitals, feeling that they could not engage in sex, *'they cut off my male genitalia at birth and now i wish i had it so i could have good sex the right way with my mate'*. The other participant simply stated that they cannot receive penetrative sex with a man.

Positive outcomes

Two participants highlighted positive outcomes of their surgical intervention. One participant mentioned being grateful that their surgical intervention (vaginoplasty for an enclosed/partial vagina) did not result in a loss of sexual sensitivity, though they were self-conscious with new sexual partners. The other participant discussed a boost in confidence and feeling more aligned with their gender, *'aligning my physical sex with my gender made me more confident* *in approaching people and being comfortable with the beginning phases of meeting and dating'*.

6.2.4 Sexual fantasies

The question *'do your sexual fantasies differ from existing experiences?'* was an open-ended question which encouraged participants to discuss their sexual wants and needs and to see if they differed from their existing real-life experiences. Gaining further insight to sexual fantasy may help to further understand the connections between the body and mind, how feelings such as shame may impact fantasy (Knox, 2005; Levine, 2005), as well as sexual empowerment and sexual disempowerment (Peterson, 2010; Riger, 1993). Whilst this is largely a qualitative question, themes were extracted and coded, however there were too many themes to provide an effective statistical analysis. Frequencies were investigated and it was found that 51.1% (n=24) participants stated their sexual fantasies did not differ from their existing experiences. A further 12.8% (n=6) mentioned they did not really experience sexual fantasies. It is notable that 25.5% (n=12) stated they fantasised about having typical genitalia. A total of 4.3% (n=2) fantasised about women whereas 2.1% (n=1) fantasised about men, and the remaining 4.3% (n=2) stated they fantasied about sex with bodies like theirs.

When cross-examining sexual fantasies and enjoyable sex, there are some interesting differences but no statistical significance as the sample size is both too small and has too many variables. A total of 89.5% (n=17) who stated their sexual experience did not differ from their sexual fantasies had enjoyable sex (see Table 6.10). All the participants who stated they did not experience fantasies (n=5) also stated not experiencing enjoyable sex.

Table 6.10

Participants' experiences of sexual fantasies against their experiences of enjoyable sex (n=38)

Sexual fantasies experienced	Enjoyable sex	*Not* enjoyable sex	Total
Does not differ from experiences	17	2	19
I fantasise about having typical genitalia	6	3	9
I do not really experience fantasies	0	5	5
I fantasise about women	1	1	2
I fantasise about men	0	1	1
I fantasise about sex with bodies like mine	1	1	2

Of the two participants that fantasised about women, one stated experiencing these fantasies despite never engaging in sexual experiences with other women, the other mentioned that they are bisexual, though do not mention any sexual experiences with women. The participants who discussed fantasising about men described themselves as having dated men and women, but preferred men. There is insufficient data to make any claims about whether sexual fantasy differs from sexual behaviours or identities in this group, though other studies have suggested that there are discrepancies between sexual identity, sexual fantasy, attraction and sexual behaviours, and that they should be investigated independently (Morales Knight & Hope, 2012).

A qualitative investigation found similar results but allowed for more detail to be extracted. Twenty mentioned fantasises not differing from the sex they were having, most of whom simply wrote 'no'. Two participants said, 'not really', but elaborated. One stated that they share and explore fantasies with all of their lovers and play partners while the other discussed wanting to be more comfortable, *'not much. but i [sic] wish i could be more* *comfortable at dating and could have sex more frequently'*. One participant stated they took offense to this question and found it to be an inappropriate question. Another participant also rejected the question. Both statements highlight the need for sensitivity when initiating questions around sexual intimacy.

Not engaging in sexual fantasy

Eleven participants discussed not having fantasies. Three of these participants stated they no longer have fantasies 'anymore', which indicates that at some point in their lives, engaging in sexual fantasy may have been explored. Another participant had spoken about the little success they had trying to implement their fantasies, *'Like dates, fantasies have pretty much fallen by wayside. Way back when, actually had opportunity to follow through on a fantasy; a dismal failure. Kind of killed fantasies, for me'*. One participant stated they were 'too vanilla' for sexual fantasies. Their lack of sexual fantasies supported the theory that a sexually objectified or medically objectified body, as seen in this study, can take away the level of empowerment necessary for being the subject (the fantasiser) for sexual fantasy in some cases such as the desexualisation that occurs for other minorities like people with disabilities (Eunjung, 2014).

Fantasy about 'typical' bodies

Four participants discussed fantasising about having a different body. One participant desired having a 'full sized penis', while another expressed how they wanted to be 'normal down there' for sexual intercourse with their spouse. One transgender participant expressed the desire for ‘typical’ female genitalia, *‘I have a very strong need to have sex as a female with the right parts and I wish the male partners I've had wouldn't want to suck my penis I hate my male parts’*. This points to an example of the disempowerment of intersex people in their own sexual imagination.

Fantasies about sex with particular genders

Three participants fantasised about having sex with women. A study investigating same-sex sexuality in young people identified that most women (52%) and many men (22%) experienced some degree of same-sex fantasy with women overall reporting a higher percentage of same-sex attraction and sexual fantasy compared to young men (Vrangalova & Savin-Williams, 2010) which showed a higher rate of same-sex fantasy in heterosexual people. However, as stated, there are insufficient numbers to make any statistical claims. One of whom was bisexual in an opposite sex marriage but engaged in same sex fantasies during masturbation. Another participant reported fantasies about women but had only had sexual experiences with men. The final participant was also bisexual, *‘I often fantasise that I have a penis and am having sex with a woman/women. I don't think this necessarily means anything except that I'm very much bisexual and miss having sex with women!*’. Whilst they mention fantasising about different genitalia, they highlight that it is more a reflection on their sexual attraction to women rather than a desire for different genitals.

There were two participants who reported fantasies about being a woman in a heterosexual relationship, *‘I have always envisaged myself as a female in a hetro [sic] relationship but,the older I get,the less significant that is’*. These two comments may support theories about internalised homophobia and fantasy (Downey & Friedman, 1995), as they may not feel comfortable fantasising about same sex sexual activities and make their bodies heteronormative. A further two participants expressed a sexual desire to be intimate with intersex bodies. One specified women, *'I often fantasize about sexual encounters with other women like me with bodies similar to mine'*. The other participant did not specify a gender, *'I fantasize about sex with somebody more like me'*.

Sexual fantasies about having different genitalia

Five participants mention fantasising about their aspects of their genitalia. Whilst there is no directly comparable data in previous literature, gender dysphoria or dissociation about body parts relating to gender is common for the transgender population (McGuire, Doty, Catalpa, & Ola, 2016; Smith, Jones, Ward, Dixon, Mitchell, Hillier, et al., 2014). Three participants discussed fantasising about surgically unaltered bodies, *'I fantasize about what my life would have been like without genital surgery or having my breasts removed. I can't seem to get excited thinking about anything else, really'*. One participant fantasied about having both sets of typical genitals, *'In terms of plumbing, I do fantasize about have a full set of both genitals. I sort of don't have either'*. One participant desired further surgical intervention to kickstart a sex reassignment:

> I do often wish my other testis had been removed when I had cancer and that I was started on female hormone replacement. That in turn would have lead to my transgender surgery. It will never happen but I can dream.

Other fantasies

Whilst there was not enough saturation to extract further themes, there were a number (n=8) of other fantasies raised by participants. Two participants stated their fantasies did differ but did not want to disclose further details. Wanting more sex was discussed by another three participants, one of whom also discussed wanting to get pregnant. There was one participant who expressed a fantasy for a different gender, *‘For a while I started to see myself as a boy in dreams, but not sexually, only physically’*. Two participants described violence as part of their sexual fantasies; one felt this was related to their PTSD, whilst the other went into more detail and said:

> I was disturbed for years because I watch a lot of violent laced porn, but I have no desire to hurt any of my sexual partners… I realised it was my body that made me angry and it was my body I wanted to hurt, so it took my anxiety out of the porn I watch.

This connects to Rizzuto's (1991) theories about shame and how this lead to unconscious desires such as violent fantasies. Alternatively, as violence and rape are often a demonstration of power rather than sex, particularly towards women (Ellis, 1989), these desires may stem from wanting power over their own bodies.

6.3 Conclusion

In conclusion, this chapter offered several important findings. Firstly, the data showed most participants from across contexts were assigned female or male at birth were raised accordingly, however a statistically significant portion of those who were assigned male felt their gender was inappropriate, compared to those who were assigned female at birth. It is clearly more common for intersex kids raised as male to consider this an inappropriate assignment, and these findings reflect Australian data (Jones et al., 2016). Further, this is a major international finding. Participants felt anger towards their parents for their rearing decisions, and some specifically discussed feeling subject to enforced gender roles, experiencing secrecy and shame about their sex and gender identity. Those who did change their identities most commonly experienced these feelings of wanting to be another gender around ages 3-5 years old, however it took until later in life for participants to initiate a change in gender expression or begin sex reassignment. This is an important finding, because it suggested there is an inflexibility in letting children have a say in their gender of rearing ‘at the time’ even when there are known complications to their sex assignments. This highlighted how heteronormativity privileges a certain structural functionalist view of only needing and maintaining essentialist male and female identities from birth to create a nuclear family to perpetuate social order (Repo, 2013). Clearly, children get no say in this imposition of identity, as many participants were unhappy with their male assignments. This may indicate that more male assignments are occurring than their ought to be, perhaps due to the cultural desire for male children (Warne & Raza, 2008). This may also relate to the cultural suppression of female sexuality; the discomfort people have towards females for having a large clitoris which subsequently may possess sexual power. Previous literature described the lengths gone to in order to disavow or deny the clitoris such as the clitorectomies of the 1800s in France to curb masturbation, madness, and excessive sexuality (Kulish, 1991).

Secondly, the data showed most participants did not feel comfortable dating during their teenage years and were not sexually active during this time, though these results did change in adulthood. Further investigation showed that this discomfort was sometimes due to concerns about body image and avoiding sex, using sex to affirm their gender identity, feeling physical discomfort or displeasure from surgical intervention, or sexual abuse. Although these experiences might be general experiences for the broader adolescent population. It is difficult to compare dating anxiety literature as ‘dating’ is subjective, however Glickman & La Greca (2004) found increased dating anxiety in younger adolescents compared to older ones, which reflected similar trends in this sample where adults were more comfortable dating than in their teenage years. The rate of sexual activity in these data is 12% lower than an American national average of 46.8% (n=13,583) self-report study by (Kann et al., 2014) indicating other contributing anxieties compared to the general adolescent population. However, a few participants were sexually active with no concerns in adolescence, and some participants from a range of sexual orientations expressed sexual comfort during adulthood and confirmed that they had enjoyable sex. It is important to note that almost half of this group enjoyed a form of non-heteronormative sex or BDSM practices however, which suggested that intersex people may be more likely to enjoy non-normative sexual practices than doctors may assume. Therefore, this should be considered in terms of their definitions of ‘ideal future sexual function’ in considering intervention surgeries purely based on the assumption of penetrative sex. The Australian intersex study by Jones et al. (2016) found similar results as participants enjoyed mainly non-penetrative sex activities, further illustrating the value of a range of sex act options as being part of sexual function and pleasure for people with intersex variations.

Not all participants had positive sexual experiences, with some participants being disinterested in sex or experienced unsatisfactory sex. Furthermore, several participants experienced pain, discomfort or little to no sensation during sex. Psychological factors such as negative previous experiences, body confidence, and trauma also affected the sex lives of this sample. Almost half stated that they felt surgical intervention had a negative impact on their sex life, with another fifth stating simply ‘yes’, making it unclear if they felt surgical intervention impacted them positively or negatively, whilst few stated it had affected their sex alignment positively. Participants stated that these procedures had resulted in a loss of sexual function and sensation and had increased pain and psychological trauma. This reflected how several studies of intersex populations showed ability to have sensation/pleasure/climax during sexual acts can be strongly hindered for intersex people by past experiences of genital surgery (Jones et al., 2016; Lux et al., 2009; Warne et al., 2005). This suggested that making decisions on surgical intervention based on sexual function where enhancing penetrative-sex abilities or aesthetic look above sensation are privileged, may at times be misguided or may lead to long-term negative sexual consequences for some individuals.

Thirdly, the data showed that participants with intersex variations sometimes had sexual fantasies that did not differ from their own sexual experiences, although a sizeable portion stated they did not participant in sexual fantasy or fantasised about things being different. Participants particularly fantasised about issues perhaps not unique to intersex people such as engaging in sex with particular genders, having more sex, or having more socially celebrated bodies such as the desire for phantasmal genitals (Morland, 2001), but perhaps it is fair to say the fantasies may have been experienced in uniquely nuanced ways by intersex people. For example, their fantasies including having ‘typical’ bodies, different genitalia or surgically unaltered bodies; which showed how their bodies are so devalued by society and medical institutions that they perhaps cannot therefore even enjoy them in their imagination. Some participants noted having sexually violent fantasies, related towards their PTSD or anger towards their own body; which showed that some intersex individuals may even perhaps experience some of the same anger-driven or disempowering fantasies experiences by marginalised groups such as same-sex attracted men and women who experience violent fantasies from internalised homophobia (Rechy, 1979).

By gaining a greater understanding of both gender and sexuality, a bigger picture can be developed of what may be needed from health professionals and the healthcare system to greater improve the healthcare experiences and care required for the intersex population. The next chapter will also contribute to this bigger picture from a social perspective, by exploring these ideas in relation to exploring social experiences such as friendships, school experiences, and family dynamics.

Chapter Seven: School experiences, friendships, and family relationships

7.0 Introduction

The previous chapters addressed intersex people's experiences with healthcare access and systems; and explored their sexuality, gender and sexual satisfaction. Whilst these chapters may occasionally refer to some institutionalised concerns such as healthcare access, it is vital that other institutions such as schools and subsequently, school experiences are also investigated. Further, whilst the previous chapter may have explored the depth of romantic or sexual relationships, there was minor overlap with social experiences and development of friendships. Therefore, this chapter will further examine an in depth quantitative and qualitative investigation into school experiences across both primary/elementary school and high school years. It will look at reflections on being an intersex student in primary/elementary school followed by exploring the developments of friendships at this time. This will be followed by an investigation of the same topics throughout the adolescent years during high school. It will then reflect on the friendships and other experiences during adulthood to accurately reflect the three phases of childhood, adolescence, and adulthood. Whilst chapter five discussed some aspects of family life, this chapter will further investigate the nature of family relationships within this sample. This will begin by exploring family dynamics and experiences of their reared gender followed by an investigation into the spectrum of family relationships experienced by these participants. It will finally explore the specific mentions of mother, father, and sibling relationships.

7.1 Friendships and experiences at school – Primary/elementary school years

7.1.1 Being an intersex student

Participants were asked a series of questions about their feelings on their intersex status during primary/elementary school and their experiences with socialising and friendships. There was no significant difference by sub-group (such as gender) for how participants described their childhood feelings and relationships during primary school. There were 16 (30.7%) participants who stated their intersex status did not affect their feelings and relationships at this time, whilst 30.7% (n=16) stated they felt isolated during this phase of their life; a finding which echoes data for an Australian sample of intersex students from Jones (2016). A further 11.5% (n=6) felt 'different' to their peers. Bullying from peers was experienced by four participants, and a further three participants stated they experienced symptoms of depression. In terms of seeking friendships, three participants reported they deliberately kept to themselves and three participants reflected that they gravitated towards other social outcasts.

One of the questions surrounding primary school experiences asked participants, *'In primary/elementary school, how would you describe your feelings about your intersex variation? How did you experience and express these feelings? Explain.'*. A qualitative analysis of this question revealed multiple themes for intersex children (retrospectively speaking) including: discussion of peers and gender roles, secrecy and shame, and positive experiences.

Peers and gender roles

There were 13 participants who discussed feeling like a loner during elementary school, and a further five stated that they were bullied at this early age. For example, one participant said, '*I didn't develop toward puberty the way other children did and was noticeably different…At each new school I was inevitably physically and verbally bullied. I remember my childhood as a miserable and defeated period of my life'*. A further four participants experienced depression and thoughts of suicide, including one comment that stated:

> Anger was not allowed as a female. I was alone and very depressed…Tried to kill myself at 15, but sadly, miscalculated the dosage. I only slept for two days straight, and I was not taken to a doctor or ER.

This comment highlighted the need for mental health and family support. Four participants discussed displaying aggressive behaviour towards others, and three mentioned becoming withdrawn at this age. Four participants mentioned not fitting in with their same-gender peers while a further two stated they were pretending to be someone they were not. For example, one comment was, *'Whenever I got called out for being effeminate or looking or acting girlish I would try and act super masculine. I was terrified'*. This highlighted the impact that imposed gender roles may have on intersex children.

Further, those who did mention being pushed out from their gendered peers were boys (n=3). One participant stated, *'The boys would not' allow me in the all boys groups.[sic]'* whilst another said, *'All the boys wanted to do was call me sissy, faggot and bash the shit out of me'*. Another outcast from the 'boys' group sought refuge with girls:

> I generally did not conform well to male gender roles. I was often bullied and picked on for this. I did have a few friends, almost all girls, and sometimes attended all girl sleepovers which made me feel accepted and comforted.

These statements suggest a need for masculine behaviours to be accepted by other boys. However, this same sentiment was not necessarily reflected for girls.

Girls who mentioned not fitting in described this mostly in the context of either not going through puberty with everyone else (n=2), or for being perceived as a lesbian (n=1), for example, one participant stated:

> Things got progressively worse from age 10 to 14, as it was obvious something was odd/wrong since I wasn't going through puberty ‘like the other girls’. I was constantly bullied over it and it reinforced people's belief that I would become a lesbian.

Secrecy and shame

Secrecy was a theme experienced by four participants. One of these participants stated, *‘I didn't understand why it was a bad thing but I knew I wasn't supposed to talk about it*’. Similarly, a further three participants experienced feelings of shame about themselves, their body, or their intersex variation. For example, one participant reflected, *‘Was paranoid about people finding out, kept to the cubicles’.*

Positive experiences

Five participants stated they had no issues in primary school, with one reporting they were confident and made themselves known to their peers. Another of these participants discussed how their intersex status did not affect their school life besides daily nurse visits for medication, and another reported feeling ‘normal’. One mentioned having no concept of gender as a child, and two participants discussed how they had no issues during this time, but developed some problems after puberty. One participant discussed acts of confidence and resilience:

> My dad had always taught me to be strong and stand up for myself. I knew bullying for various reasons, actually not for my appearance at all until I was older. I stood up for myself and other kids who were bullied or were different, I sort of became the leader of the misfit kids.

Three participants mentioned knowing they felt different but did not yet know of their intersex variation, one stated *'i knew something was wrong off or different all my life',* whilst another reflected intuitively:

> I had no concept of my gender as a young child. I read the word 'hermaphrodite' in a book of myths at the age of ten and knew, somehow, that it was me. But that was just a myth, right?

Word frequency query

A word frequency query was run in NVivo on these data to identify theme saturation. Words directly related to the question that would offer no context or information were removed from this search (for example, the word 'school'). The word frequency query showed that the highest word used by participants was 'different' which appeared 12 times. A text search of this word showed that nine of these responses discussed feeling different to other children or knowing their body felt different to that of their peers. Following on from this was the word 'bullied' used by nine participants. The frequency of this word supports this as a strong theme throughout these responses. 'Friends' was also used often which illustrated that participants felt that friendship (or lack of) was a vital component of their school experiences in elementary school. The Table 7.1 highlights the frequency of these phrases that informed the extracted themes.

Table 7.1

Word query for the question 'In primary/elementary school, how would you describe your feelings about your intersex variation? How did you experience and express these feelings? Explain.'

Word	Length	Count	%	Similar Words
school	6	15	2.06	school, schools
different	9	12	1.65	differences, different
felt	4	12	1.65	felt
girls	5	11	1.51	girl, girls
intersex	8	10	1.38	intersex
bullied	7	9	1.24	bullied, bully, bullying
feelings	8	9	1.24	feel, feeling, feelings
friends	7	9	1.24	friend, friends

7.1.2 Friendships during primary/elementary school

Girls were most likely to be sought friendship with, with 31 participants seeking friendships with girls in primary school, followed by befriending boys and girls (n=20). Just 14 participants sought friendship with boys. Overall, this meant that participants were seeking friendships with the opposite sex (n=18) mostly by those assigned at birth or early infancy as boys (n=12) compared to girls (n=6).

Seeking friendships with both boys and girls (n=17) was the next most common theme, followed by assigned girls seeking same-sex friendships (n=15) compared to assigned boys seeking same sex friendships (n=9). Given that seeking friendship of the same gender (as assigned gender) was the least popular, this yields similar results to Jürgensen et al. (2010) which showed that intersex children tend to make friends with both genders compared to children who were not intersex who often preferred to befriend their own gender.

Participants were asked about their number of friends in primary/elementary school. Participants could select ‘Yes’ or ‘No’ to each of the following descriptors regarding friendships: ‘Was a loner’; ‘had about the average number of friends’; ‘had more friends than average’; ‘was often teased for being ‘different’’; ‘had a few close friends’. There were 51 (75%) participants who selected ‘no’ for the average number of friends in primary school and had not marked ‘had more friends than average’.

A cross-tabulation and chi-square test looked at how many friends the participant perceived themselves to have and whether the participant found their reared gender appropriate. Respectively, it is statistically significant ($p < 0.02$) that 34 participants (50%) who found their assigned gender inappropriate also reported that they had less than the average number of friends in primary school (see Table 7.2).

Table 7.2

Gender appropriateness and having an average number of friends (primary/elementary school) (n=68)

Had about the average number of friends	Gender appropriate	Gender inappropriate	Pearson Chi-square	*df*
Yes	13	4		
No*	17	34	9.623	1

Note. * p < 0.02

Furthermore, when a cross-tabulation was investigated between those who selected that they ‘had a few close friends’ and the appropriateness of their reared gender, it was found that those who found their assigned gender to be inappropriate reported that they ‘had a few close friends’. This further supports the previous finding. Gender appropriateness also impacted the amount of bullying participants were subjected to in primary school. Those who found their reared gender inappropriate were often teased for being different ($p < 0.16$). To further investigate the relationship between gender appropriateness and friendships in primary school, a chi-square test was conducted examining the relationship between surgical intervention and those who responded ‘no’ to ‘had more friends than average’ to determine if surgical intervention had as much of an impact as finding their reared gender in/appropriate. There was a high number of participants who selected ‘no’ for this question who had also stated that they did receive surgical intervention in infancy or childhood (n=39). Whilst this number was high, no statistical significance was found.

Participants were asked to discuss their experiences at school. Participants mostly reflected on their feelings during this time, the kinds of bonds they made (or did not make) with their peers, and where they fit into the social structure at primary school. Whilst most participants discussed their peers, one participant discussed their poor behaviour at school and negative relationships with teachers.

Emotions

Feelings of isolation were experienced by 15 participants, five of whom specifically mentioned feeling like an outcast amongst their peers. For example, one participant said '*I had very little, if any friends. I was outcast by everyone around me.'*. Despite feeling isolated, six of these participants did have one or a few close friends, which may indicate that feeling isolated does not necessarily relate to friendship, but perhaps something else. One participant stated, *'i [sic] was always an outcast. i had a couple friends but none were very close.'*

Nine participants discussed feeling different to their peers, feeling alone or alienated. For example, one participant stated, *'I felt different and kept distance'*. Four of these participants felt confused or frustrated about their gender identity or reared gender roles and expectations, one participant reflected, *'I wondered if I should have been born a boy, so I felt very alone'*. Another participant discussed feeling frustrated that they were treated like a boy, another felt they were always at odds with who they were raised to be, and one discussed the difficulties of feeling transgender:

> I knew about trans and I figured that's what I was from a very early age (around 5) didn't know anything about my body just that it was strange and I couldn't tell anyone. So kept very secret and tried to act normal as in masculine.

Depression was experienced by six participants. Participant responses of this kind included quotes like *'All the other kids seemed to be so happy all the time and I didn't understand why or how*' and *'I felt alone and thought I must be some kind of alien. I became suicidal at age 13 and again at age 15'*. One participant reported feeling suicidal, another expressed feeling that they were over-treated with two therapists, both of whom misdiagnosed the participant's childhood post-traumatic stress disorder (PTSD) from sexual abuse as generalised anxiety. Another participant discussed concealing their feelings of depression, *'I was very good at pretending to be happier and more outgoing than I was. I didn't show what I was going through on the inside'*. This may highlight a lack of a support network.

Relationships with peers

Four participants further discussed being bullied by their peers. One of these participants specifically mentioned this occurring due to being gender non-conforming, whilst another did not specify the nature of the bullying, commenting *'I was teased for my gender non-conformity. It is not like I was walking around with my pants down. I also felt the whole picking [sic] order was strange and stupid.'*. Another participant who discussed bullying talked about being bullied for changing schools and always being the 'new kid'. Another participant stated that whilst they were bullied, they had lots of friends whose relationships were positive in nature, *'I had a lot of friends whom were very good etc.but [sic] also had a few bullies at times made life hectic'*.

A further three participants discussed not fitting in with their peers during primary/ elementary school. One specified not fitting in with the same-gendered classmates at school, while another discussed how not fitting into any particular clique was an advantage, *'…as I was navigating who and what I was [sic] and it made me realize I didn't fit in anywhere which allowed me to fit in everywhere'*.

7.2 Friendships and experiences at school – High school years

7.2.1 Being an intersex student

The same questions for primary/elementary school were repeated for high school with additional questions about dating and sexual activity. Using the same questions allowed the researcher to compare data over the junior and senior years of school. The qualitative analysis identified nine themes in this question. The most common themes were aggression/anger, avoiding school or school activities, being bullied, denial (of their intersex status), depression, being a loner, pretending to be someone they were not, secrecy and shame. There were 14 participants stated that they were a loner or preferred to keep to themselves in high school. Participant responses of this kind included quotes like '*I was a loner in a group of people. Could not quite fit in to whatever activity was happening. Was a proverbial 'fifth wheel.'*' Another participant mentioned, '*I did my best to stay away from most people, keeping to myself as much as possible.*'. Half of these participants also stated they were either depressed or had suicidal thoughts. Examples included quotes such as *'I was often depressed and still spent most of my time with girls even though most people didn't see me as a girl'* and '*I was suicidal all through out [sic] middle school (grades 6-12) and high school. I was very depressed, and emotionally unstable. I had zero genuine support'*. Depression was experienced by a further nine participants throughout their high school years compared to primary/elementary school.

Bullying

Bullying was experienced by eight participants in high school. Four of these participants discussed being bullied because they were not conforming to gender expectations or heteronormativity, one stated *'I was bullied and teased about being gay and fem, high school was hell'*. Another participant discussed aspects of school ethos and/or policy, ***'****I went to a conservative Catholic high school. You did not express feelings of difference without risk. If you were gay you stayed in a hole in the ground'*. This may highlight a need for intersex inclusion in school policies and indicates potential issues in private or religious education institutions.

Acceptance and reaffirming gender

Eight participants stated that they exhibited certain behaviours or engaged in specific acts to fit in with their peers. Participants talked about pretending to be someone they were not, adapting to fit into different social circles, or going to various extremes for peer approval. Two female-assigned participants discussed having 'lots of sex' to 'prove' their femininity, *'I did things to try to prove that I was as much of a girl as the other girls. Examples: wearing the highest heels with the shortest skirt; having sex with boys starting at age 15*'. One other participant mentioned having to 'defend his manhood' against his peers, whilst another discussed *'playing the role of a good girl'* which helped her become popular in school. As these statements show, there were several ways these participants tried to fit in or reaffirm their gender identities and sexualities. Similar to themes from primary/elementary school, boys are seen defending their masculinity (or being bullied for a lack of it) to others, whereas girls tended to 'prove' their femininity intrinsically rather than to please same-gender peers.

One other participant reflected on usually not fitting in, but a positive experience when experimenting with another gender:

> My greatest experience in high school was when I went to a Halloween party dressed as a girl. …Many of the boys asked me to dance and for the first time I was popular. I also felt a bit guilty, but [sic]did allow two of the boys to kiss me. Yet it felt wrong as I knew I was not a girl or a boy.

Whilst they have reflected upon this as one of their most positive memories, there is an underlying element of shame and secrecy as they express guilt for 'tricking' their peers. Furthermore, some participants mentioned being drawn to other outcasts or minorities, but still not feeling like they fit into that social circle, for example one participant explained that they ***'…****felt connected with LGBT students but still didn't feel like I really fit in or was relatable'.* Others did find solace in particular groups, for example, one participant mentioned *'I was active in theatre, where everyone was different'* where they found a sense of belonging.

Secrecy

Secrecy was discussed by eight participants. Participants reflected on repressing feelings surrounding their bodies (n=2), lying or avoiding questions (n=3), or were actively being told to keep it a secret (n=3). One participant stated, *'I had not started my periods, and I felt like I had to keep it a secret'* and another explained that they *'…always felt like I had a secret and I* *was not 'real''*. A further two participants specifically mentioned feeling shame. For example, one of these participants said:

> Got bullied a lot, showered with my shorts on or when people would leave. Was the smallest of the boys, stood out as well for being from a different ethic [sic] group, being socially awkward, ashamed of my body, stayed in my bedroom most of my teenage years feeling really angry and dysphoria [sic].

Another three declared feelings of denial. An example included the comment, *'Again… I was in total denial. I am not sure I even understood my condition very well. Except I had a lot of shame and feelings of sadness and loneliness*'.

Aggression and at-risk behaviours

A further five participants mention feeling angry or exhibiting aggressive behaviours. This was either 'lashing out' due to being bullied (n=1), two experienced feelings of anger, for example, one stated they felt *'Lonely, depressed. Angry'*. Another displayed reckless behaviour and self-harm and commented, *'I did a lot of drugs and put cigarettes out on my body. I put myself in dangerous situations with dangerous people so that I would die. I wanted to die accidentally on purpose.'*.

Avoiding school activities

One participant discussed frequently dropping out of classes and school altogether. Their comment explained, *'I ditched school constantly and still got good grades. I eventually dropped out at 15, got my GED at 16 and got legally emancipated from my mother.*'. A total of four students discussed difficulties either in Physical Education classes or showered with shorts on (after Physical Education or sport); one participant mentioned, *'I did not for instance participate in sport and was granted a permanent exemption thus avoiding changing and showering with other pupils'.* Others had difficulties or conflicts with the teachers regarding the subject (and moved to other areas of independent study) or avoided the class entirely. For example, one stated, *'I couldn't face PE (for many reasons) and would make excuses to miss it'.* One participant mentioned that being intersex had no impact on their school life in primary school or high school, despite knowing their intersex status at the time and stated that it *'did not really affect my life at that age either.'*

Word frequency query

The word frequency query indicated that this question elicited an emotional response (see the highlighted *feelings*) and experiences of difference were felt by participants. Friendship was also an important factor in this question, followed by discussions of being bullied and feeling depressed, which corresponds with the themes extracted from this data. Table 7.3 highlights relevant word frequencies that correspond with the themes extracted from this data set.

Table 7.3

Word query for the question 'In high school, how would you describe your feelings about your intersex variation? How did you experience and express these feelings? Explain.'

Word	Length	Count	%	Similar Words
felt	4	18	1.89	felt
different	9	13	1.37	difference, differences, different
girls	5	13	1.37	girl, girls, girls'
feelings	8	12	1.26	feel, feeling, feelings
like	4	11	1.16	like, liked
high	4	10	1.05	high
lot	3	10	1.05	lot, lots
still	5	10	1.05	still
people	6	9	0.95	people
really	6	9	0.95	really
time	4	9	0.95	time
boys	4	8	0.84	boy, boys
friends	7	8	0.84	friend, friends
depressed	9	7	0.74	depressed, depression, depressive
much	4	7	0.74	much
bullied	7	6	0.63	bullied, bullies, bullying

7.2.2 Friendships and other experiences during high school

The overlapping questions with primary school regarding friendships yielded similar, but amplified patterns in high school when looking at the development of friendships during adolescence. When looking at participants who selected 'no' to 'had about the average number of friends' who also responded to the question regarding the appropriateness of their gender rearing, the total number (73.5%) had decreased by 1 (n=50) since primary school. It was statistically significant ($p < 0.002$) that those who found their assigned gender inappropriate reported not having the average number of friends in high school.

Being teased for being different was a common issue amongst participants. A total of 61.1% (n=47) of participants stated they were often teased for being different, of which, 45.6% found their assigned gender inappropriate. Therefore, it is statistically significant ($p < 0.012$) that those who found their assigned gender inappropriate were often teased for being different (see Table 7.4). This rate is slightly higher than the 45% (n=50) of trans and gender variant children who were bullied in the study by Riley (2012).

Table 7.4

Chi-square test of reared gender appropriateness against being teased for being different in high school

	Value	*df*	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	6.317[a]	1	.012		
Continuity Correction[b]	5.023	1	.025		
Likelihood Ratio	6.364	1	.012		
Fisher's Exact Test				.016	.012
Linear-by-Linear Association	6.224	1	.013		
N of Valid Cases	68				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 8.38.

b. Computed only for a 2x2 table

A qualitative investigation into the question '*Please comment on your childhood feelings and relationships during high school*' showed a great range of themes regarding friendships and other school experiences. Most commonly, participants discussed not fitting in with their peers (n=17), as well as commentary regarding sexuality or gender identities (n=17). Close friendships were also a common theme (n=11), as well as bullying (n=8), depression (n=8), and feeling alone (n=8). Puberty was discussed by six participants, five participants reported no issues during high school, while another four experienced feelings of anger, and just three participants discussed family dynamics for this question.

Not fitting in with peers

Not fitting in with peers or being an outcast was experienced by 17 participants during their high school years. Participants discussed feeling like a freak, being introverted or anti-social, and being alienated. One participant mentioned pretending to belong to a peer group, while another mentioned simply not being able to relate to their peers, for example, one participant stated, *'felt unable to connect with my peers,like I was on a different wavelength [sic]'*. One participant noted having no friends at school, but healthy friendships outside of school and engaging in a variety of non-school activities.

One participant discussed feeling isolated, potentially as a result of school curriculum, *'Five years of sex ed. classes with nary a mention of people who were 'differently sexed'. Nothing. I felt isolated and alone. There was no one to ask a question of. I had no peer group for such things'*. This statement illustrated the heteronormative approach of sex education as well as highlighting a lack of peer group for this participant.

Sexuality and gender identity

Sexuality or relationships were discussed by 12 participants. Four participants discussed not dating; one discussed having no interest in seeking relationships, another questioned why it was so easy for others to form romantic or sexual relationships. Two other participants simply felt too uncomfortable or self-conscious to date others. *'…hung out a lot with their girlfriends but never had a gf myself, too body conscious, too confused'.*

Other participants discussed their experiences and feelings with same sex attractions or other non-heteronormative sexualities, *'I felt like I was an outsider…wasn't interested in normal male attractions'*. One participant identified as a lesbian and was out to her friends, whilst another discussed being same sex attracted to her friends and thinking it was problematic. Another participant embraced their individuality and sexuality, *'Women were always curious if because they liked me were [sic] they gay or straight, to which I would reply; 'Neither, you just like me!''*.

Two participants discussed being popular with the opposite sex, *'I felt lonely at times. I was very tall. But I felt people thought I was attractive and asked me out'*. As discussed in the literature review, being tall is common for individuals with Swyer syndrome or AIS due to the above average levels of testosterone and therefore, may be experienced by people with these intersex variations. Another participant mentioned being tall, but was teased for this trait. One participant talked about promoting her sexuality as a way of affirming her gender identity, such as engaging in heterosexual sex, and wearing high heels and short skirts.

Issues surrounding gender identity were discussed by a further five participants. Another participant disclosed trying to affirm their gender, but with masculine behaviours, *'I was seen as a boy and treated as such and any 'feminine' activities or behaviors drew negative attention. I had to pretend to be overly masculine in order to maintain relationships'*. Two participants talked about feeling greatly depressed and experiencing gender dysphoria, and one other disclosed about being confused about their gender.

Additionally, one participant noted feeling that they had a poor future ahead of them in terms of developing future relationships, *'I was really very depressed and felt like I didn't fit in anywhere. I thought my future was poor in terms of relationships and family'*.

Close friendships

Close friendships were discussed by 11 participants. Two participants specifically mentioned having close friendships as an improvement since primary school. Two participants reflected upon becoming friends with other outcasts or subcultures*, 'had a few friends who were also ostracized dorks. We banded together'*. Whilst one participant was content with few friendships and had no interest in conformity, another participant engaged in peer culture, *'I had close friends in high school and played a lot of sports and started drinking and using marijuana to help cope and to become 'more popular' [sic]*. This is the second instance of engaging in at-risk behaviour discussed by a participant during their high school years.

Feeling alone

Feeling alone, lonely or isolated was experienced by eight participants. Two of these participants noted being popular or well-liked but felt alone despite this, *'I was well liked and had many friends but at times felt very alone'*. One participant reflected on spending *'more time at home than what was normal'* and another spoke of reading as an escape*, 'felt as an outsider, I escaped reading books and keeping to myself. It became more obvious in my teens that I wasn't a 'normal' girl'*.

Bullying

Bullying was discussed by eight participants in relation to this question. One participant responded with violence and aggression, whilst another discussed how bullying had intensified from primary school to high school years. Three participants were teased for non-intersex related reasons; one for being from a different part of town, one for being tall, and one did not specify, but stated it was not regarding their intersex variation. Another participant mentioned being bullied, but not necessarily feeling targeted*, 'lots of people were teased for all sorts of physical and other differences. I didn't feel in any way unique'*. This indicates a bigger issue of bullying in schools, rather than bullying behaviour specifically targeted towards intersex variations. Two participants did reflect on being bullied for intersex *related* reasons, one for reaching puberty late, and the other for developing differently to other children, *'I was bullied for not developing breasts, for growing sideburns and a moustache, etc. People equated it to sexual orientation and I was on the receiving end of much humiliation, speculation, etc'*. These results are different to the Australian study by Jones (2016) who identified 75% of participants were bullied. Similarly, they found that bullying occurred for a variety of reasons such as different physical traits stemming *from* intersex variations rather than a knowledge *of* intersex variations. Therefore, it is clear that bullying may be happening for a variety of reasons rather than bullying behaviour being targeted specifically towards intersex students.

Depression

Eight participants discussed feeling depressed or experiencing depression during their high school years. Two of these participants discussed thoughts of suicide, feeling withdrawn, feeling numb or defeated. Another two mentioned a lack of friendships, another two participants also discussed depression associated with their gender dysphoria, for example, one stated, *'Depressed and unable to cope with people I was very withdrawn and suicidal I hated my body it just felt wrong, I very much wanted to look female'*. One participant reflected on trying to be 'normal', *'I pretended to be a normal, happy girl. I was really very depressed and felt like I didn't fit in anywhere'*.

Puberty

Issues surrounding attitudes and experiences regarding puberty were reflected upon by six participants. Two of these participants (mentioned previously under *bullying*) discussed being teased for either not reaching puberty or developing differently to their peers. A further two discussed how not reaching puberty affected them socially, *'I felt much more normal than the rest of my group members as I did not get puberty and was still acting normal'*. This extended to attitudes towards dating, *'I wasn't interested in dating or had any feelings towards it at the time as I was essentially still a child'*. Whilst this highlighted the different way that these participants experienced adolescence, they are not necessarily negative experiences. This is particularly evident in the first participant discussed in this point, as they identify others behaving 'not normally', creating their subjective sense of what is normal.

One participant reflected on how puberty via hormone replacement therapy (HRT) impacted their experiences, *'Going through puberty on HRT furthered my feelings of isolation, I did not understand the changes my peers were going through, why was I not experiencing them'*. This highlighted a potential negative outcome of either intervention, or simply experiencing puberty differently to others.

No issues during high school

Five participants self-reported experiencing no issues during high school. Two of these participants refer to this time as being ‘normal’, and two participants described introverted behaviours (in positive language), or happily pursuing academic activities*, ‘I was quite introverted and liked to be by myself a lot of the time’*. Another participant mentioned having a very positive high school experience, though does compartmentalise being intersex and interventions, *‘Loved high school and was generally happy - I was good at pushing my difference and medical experiences away’*.

Anger

Feeling angry or aggressive behaviours were experienced by four participants. Two of these participants discussed feelings of anger or aggression alongside feelings of sadness or loneliness. One used school sport as an outlet for their aggression, they stated *‘Feelings - sad except when I dod [sic] sport which was an outlet for my aggression’*, while another reflected on responding with aggression to being bullied, *‘I tended to lash out when teased. Violence was much closer to the surface. I was told to keep my condition secret’*.

Family relationships

Family relationships were touched on by three participants when discussing their experiences in high school. Two of these participants described this as a turbulent time with parents, *‘My parents, when they were around, only compounded matters by being so anxious at my lack of* *feminisation'*. The remaining participant struggled to connect with peers and experienced bullying, turning towards building relationships with their family as an alternative, *'I turned to my extended family and even though they all knew I alway´s [sic] felt accepted and euqal [sic]. I spent a lot of time with adults during my teens'*.

Disclosure

Issues surrounding disclosure were expressed by six participants. Three chose not to disclose their intersex status to their peers; for example, one stated, *'I did not know how to talk about being intersex so I did not disclose to anyone. I felt I was a freak and didn't really know my place in the world',* and another avoided discussion surrounding puberty with their peers and teachers altogether. One participant chose to disclose their intersex status to a close friend with no indication of it being a positive or negative experience, while another disclosed their intersex status to close friends with undesirable results, *'I disclosed my intersex variation to my closest friends from primary school towards the end of high school and they drifted away in the following months'*.

7.2.3 Friendships and other experiences during adulthood

Participants were asked the question, '*please comment on your current feelings and relationships as an adult*'. There were three stand out themes that emerged from the data of the 66 participants who responded. Participants discussed their friendships (n=26), their relationships (n=24), and their feelings around being intersex (n=28); five of whom felt very empowered by their intersex status. Following this, a further seven participants talked about their difficulties trusting people, three mentioned being transgender, and two discussed experiencing feelings of depression.

Friendships

Friendship was a common theme expressed amongst participants. Three participants discussed finding friendships and solidarity through online networking and support groups,

> I have been lucky enough to find people who have similar feelings of being different, in the LGBT+ community and I now have many friends who I love very much and enjoy talking with, both locally and across the world on the internet.

A further seven participants described finding friendships or feeling a sense of belonging in peer support groups and communities. Introversion was a dominant trait with 10 participants identifying as being either introverted or having just a few close friends. One participant said, *'I still am an introvert, but have some precious friends with whom I love to spend time'* in contrast to the four participants who mentioned having many friends*, 'As an adult I have more friend than you can imagine, I tell all about being intersex and more than a few about being transgender part of who I am.'*. One participant discussed seeking out friends from other marginalised groups, finding solidarity in being different, *'I still see to find more friends among marginalize groups than in the 'mainstream''*. Difficulty with disclosure of their intersex status was described by three participants who recalled concealing their intersex status from others and how it had caused a barrier to developing friendships, *'There is always a barrier I do not want to cross in case people discover I am not like them*'.

Relationships

Relationships were the second most prominent theme for this question (n=24). Currently being in a positive relationship was discussed by 11 participants, varying from long term relationships (n=5), to opposite-sex marriages (n=1), same-sex marriages (n=1), histories of positive relationships, and polyamorous relationships (n=1). Two participants discussed identifying as lesbians for this question and one other participant identified as gay, who experienced attacks of homophobia.

Other participants (n=3) described being hesitant to enter relationships, *‘I go back and forth on whether I should live asexually or if it's worth continuing to try and develop a healthy sexual/romantic life’*. One participant noted feeling that being physically different to others is a barrier, *‘I have accepted that I will always be different, and this will always be an issue in relationships’*. Both statements highlight struggles with self-stigma and relationships that may be experienced by those with an intersex variation.

Difficulties with trust

Trusting people as an adult was a difficulty voiced by seven participants. Participants discussed feeling ‘guarded’ or experienced difficulties with developing close or intimate relationships, *‘I am a guarded person, experiencing difficulty letting people get close’*. Difficulties with intimacy were mentioned by two participants, *‘Intimacy and trust are still very complicated’*. Further, there appears to be some overlap between trust, intimacy, and body image, *‘I do have body image issues, as well as trust issues and its very difficult for me to overcome those’*. All aspects (trust, intimacy, and body image) need to be positive to have a positive experience, particularly when it comes to sexual intimacy.

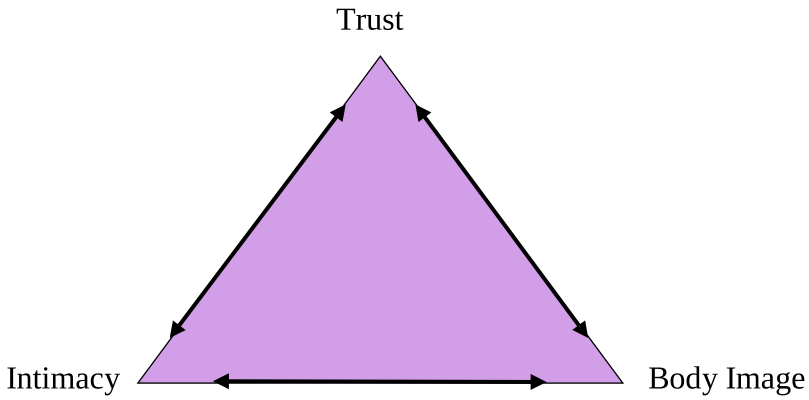

Figure 7.1 The interrelationship between trust, body image, and intimacy

7.2.4 Intersex identity and experiences of adulthood

Reflecting on their intersex status or identity in the context of adulthood was discussed by 28 participants in the question, *'Please comment on your current feelings and relationships as an adult'*. Common themes included issues of acceptance, their changes in attitude about their intersex status over the years, feelings of empowerment, transgender intersex identities, and experiencing depression.

Acceptance

Four participants discussed feeling like they have accepted who they are in relation to their intersex status. One participant discussed this in the context of acceptance being a journey, *'It's taken me a really long time to get to this place of satisfaction but, I'm here now, and that's all that matters'*. A further five participants talked about being accepted by others such as their friends, family, or communities, *'Everyone I [sic] know knows about my intersex variation and is completely accepting'*. Another participant noted being accepted, but not letting their body define who they are, *'...don't let my body define who I am. I am a lot more comfortable with myself and have found communities where people accept me as I am'*.

Acceptance was not necessarily always a positive experience, *'I have accepted that I will always be different, and this will always be an issue in relationships'*; this statement indicates that while they may feel acceptance for their own bodies, they feel this may be an issue for others or for relationships. These statements highlight the many forms of acceptance that may be experienced including self-acceptance (both as finding peace with themselves but also identifying and accepting it as a potential barrier), acceptance by others, and a sense of belonging. One participant described a lack of self-acceptance, *'Still feel different, I'll always feel like an alien and kind of look like one'.*

Whilst self-acceptance was explored, two participants voiced how they continued to experience difficulty with acceptance from others. Two participants noted that they were subjected to experiences of homophobia. One stated that this was from their own community, *'I think I have a good network these days but I am still the subject of homophobic attacks and ridicule especially laterally ...that is from my own community'*, and the other because of confusion and misunderstanding from others, *'it's often hard dealing with people who are trans/homophobic, because they don't understand what i am'*. This statement also highlighted the need for greater intersex awareness to avoid public confusion with transgender and sexual orientation.

Attitude changes over time

Feelings and attitudes regarding their intersex status changed over time for participants. Some participants now feel happier than they did as a child or adolescent, and one respondent offered, *‘I’m very happy, I still feel different; but now that's not a bad thing. It's uniqueness’*. Another participant reflected on how this improvement feels truer to themselves, *‘Much better than during childhood/teenage years. Much closer, more authentic’.* Whilst most of these changes were positive, getting older meant some shifts in priorities and concerns, for example one participant noted*, ‘I do still have feelings of being different as they [friends] are now all married with children, Not being able to have children is now a thought, Scared of being lonely when older’*. Some attitudes or feelings did not change at all, *‘am still angry about all that happened, particularly the lies, negligence, poor treatment and deceit’*.

Empowerment

An Australian study found that participants were more likely to feel positive and empowered about their intersex status at a later age (Jones et al., 2016). In this study, five participants discussed feeling empowered by their intersex status and happy in their own bodies. One participant discussed feeling confident, *‘…have more confidence in myself, as how I feel about my gender identity (i.e. female, but partly androgynous) aligns with my physical reality’*. Another simply stated they are feeling good, whilst another celebrated their diversity, for example, they stated, *‘Totaly [sic] ok with it. Feel blessed by the diversity of my being’*. One participant described how changing genders and sex on *their* terms was an empowering experience, *‘I lost a lot of the anger, let go of so much. I'd [get] my genitalia 'sorted' and look what I would consider 'normal'. The scarring and stitching up was excised - *my* choice this time. That was majorly empowering. My body, *my* terms’*. This highlighted the issue of consent, a strong theme throughout these analyses.

Transgender intersex identity

Participants described their experiences of being a transgender intersex person. One found this to be an empowering experience, whilst another discussed being generally very open, but felt they were somewhat more open about discussing intersex than transgender. Another participant reflected on working through gender variances for 22 years and currently living as a woman, *'I no longer 'try' to explain or make everyone feel okay about who/what I am'*. This also demonstrates a sense of self-acceptance.

Depression

A few participants used this question as an opportunity to discuss how they still experience depression. One participant reflected on how they experience depression from having surgical intervention*:*

> I never had any tendency towards depression prior to surgical interventions. I now do: I lost control over my own bodily autonomy, and was made to feel like I must fit in, be normal. I've found that to be incredibly damaging.

This is further evidence of the need for consent when dealing with the decisions regarding surgical intervention. The other participant describes feelings of low self-esteem*, 'I still have some negative views of myself as a person, and I wish I didn't have them'*.

7.3 Family relationships and dynamics

7.3.1 Family relationships and gender appropriateness

Family dynamics may change over time from childhood, to adolescence through to adulthood. For example, some participants in an Australian study had turbulent relationships with parents due to the secrecy and disordering of intersex variations (Jones, 2017). Lev (2006) also noted that dissatisfaction regarding gender assignments may result in fostering feelings of anger or resentment towards family members.

Participants in this sample were asked to describe their current relationship with their families and if this relationship had changed since they were a child. Responses were categorised as the following: ‘I have always had a good relationship with my family’; ‘I have always had a strained relationship with my family’; ‘I currently do not speak to my family at all’; ‘my relationship with my family has improved as an adult’; ‘I would like to be closer with my family’ and ‘My relationship with my family has worsened as an adult’. Looking at this in a cross-tabulation with finding their reared gender appropriate or inappropriate, it was found that 41.6% (n=10) of those who found their reared gender appropriate had always had a good relationship with their family, in contrast to the 15.6% (n=5) who always had a good relationship with their family but found their reared gender inappropriate (see Figure 7.2).

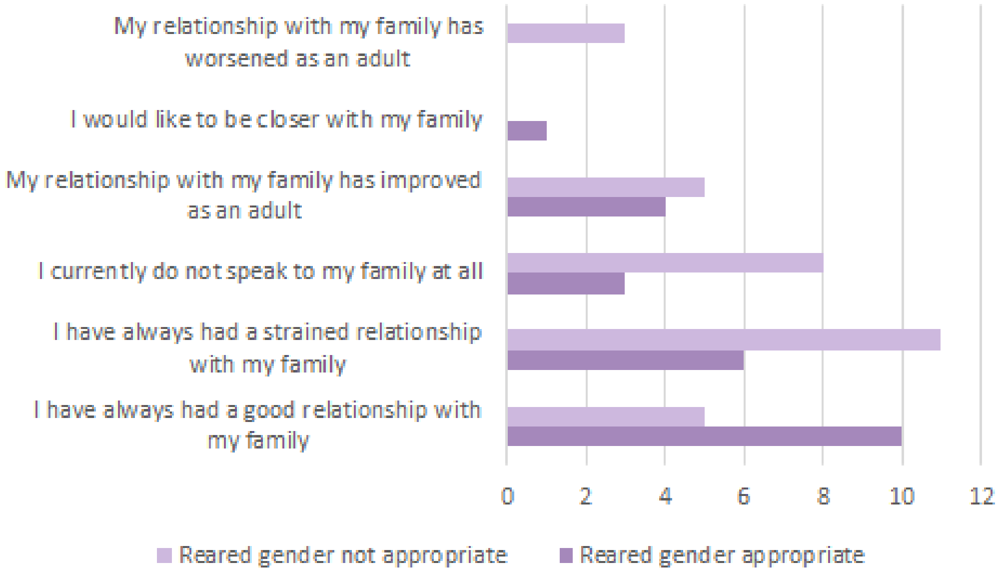

Figure 7.2 Appropriateness of participants' reared gender against their assessment of their family relationships over time (n=56)

As there were too many variables in determining the kinds of existing and previous relationships with the family, these categories were then collapsed into two variables 'good relationships' and 'poor relationships' (see Table 7.5). Cross-examining this once more with the appropriateness of reared gender, a chi-square test revealed that it was statistically significant ($p < 0.029$) that 84.4% (n=27) who found their reared gender inappropriate had poor relationships with their families.

Table 7.5

Reared gender appropriateness against relationships with family (n=56)

Gender appropriateness	Good relationships with family	Poor relationships with family	Pearson Chi-square	*df*
Reared gender appropriate	10	14	4.743	1
Reared gender Inappropriate*	5	27		

Note. *$p < 0.029$

Further investigation was conducted into when participants identified their reared gender as being inappropriate. When cross-examining this with good or poor relationships with their family, no statistical significance was found. It is meaningful that 90.5% (n=19) of those who identified wanting to be another gender under the ages of 10 also stated they had poor relationships with their families.

7.3.2 Spectrum of family relationships

To further examine these relationships between the participant and their family, a qualitative analysis was used to investigate the nature of these relationships. From this analysis, it was evident that 16 participants had a neutral to good relationship with their family, a further 16 mentioned a strained relationship with their family, four discussed not being close but on good terms with their family, whilst 10 participants did not speak to their family at all. Relationships with their family had improved in adulthood for 10 participants but worsened for seven others. Amongst this discussion, 16 participants talked about parents specifically and 11 talked about relationships with their siblings. No other specific relatives were mentioned.

Positive relationships with family

Eleven participants experienced 'Always having a good relationship with family members'. Four of these participants described their family relationships as being 'very good', with three out of four of these participants additionally stating that their family was very supportive. Further, two of these participants specifically mention their mother as being supportive, for example, one stated, *'Very good. My mother, in particular, was a strong source of support post-diagnosis and post-surgeries'.* Another participant mentioned also being close to their father who has since passed away. The other of these four participants discussed having very good family relationships, but avoided addressing potentially harmful issues, *'Very good family relationships…I try not to force issues that can do harm'.* Other positive relationships with family that were explored consisted of relationships that differed person to person, or have remained consistently good from childhood to adulthood. One participant discussed how discussing their intersex status has allowed for an array of strong relationships in their life, *'All of my relationships are strong. Honestly talking about my body has been crucial in creating real relationships'*.

Neutral relationships with family

Five participants concisely mentioned having neutral relationships with family or gave no further indications as to whether these relationships were particularly negative or positive.

Neutral language was used such as *‘normal’*, *‘not so bad’*, or *‘okay’.* Another five participants mentioned a lack of closeness or superficialness to their family relationships. Two of these participants discussed having good relationships that lacked closeness, *‘Very closed. We are friendly to each other, but not close’*. One participant was dissatisfied with the closeness between themselves and their family*, ‘More closed off emotionally than I would like’*. Another participant discussed that their relationship with their family had always been ‘shallow’.

Strained relationships with family

Sixteen participants reflected upon their strained relationships with family members. Four participants specifically stated the word ‘strained’, *‘My parents and I have a very strained relationship, always 1 straw away from breaking the camel's back’*. Another of these participants simply noted that some areas of their relationship with their family were strained. Whilst some just stated they had strained relationships, others were more specific in discussing their family dynamics. Two participants described strained relationships with their family due to their intersex status and gender identity*, ‘Yes it has changed they still have problems with my transition and excepting my intersex condition’*. Conversely, one participant noted that the strained relationship was not the issue, despite family assumptions, *‘my current relationship with my family sucks.but [sic] not because of me being intersex, which they still dont understand’*.

Lack of support or acceptance by the family was mentioned further by another two participants. However, both participants noted they now have a more supportive family, *‘I rarely see them, and I'm happy with that. I have my own family now, who accepts me’*. One participant noted that minimal contact with their family was optimal, *'They have decided to be as little involved in my life as possible. This is actually beneficial for my health and well being [sic]. We stay in contact but opt to keep our lives separate'*. This differs to the aforementioned neutral relationships that lacked closeness as there is a clear mention of decisions to be distant, but civil. Another participant discussed experiencing trust issues with their family, and another mentioned barely being in contact, but *'not officially not talking'*.

Negative relationships with family

Ten participants explained that they were either estranged from their family, had hostile relationships with their family, or were not on speaking terms with some or all their family members. Four participants specifically mentioned being estranged, whilst a further two described how they have not had contact with their family for a specific amount of time (eight and 35 years respectively). Participants who gave details behind their poor relationships with their family reflected issues that pointed towards two themes; acceptance and trust. Three participants discussed a lack of acceptance, particularly regarding being transgender or non-binary (n=2). One stated:

> I have not had contact with my family in 8 years. They are abusive, homophobic, transphobic, racist, very religious, and do not acknowledge the existence of intersex people or non binary gender identities (my partner identifies as a non binary gender).

The other participant who discussed this stated that there was no longer a relationship with their family as they never accepted her new gender identity. A third participant mentioned discussed a severance of the relationship with their family as they *'did not support me for* *who I am'* but this does not necessarily indicate a lack of support regarding gender identity or intersex status. The aforementioned quantitative analysis further supports these findings regarding the relevance of acceptance and gender identity or gender appropriate rearing.

A lack of trust or feelings of betrayal was described by two participants. One commented:

> My family was told to keep my intersexuality (and history of sex change) secret. I did discover the truth, and when I eventually spoke out about it it created a terrible rift in my family, leaving me estranged from family as a result.

The other participant reflected that 'family' meant 'betrayal' and that they no longer loved their parents. Both statements highlight the importance of trust and openness regarding intersex statuses and decisions. It may be notable that three participants stated their parents were now deceased, therefore having no opportunity to repair these damaged relationships in the future.

7.3.3 Relationships with parents

Whilst this question was deliberately open so that participants could discuss a range of family dynamics with different family members, sixteen participants specifically discussed their relationships with their parents. Whilst much of this content was explored in prior themes, there are still some notes worth exploring. For example, one participant mentioned a previously strained relationship with their parents, but a more recent closeness with their siblings, *'But my parents are dead, and I only disclosed my status to my siblings about 10 years ago. So, it was really my parents who were the problem. My siblings are very supportive, now that they know the situation'*. Two participants discussed forgiving their parents for their decisions or attitudes due to their age, *'Parents are older so I have forgiven them and we are at peace'.*

Mothers

Whilst many participants discussed 'parents' as a unit, four participants specifically mentioned mothers. Three of these participants talked about having close relationships with their mother, *'My relationship with my mom is wonderful. I have come to notice how it is rare, unfortunately. She is not perfect, but [sic] has always been supportive of my dreams'.* Two of these participants specifically mentioned being close with their mother and a sister. Of those who stated that they were close with their mothers, two participants identified as being a kind of gender neutral (one not assigned a sex and birth and one assigned female), and the other identified as a being male to female transgender. Therefore, it is possible that mothers may be more accepting of gender fluidity than fathers, however as there is not enough evidence to support this, further exploration of this relationship dynamic may be an area for future research. One participant discussed a strained relationship with their mother, *'my mother I speak to 2 or 3 times a year on the phone and that is safer for me. She is still toxic'.* Another participant mentioned not speaking to her mother for 35 years.

Fathers

Few participants elaborated on relationships with their fathers. Five participants disclosed that their father was deceased, compared to only one participant who stated their mother was deceased. One participant reflected on how they had a close relationship with both of their parents, *'...I was very close to my dad as well, but he passed away'*. No participants discussed a close relationship with only their father. One participant recalled a negative relationship with their father, *'I have no relationship with my father however last I had any words with him he ridiculed me on the basis of my differences'*. Whilst the numbers are small, participants in this study were more likely to have a close relationship with their mother rather than their father.

7.3.4 Relationships with siblings

Eleven participants specifically mentioned their siblings when asked to describe their relationship with their family. Whilst some participants just stated siblings, others would specifically mention a brother or sister, or discussed both. Sisters were mentioned eight times whilst brothers were discussed five times. Whilst they were mentioned, the nature of the relationship was not necessarily explored in depth.

Sisters

Relationships between participants and sisters were largely positive, with five mentions of positive relationships with sisters. Three of these mentioned being very close or having very supportive relationships with their sisters. One participant discussed how her sister was a source of information about their intersex status:

> My sister is the only one who sometimes talks a little bit about personal stuff, she is also the one who told me a lot about what was going on when I was little, she is significantly older than me and remembers it.

Two participants reflected on having poor relationships with their sister; one rejected their new gender identity. The other participant discussed that they had unspecified differences with their sister, *'One sister struggles terribly with the effects of our childhood and now has no relationship with me informed in part by my differences and my choices as an adult around my differences'*. Another participant noted changes in their relationship with their sister, *'My sibling and I became estranged when I transitioned, she seemed to think it was a reflection on her because we share the condition. But we've come back together as she plans to have her next medical intervention in 2 weeks in her efforts to become a parent'*. It is clear that gender transitioning may be an issue of contention with family members.

Brothers

Specific relationships with brothers were not mentioned as frequently as relationships with sisters. Three were identified as positive relationships, one was a negative relationship, and another participant simply described, *'I'm not close to either of my brothers'*. One participant experienced partial acceptance by a younger brother, but was disowned by her older one, they reflected, *'An older brother and younger sister have disowned me because I changed my name and my gender status. A younger brother, although he won't call me by my current name, fells [sic] no ill effects towards my actions.'*

Support from siblings

Support varied even between specific participants' siblings, for example one participant explained, *'An older brother and younger sister have disowned me because I changed my* *name and my gender status. A younger brother, although he won't call me by my current name, fells [sic] no ill effects towards my actions'*. Another participant described reaching out to their brother but not their sister. Conversely, another participant noted a positive relationship with both a brother and a sister, but that their sister was particularly a good source of support, *'an elder brother and sister have followed me on my most difficult years and the sister has been very supportive'*. Language was occasionally ambiguous, for example, phrasing such as 'one sister' instead of 'my sister' may indicate that there is more than one sister in the family. As nuclear family members were not recorded, it is difficult to accurately assess the nature of each relationship in the family, as neutral relationships may not have been discussed, highlighting only positive or negative relationships.

7.4 Conclusion

The data on social relationships explored in this chapter showed that when it comes to developing friendships, there were some improvements from childhood to adolescence and again in adulthood for the intersex individuals surveyed. Whilst the thesis question sought answers as to whether surgical intervention influenced these experiences, there was statistically significant data showing that participants who found their reared gender inappropriate were more likely to report that they 'had a few close friends'. Surgical intervention showed similar impacts, however these contributions were not as statistically significant. Whilst there were similar, yet amplified results for high school, it was statistically significant ($p < 0.012$) that those who found their assigned gender inappropriate were often teased for being different during high school years. High school was a turbulent time for some participants who discussed being bullied, seeking acceptance from themselves or peers and trying to reaffirm their gender identity. Issues surrounding disclosure and secrecy was a common theme at this time, with some participants acting aggressively as a result. This forcing of intersex children to remain secretive about their intersex variation is an example of Foucault's discussions surrounding the 'repressive hypothesis'; how power, or 'insistence of rule' is exercised to mask any sexual deviations where it is only to be discussed behind closed doors (Foucault, 1981). Further, these closed door discussions were also minimal as parents would not discuss this with them either, resulting in some poor relationships with parents.

Whilst few participants in this sample discussed disclosing, those who did only told close friends. This is similar to the results from Jones et al. (2016) who found that students were more likely to disclose their intersex status to peers but not as often to their teachers or principals. Others avoided school activities such as Physical Education classes. Some participants had close friendships, however overall other themes that emerged during this time were feeling alone or not fitting in with their peers.

Participants discussed their sexualities, their disinterest in dating or non-heteronormative experiences and desires during school years. Whilst some participants also reported having no issues in high school, depression was experienced by several participants and it was a difficult time with family members for some. This highlighted the impact of gender imposition on intersex children and how this imposition and subsequent infantalisation of their own wants, needs and expression may lead to negative experiences.

Friendships overall improved from adolescence to adulthood, particularly for those who sought peer support groups. This supports the findings of Jones et al. (2016) who also found that intersex people often had low self-esteem during their younger years, but this improved over time, particularly when meeting other people with intersex variations. This highlighted the value of peer support groups for intersex people.

When looking at relationships with family members and this sample, this concept of gender appropriateness was significant once more. It was found that it was statistically significant ($p < 0.029$) that 84.4% (n=27) who found their reared gender inappropriate had poor relationships with their families. Further, 90.5% (n=19) of those who identified wanting to be another gender under the ages of 10 also stated they had poor relationships with their families. These statistics highlight the importance that gender appropriateness and potentially, family support, plays in the overall happiness of intersex participants. These findings support statements made by Karkazis (2008) who described how some parents may read into gendered behaviours more for their intersex children. Therefore, these pressures of gender conformity may elicit negative relationships towards parents.

Further qualitative investigation into these relationships showed that the nature of these relationships was quite complex, and in fact, showed a spectrum of relationships with their families. These relationships ranged from positive to negative, even hostile relationships with family members. Most participants who answered this question had a strained relationship (n=16) with their families, followed by 11 participants who had positive relationships. This was closely followed by negative to hostile relationships (n=10) and five participants experienced somewhat neutral relationships with their families. Strained relationships with family members were attributed to a lack of acceptance with their intersex status or gender identity (n=2) or a lack of support (n=2). This is amplified with participants who discussed in detail about their negative or hostile family relationships that stemmed from a lack of acceptance by their family (n=3) or a breach of trust (n=2). These themes of acceptance and trust are seen heavily throughout all three results chapters of this thesis.

This breach of trust is supported by Lux et al. (2009) who found that the coercion or influence of parents to pressure intersex children into surgical interventions resulted in significant disturbances in family relationships. Strained relationships with families was also reflected in Jones (2017) who identified that family members were generally very secretive about their own intersex status, particularly if the family had hereditary variations, which caused tension and silences which negatively impacted family dynamics. Both this study and Jones (2017) identified this notion of secrecy around intersex variations and interventions and how this may result in negative family relationships.

Those participants who specifically discussed mothers and fathers showed that those who were close or had very positive relationships with their mothers were a form of gender fluid or gender neutral. Whilst this may indicate that mothers may be more accepting of gender fluidity than fathers, there is no further evidence to support this, however this may highlight an area for future research. Based on the themes extracted from this topic, it is clear from these data that participants were more likely to have a close relationship with their mother rather than their father.

Relationships with siblings were discussed less frequently than relationships with parents. Overall, participants noted having mostly good relationships with their sisters (n=5) compared to poor or negative relationships (n=2). This supports the findings of Jones (2016) who found that sisters were more likely to know about their intersex variation, though this does not necessarily correlate with closeness.

Brothers were not mentioned as frequently as sisters, however, as the amount of family members was not recorded, it is difficult to accurately assess how many members there are in each participant’s family. Therefore, as neutral relationships may not have been discussed, participants may have only highlighted particularly positive or negative relationships with their families.

Chapter Eight: Discussions and Conclusions

8.0 Introduction

The previous chapters provided data about intersex people's concerns in healthcare management (chapter 5); intersex people's gender, sexuality, and sexual satisfaction (chapter 6); and intersex people's school experiences, friendships and family relationships (chapter 7). This chapter considers this data in light of the theoretical framework and existing research to discuss the new learning offered by the study about early *intervention* and support, *imposition* of gender and sexuality on people with intersex variations, and *isolation* in social settings. Building on this discussion, this chapter then draws conclusions in response to the study's aim of identifying the needs of people with intersex variations in healthcare; sex, sexuality and gender; and in social settings. It then presents the limitations of this study, followed by implications for a range of stakeholders. This chapter will conclude with future directions moving forward in intersex research.

8.1 Discussion of Health Care Findings

8.1.1 Findings Apply to Western Health-Care Broadly

The first research question inquired into intersex people's concerns and experiences in healthcare management via their own stories; this established a narrative constructed under a critical and postmodern frame in order to explore the marginalised groups' own perspectives within institutions (Davis, 2015a; Jones et al., 2016; Liao & Simmonds, 2014; Morland, 2008). Rather than focusing on the leaders of marginalised groups (as in some of Davis'

(2015a) work which considered key contributors' ideas at conference events) or people who had agreed to clinical interventions (as seen in some of the clinical studies of adults); this study focused on the lived experiences of all members of the intersex community including many who experienced interventions in their youth. Also, rather than focussing on a population from a key country (such as the Australian population in Jones [2015]) the study contributed an international participant base to the field. This approach followed Morland's (2008) emphasise the importance of non-authoritative voices and narratives on the lived experiences of being intersex *in general*. Whilst healthcare systems differed from nation to nation, the problems experienced were mostly the same. Therefore, the study this thesis focused on explored the key problem of intersex peoples' sociocultural experiences of healthcare from the perspective of people from the *general international intersex community* without a focus on intersex or medical authority or national specificity. Therefore, the findings are more relevant to general discussion of intersex populations (particularly in the West where participants mainly came from such as the USA, UK, and Australia) instead of one specific nation's healthcare system.

8.1.2 Negative Experiences of Medical Interventions

There were very few positive experiences of medical intervention in the cohort of this study which, as stated, mainly focussed on people from Western countries with CAH, pAIS, cAIS, idiopathic 'ambiguous genitalia', and Klinefelter Syndrome. When asked how they felt about the status of their surgical intervention, the overwhelming majority (95.5%, n=64) of participants stated they felt the surgery they experienced was inappropriate. A later question asked '*if no, reflecting on this as an adult, do you wish you had received surgical intervention* *as an infant? Why?*'. This question was answered by 46 participants, despite it being targeted only towards those who had not had surgery in infancy or childhood (n=30); highlighting it as a key concern for people with intersex variations. Internationally there were no key differences as all countries privileged early interventions. Reflecting on these experiences of surgical intervention brought participants feelings of shame and regret, and their data emphasised their feelings of being disempowered at the lack of consent and bodily autonomy they were given. The infantilism of people with intersex variations was imposed by institutions as they made lifelong decisions for the intersex population, with little or no presumption of their ability to grow up and make such decisions themselves. This highlighted the lack of bodily autonomy that intersex people have, particularly in Western countries. These findings are synonymous with theory and data in other studies in Western countries including Jones et al.'s (2015) quantitative and qualitative study in Australia, Lux et al. (2009)'s clinical interviews in Austria, Germany, and Switzerland; qualitative interviews by Davis (2015a) in the USA, and the numerous individual narratives from intersex voices in the special issue of *Narrative Inquiry in Bioethics* (Inter, 2015; Pagonis, 2015). This illustrated that this is an issue not restricted by national boundaries.

The theoretical writing around medicine and people with intersex variations emphasises the problem of the positivist paradigm for doctors and the lack of recognition of bodily autonomy. These were the key areas to consider in analysing the data. For example, it is clear in these participant statements that doctors felt they needed to be treated in a certain way based on their positivist attitudes without asking, without consent. This lack of consent and consultation with individuals about their own healthcare was also identified in the Jones (2016) study of Australian data for people with intersex variations. Davis (2015a) noted how health professionals talk about people with intersex variations is vastly different to how this group will refer to themselves. For example, health professionals will use medicalised language, stating that these people have ‘disorders’. Further, this language asserts their authority over intersex bodies as a ‘disorder’ that *requires* medical treatment. The diagnosis of a ‘disorder of sex development’ (DSD) illustrates the essentialist notion that sex is a scientific binary which is used to increase credibility to health professionals via their positivist approaches. Conversely, people with intersex variations (largely) do not see themselves as having a ‘disorder’, and often prefer other terminology such as ‘intersex’ to better reflect their experiences, or to de-pathologise their bodies. The themes in all of these stories highlight the need for consent and the clear lack of bodily autonomy experienced in their lives; surgeries and other interventions were happening to them rather than with them. Further, these voices highlight the need for more narratives to navigate lived experiences rather than quantitative snapshots of clinical studies where details are often lost.

Davis (2015a) proposed that healthcare around intersex people currently occurs in the later stages of Conrad and Schneider’s (1992) five-stage model of deviance. Specifically, much Western healthcare around the world (though not all) reinforces the legitimacy of medical ownership of intersex variations and institutionally recognises a medicalised deviance despite the resistance by intersex advocacy groups. The nature and extent of the resistance varies country to country despite the existence of organisations such as OII and Accord Alliance. This must be considered in the internationally focused study that this thesis reports on. Therefore, while this study draws on the five-stage model, it does not assume that all participants exist in a context that has reached the fifth stage as Davis’ US model may be able to (see theory chapter). This study had four participants born in non-Western countries, however only one participant remained in their country of origin. The study had inadequate data to suggest when they had moved from these countries to Westernised nations, and no additional information about whether any diagnoses, treatments occurred at their country of origin or new country of residence – a key deficiency in the study mainly arising from the difficulty of editing the survey down to a smaller number of questions. Therefore, it is difficult to determine whether cultural influences affected these participants, or what stage of deviance their country of origin may potentially be in. Additionally, the participant who was born in Asia and currently resides in the same country provided no further information that may contribute to this understanding. Therefore, there were no other distinct trends for these participants as a sub-group that separated them from other participants and they like other participants reported dissatisfaction with their interventions despite their country of origin or residence. That intersex people may move across different nations' healthcare systems may be a factor to consider when conducting further international research.

Lack of Adolescent to Adult Transitional Healthcare

Some participants expressed displeasure at how the transition from adolescent healthcare to adult healthcare was managed, highlighting the fallout of care completely or lack of transitional care between these life phases. Recalling the participants who discussed receiving no care as an adult, and others who reflected on the absence of healthcare entirely, it can be said that both these attitudes represent the disconnect between adolescent and adult healthcare and the lack of transition to adult healthcare services. This concern was also raised by Crouch, Minto, Laio, Woodhouse, & Creighton (2004) who noted there are minimal studies exploring evidence-based models of transitional care when it comes to intersex healthcare management. Crouch & Creighton (2014) also confirmed this lack of transitional care between these two life phases.

Additionally, there appears to be a lack in adult care services for people with intersex variations. While the literature review highlighted a lack of clinical guidelines for intersex youth and populations regarding their rights to bodily autonomy, there are currently Australian clinical guidelines for trans and gender diverse youth (see chapter 2) that privilege this concept. These guidelines for trans and gender diverse adolescents recommend a delay in surgery until adulthood. The findings from this study bring these needs of intersex youth to the foreground; there is a need for similar clinical guidelines for intersex youth, to return to them the right to determine their bodies, and to delay any unnecessary surgical intervention on genitalia until adulthood, as well as to develop clearer definitions on what is and is not necessary surgery.

Some participants also reflected the need for *intersex specific* services and noted how they were at times confused with or treated as transgender individuals, an issue also uncovered in other studies (Jones, 2015). Whilst transgender and intersex young people share somewhat similar adversities (issues around broad discrimination and the concept of autonomy for one's body) and may benefit from some of the aforementioned shared guidelines (on anti-discrimination issues in treatment and the problem of delayed age-related body autonomy broadly), however it is vital to treat each group with individualised care and as a community in their own right with specific issues they are more likely to face in healthcare institutions. The data showed people with intersex variations are likely to have negative experiences from surgeries being imposed upon them in their youth, whereas transgender people have been known to advocate for access to intervention in their youth (Riley, 2018; Smith, Jones, Ward, Dixon, Mitchell, Hillier, et al., 2014). This study's findings therefore lend support to work by Crouch & Creighton (2014) noting that there are minimal evidence-based models of transitional care when it comes to intersex management.

Lack of Quality Mental Health Support

The need for greater mental health access and support was expressed by a number of participants; reflecting other studies (Diamond and Watson, 2004; Jones et al., 2015; Leidolf, Curran, Scout, & Bradford, 2008; Liao, 2015). This study found that 23% of participants who sought mental health services and support did not find it helpful; lending weight to the similar finding in the intersex study by Jones et al. (2015) which found that 23% participants' experiences with mental health services were either 'bad' or 'very bad'. It is clear then across these two studies that a notable portion of intersex people have characterised their experiences of mental health services negatively. Where these studies differed was on the offering of mental health services; this study found that 5% of participants were not offered mental health support throughout childhood, adolescence and adulthood. Contrastingly, other studies found a greater number of participants were not offered mental health services: Jones et. al (2015) found that 19% of Australian intersex people were not offered mental health services; and Diamond & Watson (2004) found that only 16% of intersex participants were referred to counselling by their physicians. The other studies had more participants answer this question compared to this study (64 participants answered the question), so it is unclear if this impacts the saturation of answers being smaller in this study, or if this difference is due to the international scale of this study versus the single country approach in the other studies. If it is the latter, this could point to a much higher deficit of offering mental health support in Australia compared to other countries.

Whilst not statistically significant, it is evident that this study found those who received further surgeries during these childhood and adolescence were more likely to seek more mental health support services in adulthood. This may indicate how repeated surgical interventions instigate further trauma. Jürgensen et al. (2014) did not necessarily investigate mental health access but did identify emotional distress in their study of intersex children. These participants reported significantly lower overall self-esteem, school functioning and physical wellbeing (n=86) via a Health-Related-Quality-of-Life (HRQOL) test when compared with the reference data. These results further emphasise the need for mental health support and access for the intersex community at all life stages. Whilst Warne et al. (2005) investigated ‘psychological outcomes’ for people with intersex variations relating to medical intervention, they did not directly ask people with intersex variations how they felt regarding said interventions they were subjected to; they were asked only how mental healthcare services could be improved. The most common desire was for mental health professionals to seek further education on intersex variations, and for youth specific services that were supportive and empowering, and to have input in any medical treatment. Most of these results are synonymous with findings in this study regarding the broader topic of desires and needs in healthcare management (see 8.1.6).

Liao (2015) argued that not offering mental health support services to intersex people constitutes a form of stonewalling from doctors. Liao (2015) reflected on 13 narratives around intersex medicine and identified the trauma experienced by intersex patients as a result of not just surgical intervention, but the stonewalling of doctors. These stories showed doctors not showing empathy or sympathy, emotional detachment and potentially not allowing certain questions to be asked. While this has ideally improved in recent years, the idea of not offering further services or withholding information is not doctoring with candour. Liao (2015) went on to discuss the remembering body and recalled participant reflections about recurring nightmares which in actuality were early memories of surgical intervention, feelings of shame and discomfort experienced by repeated examinations, all symptoms of emotional distress. The stories reflected on by Liao (2015) are congruent with the findings in this study, with participants also reflecting on the trauma experienced from surgical intervention as well as the emotional mistreatment from doctors (misuse of language, disregard for pronouns, traumatic physical examinations). Overall, the study's findings on the lack of mental health care provision support that of other studies and perhaps under-represent problematic findings seen more strongly in some specific countries.

8.1.3 Intersex People Want Healthcare Reforms

When asked, most participants had insights and desires when it came to the management of healthcare for people with intersex variations. The most dominant responses were a need for better education for health professionals and delaying all medical and surgical intervention until the age of consent. Further, participants also expressed desires for greater mental health support and access, more resources about intersex variations, peer support groups for both individuals and parents, and better long-term support and follow up for adults with intersex variations. Finally, a need was expressed for greater access to treatments, records, and identification changes. In earlier research, there are minimal findings regarding clear methods of improvement for healthcare management (Jones et al., 2016; Lux et al., 2009). This study yields similar results to Jones et al. (2016) who found that the most common needs expressed by intersex participants included wanting to choose their own treatment paths (if any); the participants also expressed a desire for greater education for healthcare staff on intersex matters, a need for more information for intersex patients and referrals for support groups. Smaller themes emerged including wanting health professionals to stop pushing families to treatments, wanting health professionals to listen to their needs, to stop making assumptions about their bodies and identities (a desire also expressed by some participants in this study), and a need for more sensitive treatment including appropriate language. These results (and the results of this thesis) are similar to a small UK study of 14 young intersex women which found that many participants were frustrated regarding communications with health professionals; as their 'conditions' were lifelong, health professionals needed to be prepared to have empathetic ongoing conversations with them, particularly through development phases (Sanders, et al. 2015). These needs and desires for alternative or better healthcare and healthcare options challenge the status quo of how the medical system manages intersex variations. Using a critical framework, it is clear that people with intersex variations are a marginalised group whose rights to self-determination and access to non-discriminatory treatment are being violated by medical institutions (Jones, 2017). This further reiterates the notion of institutional (in this case, by medical professionals) protection of the child by removing autonomy and consent when it comes to their own bodies. This framework proposes that intersex bodies should instead be empowered; they should be accepted and valued and the current status quo in medicine should be challenged. A critical approach supports the notion of contesting the systematic bias in institutions and questioning whether any kind of medical intervention is compulsory (Davis, 2015a; Jones, 2017; Liao & Simmonds, 2014).

Empowerment in decisions for one’s own body may also be paired with developing the right to define oneself. Morland (2006) discussed how the postmodernist ambivalence to sex categories is well suited to the diverse identities held by people with intersex variations. This approach allowed for a deeper and broader understanding of the scope of intersex identity. To capture this diversity in identity, listening to intersex voices is crucial in research to explore the lived experiences and needs of the intersex community. Further, this privileges the empowerment of their voices and bodies. These voices heard in this study show clear indications of the lack of empowerment given to them by institutions, whether it be by having no autonomy over their body, ignoring their needs, or being ignorant to their variations. Institutional power structures are disempowering people with intersex variations under the guise of protectionism, especially as children. A critical framework clearly highlighted a great need for reform in intersex healthcare. The data also showed the great need for bodily autonomy in healthcare processes. Participants were often spoken about, not to, when it comes to the treatment of their own bodies; their desires were often dismissed by health professionals or they were coerced into certain treatments. These findings are reflected in other studies mentioned earlier (Jones, 2016, Lux, et, al. 2009, Davis, 2015a), though Davis (2015a) specifically noted how some people with intersex variations are belittled, or blame is placed on the family for not disciplining their ‘poor behaviour’ if they were acting out against their imposed gender role. This blame puts tremendous pressure on the family as well as blatantly ignoring the needs or desires of the individual with intersex variation which not only illustrates the lack of bodily autonomy, but also highlights the strain it can put on a family unit.

This blame emphasised the essentialist view held by some physicians and allows for health professionals to evade responsibility if their imposed interventions are unsuccessful (Davis, 2015a). A multidisciplinary team may come up with a particular approach for what will be ‘medically best’ for the child for them to achieve ‘normalcy’. If parents are ‘failing’ to enforce this normalcy or opt out of particular interventions, they are seen to be embracing or ‘choosing abnormality’ and again, the responsibility is moved from health professionals to the family (Davis, 2015a). Through this example, it is clear how there is a lack of bodily autonomy for individuals with intersex variations, along with the disempowerment that accompanies such actions caused by the essentialist authoritarian approaches of health professionals.

8.2 Discussion of Gender, Sex and Sexuality Findings

8.2.1 Imposition of gender identities

The number of participants raised as girls was higher to those raised as boys (36 and 26 respectively), however only five of those (19%) who were raised as boys found this to be an appropriate gender rearing choice for them. In terms of assigned sex and gender appropriateness, 23.1% of assigned males found their reared gender to be appropriate, still showing regardless of whether they were assigned male, or raised as boys, these participants found this to be not an appropriate rearing choice for them. This concurs with findings from Jones, et al. (2016) who found a distinct drop in participants who currently identified as male when compared to their assigned sex at birth. This highlighted how children get no input in this imposition of identity. This may indicate that more male assignments are occurring than their ought to be, perhaps due to the cultural desire for male children (Warne & Raza, 2008). This may also relate to the cultural suppression of female sexuality; the discomfort people have towards females for having a large clitoris which subsequently may possess sexual power; as previously literature described the lengths gone to in order to disavow or deny the clitoris (Kulish, 1991).

Almost all of the participants who were raised gender neutral found it appropriate. This fits the narrative that leaving a child to discover their own identities is an appropriate choice for rearing for parents and health professionals alike. Further, all the children raised gender neutral were assigned female at birth. This may speak to the fragility of masculinity and the accepted fluidity of femininity or even the cultural preferences to raise men. For example, Lev (2006) discussed the heteronormative social expectations of these individuals and the expectation that men may suffer psychological harm if they reached adulthood with a small penis or be unable to urinate standing up. Further, they note that the criteria for assigning males and boys is largely dependent on the size of the infants' phallus rather than any preservation of internal reproductive organs, giving further emphasis on the 'medical need' for phantasmal genitals. Some participants rejected their imposed gender roles and felt they either did not belong in this traditional and rigid gender role assigned to them, or they struggled to fit in with other members of their sex and gender. This was particularly the case if they were not completely binary in their interests or activities, resulting in either exclusion from friendships or even physical abuse at home.

The word 'choice' was one of the most common words expressed when asked *'Who made the decision [to decide their gender]? Was this satisfactory?'* highlighting that it is not just treatments and medical interventions, but that gender expression is also something that participants had little autonomy over. However, one participant reflected on being able to choose their own clothes and haircuts and was very involved in the decision-making process for their gender which allowed for agency, self-expression and meant they were able to engage in performative gender their own way and have bodily autonomy. As this resulted in a positive experience, once more this highlighted the important of consent and being involved in any decision-making to achieve bodily autonomy for people with intersex variations.

8.2.2 Authoritarian delegation of gender identities

Whilst some participants were satisfied with their sex and gender assignments, some participants expressed wanting to be raised outside the gender binary, feeling they were being reared an incorrect gender, lamented not being involved in the decision-making process. Dissatisfaction with gender assignment not only causes gender identity issues, but may also result in body image issues (Lev, 2006). This is not just an intersex issue, as there is often pressure on most young people to be gender conforming throughout childhood and adolescence.

Parents were enforcing gender roles by forcing their children to engage in strict gendered behaviours or activities, such as making them wear dresses and makeup to leave the house, only play certain sports, or not allowing certain toys or friends. In some instances, acting out of line of the expected gender norms resulted in physical abuse from parents or family members. Not being involved in the decision-making process or lack of consent around their own gender rearing was a common theme expressed by participants. Further, seven participants mentioned feeling that physicians may have heavily influenced their parents' decisions, or that they were misguided or misinformed by physicians. This showed intra-power plays from parents to children, but also doctors to parents.

Schools may also be an authoritarian institution that imposes gender roles. Grabham (2007) discussed how the corporeal (the body) on institutions and structures such as education may influence intersex citizenship. For example, one participant discussed being banned from certain school sports that may be too masculine and experienced isolation from other students for being different as a result. Others refused to undress in front of their peers in physical education classes for fear of being different which was also identified in Jones's

(2016) study. Given that school can be a time of exclusion or isolation (for a number of adolescents, but particularly for intersex youth), Jones (2016) also found that intersex students desired more inclusive sex education and science or biology classes to show more realistic bodies and variations to feel less isolated.

8.2.3 Transgender and gender diverse identities

This study had a particularly high number of transgender or gender diverse intersex participants compared to other similar studies (Furtado et al., 2012; Jones et al., 2016; Martina Jürgensen et al., 2014). Only 23 participants (19 women and 3 men) remained unwaveringly the same sex and gender that they were assigned at birth and nine others choosing not to disclose their current gender identity. Whilst 16 participants (30%) identified as being a complete opposite gender (from man to woman or woman to man), the remaining participants did not necessarily identify as being transgender, many identified elsewhere on the gender spectrum; 10 disclosed being either gender fluid or identifying as a range of genders and seven stated that ‘intersex’ was their gender identity. Therefore, of the 53 participants who answered both questions, 62% of participants were either transgender or gender non-confirming or variant in some way. It is important to note whilst some people with intersex variations have changed their sex marker or their gender identity, that this is not the same as identifying as transgender. As 30% of participants did change their identity from one end of the spectrum to another, these findings are similar to Preves (2003) who stated that 24% of intersex individuals had reversed their gender assignment, indicating that there are high levels of dissatisfaction with their initial sex and gender assignment amongst the intersex community. Additionally, eight participants described their gender identity as ‘intersex’, illustrating that these participants do not view their variation as a biological diagnosis assigned to them, but instead embrace it as a form of identity.

It is observable that 24.5% of identifying women also described additional gender identity detail, or kinds of identity (for example, ‘ambiguous female’, ‘butch female’), however all 10 identifying men had no further ambiguity or descriptors when it came to their gender identity. This may indicate that women are more comfortable experimenting or ‘playing’ with their gender identity than men. When comparing these findings to the Australian Jones, et al. (2016) study, it was found that just 8% identified as transgender. N=23 (8%). Whilst some participants did not actively identify as transgender, other participants currently used sex markers outside the two-sex binary than initially assigned at birth; with 7% using ‘X’, 6% were unsure, and 12% used something else. Some of these participants did not necessarily transition from male to female or vice versa but may now identify as a non-binary/genderqueer identity or elsewhere on the gender spectrum.

Jürgensen et al., (2014) found similar figures to Jones et al., (2016), with 12.7% of the 8-12 year olds (n=11) interviewed using the gender identity interview (GII) who were flagged as being potentially transgender and were more common in those with CAH. Tamar-Mattis (2012) also noted that 10% of XX CAH individuals later identified as male. Opposingly, Furtado et al. (2012) found that participants with CAH had lower incidences of transgender identities and found it was more likely to occur (up to 63%) in those with 5α-reductase 2 (5α-RD2) and 17β-hydroxysteroid dehydrogenase 3 (17β-HSD3). The findings of this thesis’ study did not find that any particular intersex variations resulted in higher occurrences of changing or more fluid gender identities.

A European study by Kreukels et al. (2018) of 1,040 intersex participants found that only 5% of participants changed genders with just 1% changing after puberty. A further 4% identified as another gender variance and identified that this group had lower self-esteem and higher rates of depression than other participants. This yields different results to other studies, including the findings of this study, however this may be due to the clinical methodology used, as they used a shortened version of the Utrecht Gender Dysphoria Scale to measure gender dysphoria rather than simply asking participants about their gender identity. Given how differently all these studies obtained data on gender identity (be it through self-reporting, scales, etc.), how the data was analysed (if details were condensed into categories in quantitative studies), and the diversity and subjectivity of identity and the gender spectrum, it may be difficult to get consensus across research (particularly that of different disciplines) about incidence rates of transgender or gender diverse populations within the wider group of people with intersex variations.

Further, some quantitative studies may have an essence of essentialism when it comes to analysis; the breaking down of participants into male, female, or those who have crossed from one sex wholly to another. This again is problematic as it leaves no room for other identities on the gender spectrum and does not allow for the subjective voices of gender variance to be heard, particularly when this needs to be recognised and celebrated. Two participants voiced displeasure at the word ‘transition’ used in the survey, which was an oversight in the development of the questionnaire and is something that future research should take into consideration. This question may have been better off to be more open, such as ‘please describe the journey of your gender identity’. This avoids the implication of transition from an A to a B.

When participants in this study were directly asked if their gender identity differs from the one they were reared as, 17 participants stated that their current gender identity did differ in some way. This emphasises the importance of how questions are phrased and posed to participants as it may affect their answers or their interpretation of the question. Allowing participants space to describe their gender identity is vital as it not only allowed them to be heard and have their identity validated on their own terms, but being able to describe one’s own gender is particularly useful for building resilience in young people (Singh, Meng, & Hansen, 2014; E. Smith, Jones, Ward, Dixon, Mitchell, & Hillier, 2014).

8.2.4 Most intersex people are sure of their gender identity at a very young age

The participants who identified with a different gender identity than to the one assigned to them often knew from a very young age. This study found a trend showing that the most common age of wanting to be raised as a different gender was between the ages of 3-5 years old. As the next most common was 6-10 years of age, a cumulative 71% wanted to be a different gender by the time they were 10 years old. In terms of when they firmly decided to be another gender, this majority was usually later in life (after 20+ years). When comparing these data to other recent studies, the Australian study of gender diverse and transgender children by Smith et al. (2014) identified the age of 14 as the most common age to begin to question their gender. Whilst the Kreukels et al. (2018) showed much lower incidences of gender variance, it does support the findings that the majority of participants identifying with a different gender than that which was assigned happens at a pre-pubescent age.

8.2.5 The imposition of heteronormative sexual behavioural expectations

Most participants did not feel comfortable dating during their teenage years. Anxiety or fear around dating can result in feelings of depression and loneliness which may impact future sexual relationships and increase the risk of sexual 'dysfunction', perpetuating the cycle of fear and anxiety in sexual experiences (Chorney & Morris, 2008). Finding studies that inquired about dating anxiety are fairly minimal. Additionally, it is a concept that can be difficult to quantify, particularly if the study is self-reporting as dating may mean different things to different people. Most studies that did explore this investigated heterosexual adolescent relationships. For example, Glickman & La Greca (2004) developed the Dating Anxiety Scale for Adolescents, resulting in an American-based study that indicated higher rates of dating anxiety in younger adolescents compared to older groups. Further, they found that boys reported more dating anxiety than girls, fitting with the results of the La Greca & Mackey (2007) that boys were less likely to have a romantic partner than girls. Conversely, Boyle & O'Sullivan (2013) conducted a Canadian study which found the opposite, with girls reporting higher levels of dating anxiety, particularly around being negatively judged by a dating partner, as well as more social distress mixed-sex groups and other dating scenarios. Additionally, this study identified that dating anxiety may result in fewer dating experiences, and similar to Glickman & La Greca (2004), found increased dating anxiety in younger adolescents. Given that the study of this thesis found an increased comfortability in dating during adulthood, this supports the findings that dating anxiety *decreases* for most populations over time. None of the aforementioned studies gave percentages which made it difficult to compare specific results with this study.

Being comfortable dating was not necessarily synonymous with being sexually active, as just 38.8% of participants stated they were sexually active during adolescence. Participants in this study avoided dating or sexual activity in high school because they were either not interested, confused by their sexuality, or experienced negative body image and became sex avoidant. This is concurrent with the previous literature that discussed how increased dating anxiety results in limited dating and subsequent sexual experiences (Boyle & O'Sullivan, 2013; Glickman & La Greca, 2004). This rate of sexual activity is 12% lower than an American national average of 46.8% (n=13,583) self-report study by (Kann et al., 2014). An earlier American study reported that romantic and sexual relationships increased over time in adolescence with 15% of 15 and under adolescents being sexually active compared to 70% of 19 year olds (Abma, Martinez, Mosher, & Dawson, 2004). As previously mentioned, dating anxiety did reduce slightly during adulthood. However, one of the biggest barriers to being comfortable dating others was avoidant tendencies due to body image concerns. This included previous negative issues with disclosure of their intersex status, feeling self-conscious about their intersex body, and seeking romance but avoiding sex.

Whilst in the minority, three participants used sexual activity as a means to affirm their gender identity as a coping tool to take control over their own identity. One felt that intercourse would allow her to be considered a 'real girl' (a sentiment expressed by another participant) and only had sexual relationships and avoided romantic intimacy as she deemed herself unworthy of relationships. Another participant used sex to control others and gain validation and found it to be a dissociative experience during adolescence, prior to their transition to another gender in adulthood where they then felt desired and accepted for who they are.

All these participants were born female with one now identifying as genderfluid, one identifying as a man, and another identifying as genderfluid; no assigned boys discussed using sex to affirm their gender identity. This notion of women using sex to affirm their identity is concurrent with research in other LGBTI communities including a large Australian study by Hillier et al. (2010) which found that of the 15% of young women who reported being pregnant (37% of which were solely attracted to women). This was also found in a study by Smith, Agius, Mitchell, Barrett, & Pitts (2009) in which the pregnancy rate of same sex attracted or gender questioning (SSAGQ) young women was double that (10%) of their heterosexual and cisgender peers (5%). The findings in this study thus support earlier findings regarding young women trying to fit the norms of heteronormative behaviours.

Half of the participants in this study had romantic or sexual partners, similar to the findings of Jones et al. (2016), though the slightly higher number (62%) in that study may be due to the wording of ‘relationship or dating’ which is broader than the question this study asked, as whether or not they had a ‘partner’. Again, confirming the findings of the adult dating studies mentioned. However, sexual experience did not necessarily correlate with sexual desire or identities, a finding also identified in Jones et al. (2016). Further, the spectrum of sexuality, gender and sex for this population (or indeed, any population) makes it even more difficult to classify a particular sexuality in this study so further itemisation of these factors would be useful in future research. Some participants lamented how surgical interventions from infancy or childhood impacted their sexual experiences during adolescence. They reflected that it made sex painful, uncomfortable or not pleasurable. This also impacted masturbation as well as sexual experiences with others. As adults, they reported other physical issues such as painful or irritated scar tissue, vaginal dryness, lowered libido, and issues with penis in vagina (PIV) sex. The conclusion that surgical intervention may harm sexual function has been confirmed by a number of previous studies including Frank (2018); Minto, Liao, Woodhouse, Ransley, & Creighton, (2003); Jones et al. (2016); Lux et al., (2009); Warne et al., (2005). Jones et al. (2016) identified a higher figure, with 65% of participants who stated that their intersex variation or related treatments impacted on their sexual experiences – this may have related to additional Australian-specific practices.

Besides physical implications, there were psychological components that were harmed by surgical intervention in this study. A few participants mentioned 'failing' at sex, another reflected on wondering if their body would be accepted if it were 'all intact' and that doctors instilled the belief that they would not be loved as they were. These feelings described illustrate the perpetuation of the imposition of heteronormative sexual expectations from health professionals and others for intersex bodies, such as how vaginas are often constructed to accommodate a 'normal' penis size for heterosexual intercourse (Kessler, 1998). Similar themes were found in a small UK study of 14 intersex women where three discussed being concerned that their vaginal surgeries would result in painful sex, however one decided to try dilation therapy again in hopes to improve their perceived ability to be a potential sexual partner (Sanders, et al. 2015). Further, they identified many participants who reflected on the need to have personal control their own bodies including its limitations and potential performance in intimate scenarios. This study reflected the expectation around heteronormative sex and the anxiety that induces following surgical intervention. Additionally, this study is further evidence of the need for bodily autonomy as participants wanted control over their own bodies.

Further, some participants discussed feeling self-conscious about scars, or had developed trust and intimacy issues, or were consuming alcohol before sexual encounters. These themes were revisited in a later question about experiences as an intersex adult, where more participants described difficulty trusting others. They described feeling guarded, developing body image issues, and difficulties with intimacy. This illustrated an interrelationship between trust, body image, and intimacy; all aspects need to be positive to have a positive experience, particularly when it comes to sexual intimacy (see Figure 7.1).

When comparing quantitative data on those who did and did not have surgical intervention in this study, those who did receive this intervention 48.5% (n=16) experienced enjoyable sex compared to the 70% (n=12) of those who did not have surgical intervention but had enjoyable sex. Whilst this is worthy of mention, it was not a statistically significant finding. This is slightly lower than the findings in a general population Australian study which found that 76% of women and 88% of men who were experiencing very or extremely physically pleasurable sex (Richters, Altman, Badcock, Smith, de Visser, Crulich, Rissel &Simpson, 2014). These figures align much closer with those who did not receive surgical intervention in this study. Participants were also directly asked if they felt surgical intervention impacted their sex life, with 47.7% saying ‘yes, negatively’. A further 10% says ‘yes’ with no additional information so it is unclear whether this was a positive or negative affect. This emphasises the importance of hearing intersex voices to get an accurate representation of the lived experience as well as the need for more qualitative data on this group in future research.

A surprising finding of this study was that incorrect gender assignments and subsequent rearing had more influence over enjoyable sex than surgical intervention according to the quantitative analysis. The statistically significant findings showed that most participants who found their reared gender inappropriate were less likely to experience enjoyable sex. Three quarters of those raised gender neutral had enjoyable sex, followed by those raised as girls. Given the small numbers for those raised gender neutral, conclusive statements regarding this cannot be made, however further research on gender neutral children should be conducted in the future. Additionally, this highlighted the importance of letting intersex children choose their own gender so that they have an opportunity to explore their own identity as well as be a key part in the decision-making process over their own identities and bodies.

8.2.6 Intersex people enjoy non-heteronormative sex

Some participants reported experiencing enjoyable sex which often correlated with being comfortable with their own body and enjoying forms of non-heteronormative sex. This included non-penetrative sex and engaging in other forms of sex such as oral or anal sex. Those who did have enjoyable sex mentioned either being confident with their body or having supportive partners. Similar findings identified in Jones et al. (2016) who’s qualitative analysis found that some participants found their intersex variation to a positive factor in sexual satisfaction. This included finding their libido to be higher than others from excess hormones, feeling that their body can ‘handle more’ sex, feeling empowered by their larger clitoris, using strap-on devices, and how trying to find themselves allowed them to be exposed to more kinds of pleasures. This is supportive of Tolman’s (2000) notion of sexual empowerment, illustrating how experiencing or being granted sexual desire and pleasure in a scenario where this may be minimised by institutional powers is viewed as an expression of this feeling empowerment. This highlighted the importance of embracing their intersex body, the celebration of diverse bodies and entering supportive relationships, particularly as those who often had negative sexual experiences were ashamed of their body or protective of their intersex identity.

8.2.7 Intersex people have no autonomy over their own bodies, even in in their own disempowered sexual fantasies

Whilst this study explored several topics that are well covered grounds in recent years regarding the intersex population such as healthcare, surgery ‘successes’, and transgender rates in the intersex community, few studies explored the sexual satisfaction of the intersex population. In particular, no one, at the time of this thesis, has explored the nature of sexual fantasy within the intersex population. The reason for exploring this was to see if their sexual desires differed in any way to their existing real-life experiences. There were insufficient numbers to determine if fantasy is different from behaviour, though previous literature of heterosexual participants suggested that there are large discrepancies between sexual identity, desire and behaviour and should all be analysed separately (Morales Knight & Hope, 2012). While half of the participants stated their fantasies did not differ to the sexual experiences, there was a high correlation of those whose fantasies did not differ to their experience and those who experienced enjoyable sex (89.5% of people who answered both questions). Conversely, all of those who did not experience sexual fantasies did not have enjoyable sex. This suggested that engaging in sexual fantasy may lead to some fulfilment or is at the very least, a contributing factor to enjoyable sex. Further, fulfilling sexual desires leads to a more satisfied sex life.

What is perhaps most of particular interest from this dataset is the high numbers of participants who fantasised about having different genitalia, with 25.5% (n=12) of participants reporting this desire. It is important to note that three of these 12 participants were transgender, and feelings of gender dysphoria or dissociation about body parts relating to gender is common for the transgender population (McGuire, Doty, Catalpa, & Ola, 2016; Smith, Jones, Ward, Dixon, Mitchell, Hillier, et al., 2014). For the remainder of this subgroup, these fantasies included a desire for being ‘normal’ or for wanting heterosexual relationships, desiring typical bodies, or having a differently sexed body, showing the extent of internalised bodily shame experienced by intersex participants. This points to an example of how disempowered intersex people can feel in their own sexual fantasies. This shows how doctors may have succeeded in projecting this need for phantasmal genitals onto their patients (Morland, 2001), so much so that they cannot even fantasise sexually about their own, true bodies. Three of these participants have sexual fantasies about their own genitals untouched by surgery, and another fantasised about full sets of both genitals (reflecting they did not have a full set of either). Further, this reflected the theories explored earlier (Greenwald & Harder, 1995; Knox, 2005; Levine, 2005; Rizzuto, 1991; Sandler & Sandler, 1986); that fantasy, for these participants, may be used to escape the reality, a means of avoidance, and to fulfil wishes of either different or not surgically intervened with genitalia. These fantasies may be used to repair feelings of abandonment or rejection and to minimise the harm caused to them by trauma (Friedman & Downey, 2008), in this case, surgical interventions or the imposition of two-sex binary onto their ‘othered’ bodies. Knox's (2005) theories surrounding shame and fantasy can be applied to these data; conforming to the imposed two-sex binary and subsequent gender roles may result in shame for their unique bodies and they may not feel worthy of love by being themselves, where fantasy is used to cope with not being able to meet the expectations of others (such as the essentialist sex and gender binary imposed by health professionals or parents). Further, these fantasies may be a reflection of an internalised helplessness (Thomaes et al., 2007) over the lack of control and ownership they have over their bodies.

Further literature on shame and fantasy explains that people experiencing shame can withdraw (Rizzuto, 1991) and how this may lead to unconscious desires such as violent fantasies. An additional two participants discussed experiencing violent sexual fantasies and acknowledged that this was a projection of their anger towards their bodies and/or post-traumatic stress disorder (PTSD). This is concurrent with the theories suggested by Rizzuto (1991), as well as the suggestion that people experiencing these emotions may arise due to not having their needs met as a child. In this instance, this may be a reflection of their voices not being heard when it came to any of the decision-making processes about their bodies, sex, or gender identity growing up. This may connect to the interrelationship between trust, body image, and intimacy (see Figure 7.1); if there is a disruption in any of these aspects, these may lead to a poor sexual experience which may extend to sexual fantasies. Alternatively, as violence and rape are often a demonstration of power rather than sex, particularly towards women (Ellis, 1989) or other disempowered groups, these desires may stem from wanting power over their own bodies.

As some participants reflected on sexual desires for genitals they never had, this fantasy should be understood in reference to the nostalgia for something that never was, or a reflection of the projection to desire what they were *told* to desire; an imposition of the medical structures that impose these sexual desires as opposed to a particularly innate desire. Given that most participants reject the idea of non-consensual surgical intervention, it may seem inconsistent that several of them experienced fantasies for typical or other genitals; however, this highlights how the medical discourse may influence subconscious or unconscious desires whilst simultaneously consciously battling for the desire or need of bodily autonomy. This highlighted the insidious nature of medical discourse, even when it is being actively combatted. This same concept is seen in older literature surrounding the notion that describes how aspects of the inner self such as internalised homophobia may result in desires for engaging in sadomasochistic (SM) practices (Rechy, 1979). Sullivan (2003) also explored the broader concept of how SM practices may be an expression of the inner self. Whilst she uses the example of the bullied boy in school now being sexually submissive, a similar concept can be applied to these participants; those who were shamed for their bodies with strict impositions of gender roles during rearing may now be experiencing that internalised shame of their bodies by fantasising (rather than engaging in SM practices) about a different sexual body altogether. This notion of trying to purge a deep self-loathing is supported by arguments made by Polhemus & Housk (1994). Here, we are simply using the same concepts of the expressions of the inner self in (psychologically harmful) fantasy rather than suggesting these participants are engaging in SM practices.

Conversely, the two participants that did engaged in bondage and discipline, sadism and masochism (BDSM) play also experienced enjoyable sex and showed a healthy exploration of their sexual identities and experiences which reflected a sense of empowerment over their bodies. Further, the participants who loved their bodies not only experienced enjoyable sex but illustrated a sense of empowerment about their unique bodies and celebrated this. It highlighted a sense of agency over their bodies and subjective power

(power-to) (Peterson, 2010; Riger, 1993). These participants were more confident in exploring their sexuality and sexual play. This supports Tolman's (2000) theory of how the ability to experience or be granted sexual desire and pleasure in a culture that minimises the sexuality of a marginalised population (in this instance, the imposition of strict gender and sex roles by institutions of power like health professionals, parents and schools) can be viewed as an expression of empowerment. Some participants discussed not having sexual fantasies at all. Their lack of sexual fantasies supported the theory that a sexually objectified body or medically objectified body, as seen in this study, can take away the level of empowerment necessary for being the subject (the fantasiser) for sexual fantasy in some cases, such as the desexualisation that occurs for other minorities like people with disabilities (Eunjung, 2014).

8.4 Discussion of Relationships Findings

8.4.1 The isolation of being an intersex student

Feelings of isolation were experienced during primary school and increased slightly once high school started and puberty had begun for either themselves or their peers. Nearly a third of participants felt isolated during primary school, with similar results echoed in the Australian sample of intersex students by Jones (2016). Feeling like a loner was experienced by 13 participants during this time, whereas experiencing depression and suicidal thoughts (n=9), not fitting in with their peers, or engaging in aggressive behaviour, and experiencing feelings of secrecy and shame was experienced equally across the remaining participants. Jones’s (2016) had a much higher incidence of depression and suicide, with 46% having experienced depression or thoughts of suicide during school compared to the drastically different comparison of 13% in this study. Conversely, only 7% stated having no issues or a positive experience in high school (n=5) compared to the 24% (n=11) having positive school experiences in Jones's (2016) study. This may indicate a difference between the national data in Jones (2016) and international data of this study.

Secrecy and shame were experienced throughout all schooling years but doubled in high school. Participants were secretive surrounding topics such as repressing feelings about their bodies, lying or avoiding questions, denial about their differences to their peers, being dissociative towards their body, or were actively told by either parents or health professionals to keep their 'condition' a secret. Feeling angry or illustrating aggressive behaviour was discussed by four participants, stemming from internalised feelings of sadness and loneliness, or even as a result of being forced to keep their variation a secret, in one instance. By forcing intersex children to remain secretive about their intersex status is an example of Foucault's discussions surrounding the 'repressive hypothesis'; how power, or 'insistence of rule' is exercised to mask any sexual deviations where it is only to be discussed behind closed doors (Foucault, 1981). Further, institutions of power such as hospitals or health professionals use this concept to both encourage the concealment of intersex status and to re-introduce intersex status into medical discourse to create knowledge; by subjecting one with an intersex variation to scrutiny by other doctors and as a subject for medical school students.

Some participants felt alone during school years, despite whether they had friends or not. This illustrated the othering from peers that some may have felt. This led to feelings of withdrawal or spending more time at home or with adults. Most participants who did discuss friendships preferred to have a handful of close friendships than broad social circles, and often gravitated towards other social outcasts or other marginalised groups. Preves (2003) noted that gravitating towards other outcasts was a key part of forming identity. Therefore, this is seen as a positive step to seeking other individuals experiencing the same potential isolations. Similarly, a small study from the UK consisting of 14 intersex women (aged 14-19) found some participants expressed uncertainty, confusion and insecurity about how they fit into friendship circles and their identity (Sanders, et al. 2015). These women reported wanting to achieve secure and safe friendships and relationships. Some remained guarded (particularly of personal information) in efforts to prevent being subjected to bullying or hostility. Despite this, three participants stated positive experiences of sharing their stories with others (Sanders, et al. 2015). This highlights the importance of wanting to connect with others, and the benefits of having the confidence to share personal information with peers to establish connections.

When discussing these friendships in primary school, participants were most likely to seek friendships with girls, and most often, sought friendships of the opposite sex, followed by both sexes. Seeking friendships with their same (assigned) gender was less common, a finding also identified by Jürgensen et al. (2010) who found that intersex children tended to befriend both boys and girls at school compared to non-intersex children who preferred to befriend their own gender. Jürgensen et al. (2010) also found that they had the same rates of ‘best friends’, particularly for girls with androgen effects, compared to non-intersex children which they assessed as not experiencing any social isolation. However, as these questions were asked to parents, this study did not provide an opportunity for the intersex child to describe their *feelings* about their friendships.

Not going through puberty at the same time as their peers also socially impacted participants. Participants described feeling more normal to everyone else who was going through puberty, feeling more isolated from using hormone replacement therapy (feeling othered to their peers), being bullied, or having no interest in dating. This sense of feeling ‘more normal’ for not going through puberty gives a new subjective meaning to what is ‘normal’.

A quarter of participants described not fitting in with their peers due to feeling introverted, feeling like a ‘freak’, being anti-social, feeling like they could not relate to their peers or being alienated. One mentioned feeling isolated from the lack of intersex information in sex education classes, reflecting that they had no peer group. A similar sentiment was found by Jones (2016) where 92% of intersex participants stated they did not have inclusive sex education that discussed intersex variations in school. This showed that there needs to be better support and educational resources for intersex inclusivity, including inclusive sex education in schools on an international scale. Not only does this illustrate the heteronormative practices of the school system, it once more highlights the protection of the innocence of the child; by an institutional disallowing of comprehensive sex education and only educating about ‘typical’ bodies in sex development. Improvements need to be made for better school policies to promote the inclusion of intersex students as well as staff training for how to react to both disclosures about intersex variations and supporting those students in an open learning environment.

8.4.2 Experiences of bullying during school

Bullying was consistent from primary to high school with eight participants experiencing this, however one mentioned how it got worse during high school. Half of this group were teased for non-intersex variation related reasons such as other physical characteristics, being from out of town, and so on. One was teased for reaching puberty at a later age and the other for developing different secondary sex characteristics to their peers. Again, this differs greatly to Jones (2016) showing 75% of participants were bullied (n=77) compared to the 11% (n=13) who experienced this in this study. It is difficult to determine whether these large disparities account for a difference in the number of participants, whether a retrospective method allows for room to forget incidences of bullying or other unpleasant memories compared to the sample of Jones (2016) who included participants still in school (aged 16+), or whether this points to a greater issue of bullying in Australia compared to an international scale. Overall, this bullying occurred for a variety of reasons such as different physical traits stemming *from* intersex variations rather than a knowledge *of* intersex variations, a finding also found by Jones (2016) and may point to a larger issue of bullying in schools.

However, not going through puberty with everyone else made some participants a target for bullying for some girls, whereas boys were bullied for not engaging in masculine enough behaviours. This showed that acceptance for boys was more about engaging in masculine behaviours, whereas girls did not feel this pressure from other same-gender peers, but at times, did so internally see section 8.2.5 and section 6.2.1).

Whilst no participants offered any insights into solutions for bullying, they did later state how finding others like them would contribute to feeling less alone, which some did achieve during adulthood. Jones (2016) did have participants offer some solutions to reduce bullying in schools, including prevention policies, more intervention from staff, and further support from the school for students with intersex variations if they are attacked. A 2010 American study found that transgender youth are often placed under the umbrella of LGBTI policy at some schools, where the strategies were realistically designed for gay, lesbian and bisexual students and subsequently, did not address the needs of transgender youth (McGuire, Anderson, Toomey, & Russell, 2010). This is likely to also apply to intersex students where their specific needs are not being met by existing school policies.

It is important to note that there are minimal studies done on intersex students, with the exception of work by Jones (2016) and Jürgensen et al. (2010), meaning that comparable data had to be sought from other LGBT studies. Non-heteronormative students are often subject to more bullying than other groups at school, however transgender and gender diverse youth are often subjected to higher degrees of bullying (Jones & Hillier, 2013). Whilst not data on intersex students, Riley (2018) recognised that bullying for transgender students is not limited to schools, but family homes, local communities or even professional services. The fear of which can discourage some participants from disclosing their gender identity. Whilst some intersex participants in this study did note violence at home, bullying was not explored outside the school area, and may be a subject for further research in the future.

8.4.3 Battling against an unwanted imposed gender led to negative school experiences

Most participants who felt like a loner during high school also found their reared gender to be inappropriate. Given this was a finding of statistical significance, this further illustrated the importance of gender expression and choice that needs to be granted for intersex youth.

Further, more than half of the participants who were teased for being different felt their reared gender was inappropriate, yet another statistically significant finding. This may be because they were acting out against their imposed gender roles and expectations in efforts to feel more like themselves and regain some control over their own bodies. Another statistical finding was 75% of participants feeling that they did not have the average number of friends in primary school who did not find that their reared gender was appropriate; it was additionally statistically significant that that those who did not find their reared gender appropriate had a few close friends. It is possible that they may have felt like being in the wrong body or having an incorrect gender imposed on them made them feel like it was difficult to make friends.

This is further evidence of the isolation caused by imposing genders on intersex children without their involvement in the decision-making process. This internalisation of gender identity requires these participants to do gender that betrays their true selves; they are forced to behave and act accordingly to their imposed gender including how they are perceived by others at an interactional level by their peers, parents, and school staff. Foucault (1979) describes how more visible identities are subject to more scrutiny, surveillance and regulation which is evident in these intersex children as they are scrutinised by institutions such as parents, schools, and doctors for how they are performing gender; being forced to self-regulate their own expressions of how they would prefer to perform gender to appease the powerful institutions that regulate them.

8.4.4 Empowerment in adulthood – selfhood and friendships in peer support

During adulthood, there was different commentary on friendship. Finding likeness with other intersex people or joining peer support groups was discussed as a positive aspect of finding friendships during this time, an element they found to be empowering. Chavis & Wandersman (1990) discussed the reciprocal relationship between a sense of belonging to a community and the connection to a sense of personal control or power. Empowerment was mentioned more frequently during this life stage than compared with adolescence or childhood. These findings are similar to that in Jones (2016) who also found that participants are more likely to feel positive and empowered about their intersex status at a later age. This empowerment theory is further supported by Zimmerman (1990) who discussed how empowered individuals are often involved in community groups and how these groups build empowerment to the individual. This theory also supported the usefulness and effectiveness of peer support organisations such as InterAct or OII Australia can have to not just develop friendships and find like-bodied people with a shared lived experience, but to gain a sense of psychological empowerment by being a part of a larger community. Further, similar findings were found in a recent study by Boyer & Galupo (2018) where adult transgender participants reported higher levels of LGBT friends (compared to cis-gendered heteronormative friends) if they were affiliated with LGBT groups compared to those who were not affiliated. Given that the participants from this study were recruited mostly from support organisations, it is fair to say that they are affiliated.

8.4.5 Intersex identity is subjective, even within its own community

Preves's (2003) five stages of ‘coming out’ were outlined in the theory chapter – (1), recognising one’s nonconformity; (2) and difference; (3) seeking the similarly outcast; (4) pride; (5) integration. Almost all the stories explored in this study go through stages 1 to 3, and some reach stages 4 and 5. Reflecting on what it means to be an adult with an intersex variation, participants discussed themes of changes in attitude over the years (stage 2), seeking peer support groups (stage 3), finding acceptance (potentially stage 4), and feelings of empowerment (stage 4-5). Additional themes included those who also identified as transgender as well as depression, which, using Preves’ (2003) model, may indicate not moving forward from stage 2. Overall, many participants felt more positive about their intersex variations in adulthood as they came to accept their variation. This sense of being more positive and empowered by their intersex status was also found in (Jones et al., 2016). It is important to note that acceptance was not always seen as a positive experience, with a few participants accepting their bodies, but still being apprehensive towards new relationships. This reflected the many forms of acceptance including self-acceptance (or lack of), acceptance by others, and a sense of belonging.

Terminology also has a great effect on identity. Few participants preferred pathologised language such as DSD, however as stated in previous literature, using these terminologies may grant further accesses to biological citizenship (Davis, 2015a). When asked to describe their gender identity, a surprising amount of participants stated that their identity was ‘intersex’ which was an unexpected finding of this study. This highlighted how some participants have embraced, or feel empowered by their intersex status, and how they have integrated this sense of self into not just their identity but are bringing it forth in their sociocultural contexts (stage 5). Whilst ‘intersex’ was used as an identity by some, there was an even wider array of non-gender conforming identities expressed which showed a degree of embracing difference.

It is important to note that whilst ‘intersex’ is an identity for some, this does not reflect all people with intersex variations, and identity for some is still the binary ‘man’ or ‘woman’ and suggesting that their identity would be anything but this may be considered pejorative assumption. This is illustrated well by the character Lauren in MTV’s ‘Faking It’ (Norris et al., 2015) who enters beauty pageants and engages in very feminine behaviour to reinforce that she is an ordinary young woman who happens to have a medical condition. Therefore, it is clear that the term ‘intersex’ can be a very subjective social construction, even within its own community.

8.5 Navigating family relationships

8.5.1 Attitudes towards parents

In this study, participants reflected on their parents’ decisions regarding their intersex variation, bringing up strong feelings of anger, betrayal, shame, frustration at not being involved in the decision-making process, and being forced to adhere to strict gender roles. These themes of negative attitudes towards parents and physicians were expressed in similar studies on intersex populations (Baratz & Karkazis, 2015; Davis, 2015a; Jones et al., 2016). Anger was a prominent theme that emerged when looking at intersex people’s attitudes towards parents, a reflection of lives lived shrouded in secrecy, shame and disempowerment.

A statistically significant finding of this study was that over three quarters of participants who found their reared gender to be inappropriate had poor relationships with their families. It also meaningful that 90% of participants who stated they wanted to be another gender under the age of 10 also had poor relationships with their families. Given that this subgroup (n=19) of participants had known from a young age that they wanted to be another gender, and were likely ignored in the decision-making process or even shielded from being given knowledge of their own bodies, this has likely fostered resentment towards their family due to not being able to have agency over their own bodies. This message can be taken from Jones' (2017) findings, where 43% of intersex participants received some form of gender coaching or 'training' from parents including pressures to be feminine or a 'normal woman' or to be masculine, by being instructed to build more muscle mass, encouraged to get 'corrective' surgery on their genitalia, or encouraged to be stoic and unemotional. Feeling forced to perform gender role that were not suitable to the participant likely contributed to these negative feelings towards family members. Additionally, some participants experienced physical abuse or other punishments due to not conforming to their expected gendered acts or behaviours, particularly for not being 'lady like enough'. Similar findings regarding physical abuse were also found in Jones (2017) but for assigned boys engaging in feminine behaviours. The findings of both of these studies are additionally supported by Witten (2004) who describes themes of violence and abuse in the lives of people with intersex variations and the trans population.

This imposed physical enforcement of gender behaviour is prompted by the idea of social control, and violence is used to control the violation of these gender norms within the family in efforts to be controlled separately. This social control ensures the perpetuation of the status quo of essentialist gender norms (Parsons & Bales, 1956). Here, parents are 'properly' ensuring that their children are conforming to sex roles as a precursor to 'normal psychological development' according to gender structure theory. However, here we see that these individuals cannot grow up to be ‘normal reproducing members of society’ as they have been stripped of their reproductive organs in infancy, yet they are still being socially enforced into these standardised, essentialist binary sex roles.

Those who had particularly negative relationships with their family stated that their family was not supportive of them, not accepting of their differences, or understanding of their needs, or had superficial relationships with their family, or experienced large amounts of distrust. Difficulties with family often occurred if the participant had changed their gender identity and their parents (or siblings) were not accepting of their new gender identity. It is possible that this lack of acceptance may be reactionary from parents’ efforts to impose a particular sex and gender identity throughout their youth.

No participants reported closeness with only their father, but few did report closeness with only their mothers or their mothers and sister/s, showing that potentially mothers may have been more accepting or nurturing of their identities. Similarly, Jones (2017) highlighted that mothers were 90% most likely in the family to know about the individual’s intersex variation, followed by sisters (64%), though this does not necessarily correlate with whether or not they were supportive. This in itself may be reflective of gender structure theory, where mothers are seen to be taking on the role of the nurturer, and thus, fostering better relationships with their children.

8.5.2 Attitudes towards siblings

Most participants were treated the same as their siblings in terms of gender rearing and expectations surrounding gendered behaviours. Whilst relationships with siblings were discussed less frequently, results were similar to the gendered perspectives of attitudes towards parents, where relationships with sisters were more positive than those with brothers. These relationships were described as close or very close with high amounts of support. One participant mentioned that some intersex information came from their sister which they found to be helpful and supportive. This supports the finding of (Jones 2017) who found that sisters were 66% of the time the most supportive family member, though friends and romantic partners were generally more supportive than families.

However, this stronger relationship with sisters showed the importance of family relationships in their lives. This importance of family support is supported by a study for LGBT youth which stated that whilst friendship is important for well-being, family acceptance has a stronger overall influence when other forms of support were considered mutually (Snapp, Watson, Russell, Diaz, & Ryan, 2015).

8.6 Conclusions from the Study

8.6.1 Intersex People Need Critical Health-Care Privileging Empowerment & Autonomy

The findings of this thesis' study, and the consideration of the theory and the other studies discussed in this chapter, showed intersex people across many Western nations want reforms to the health-care provisions for intersex people. Specifically, the data support critical health-care models privileging the intersex peoples' sense of empowerment and ownership of their own bodies. A focus on the patient's self-identity is crucial, which ties into the notion of biological citizenship or more specifically, intersex citizenship. As different identities or terminologies mean different things to different people, Davis (2015a) argues that some terminologies grant access to certain biological citizenships. Those who adhere to the nomenclature of DSD are required to believe they are ‘abnormal’ in a two-sex binary world, and as such, may have anxieties about their bodies, particularly in scenarios surrounding intimacy. However, those who preferred the term ‘intersex’ generally had a more social view of gender rather than a biological construct. This approach restricts access to biological citizenship which may result in a lack of support from family or health professionals (Davis, 2015a). Those who use both terminologies may use each when it is best suited, such as using ‘intersex’ to embrace body positivity, but DSD terminology to facilitate a more positive relationship with doctors to gain further biological citizenship. Using both terms in different appropriate scenarios may be empowering for the individual. One’s ‘citizen body’ can either be ‘controlled by’ or ‘have control’ over their body when accessing health services (Bacchi & Beasley, 2002). Often, people with intersex variations are reduced to just their bodies and objectified and often subjected to higher levels of interventions by others (Grabham, 2007). However, by having informed consent and consenting to any desired procedure as an adult, the patient becomes the consumer and empowered by their choice which can then be considered a positive step for the intersex community (Grabham, 2007).

Bodily autonomy is not just a need or desire, but a basic human right (Agius, 2015; Davis, 2015a; United Nations, 2012). In order to achieve bodily autonomy, people with intersex variations need to be given access to any or no interventions, as well as have access to appropriate mental healthcare by informed mental health professionals. This includes intersex-educated mental healthcare professionals (and other healthcare professionals alike) that will additionally not confuse them with other marginalised populations such as trans, etc. Building upon this, people with intersex variations should have access to all kinds of mental healthcare and should not just be reduced to their intersex body with no personhood. They must also have access to any or all previous health records; some participants in this study had no access to their own medical histories as their records were either restricted from them or even destroyed with similar experiences reflected in Jones, (2016) and Davis (2015a). Further, they need to be given access to treatments that do not fall under a two-sex binary system. Bodily autonomy also means that these bodies need to be accepted, valued, respected, and celebrated rather than classed as disordered and deviant from a two-sex binary system. Informed consent must be given for any interventions or treatments, and their bodies should not be judged or touched without permission. Bodily autonomy ties into the right to be able to define themselves, rather than be forced under a pathologised label (such as that of DSD). A number of participants in the study by Davis (2015a) expressed a desire to use a term that suited them and their needs. This relates to the diverse identities expressed by individuals with intersex variations. Liao (2015) discussed a need for an emotion-centred approach to care which is often sidelined for a medical focus and any emotional response is stonewalled. Liao (2015) suggested that doctors should become more comfortable with emotion which may open more conversations with patients and their families for tailored care. Further this may assist in building trust between patients and practitioners to assist in repairing what has historically been a poor relationship.

8.6.2 Other social supports for people with intersex variations

When asked what participants thought would help them and their parents in healthcare, many participants discussed a need for peer support groups for either themselves or their parents. People with intersex variations and their families need to be offered various support through all life stages.

Parents or other guardians are often given inadequate information about intersex variations upon diagnosis and are not necessarily offered all (or the opportunity to reject) treatment options, or informed of the long term repercussions of some interventions (Jones et al., 2016). Some participants reflected that they felt their parents did the best with the information they had. Therefore, by being able to fully inform parents about treatment options, and waiting until intersex infants are old enough to make their own informed choices, future harm can be minimised. This would also allow for parents to better support their intersex children growing up. Further, peer support or social groups may be useful for unpacking issues surrounding body image, and even how that is reflected in their sexual fantasies and hesitations around seeking relationships.

There is a need for greater institutional support, including supportive policies from schools, particularly as policies for intersex students are lacking both in Australia, and internationally (Jones et al., 2016). Policies that are in use are often developed for ‘LGBT’ as a group, and are geared towards supporting gay, lesbian and bisexual students which are often approaches not suitable for both intersex and transgender students (McGuire et al., 2010). Non-intersex peers and school staff were not particularly supportive, and some participants were subject to bullying due to physical differences.

Figure 8.1 The interconnected relationship between the need for satisfactory healthcare, supportive relationships and the impact on gender and sexual experiences, and body image

There is an interconnected relationship between the three main areas explored in this study (see Figure 8.1). People with intersex variations need support and consistency regarding satisfactory healthcare, supportive relationships, and positive approaches to sexuality, gender and behaviours. For example, negative or unwanted experiences in healthcare (including a lack of mental health support) may lead to feelings of distrust and apprehension towards family dynamics, social experiences, and intimate relationships. These attitudes then impact (physically and psychology) one's self image and sexual pleasure and may result in avoidance of sex or negative experiences, including a lack of body acceptance in their own sexual fantasies. Any deficiency in any of these areas disrupts the interconnectedness of healthcare, relationships, and sex, gender and sexuality experiences which may result in a negative lived experience. These negative experiences are imposed by institutional powers including healthcare professionals, families, and schools. By returning the power and creating self-determination and subsequently, bodily autonomy, people with intersex variations may be able to have more positive life experiences and relationships.

8.7 Limitations

This study was met with several challenges that had to be navigated. Firstly, the subject matter explored in this study was difficult to obtain due to the apprehensiveness of participants as an understandable result of the historical turbulent relationship between the intersex population and researchers. Thus, consideration was taken in ensuring some sensitive questions were voluntary which meant that not all participants answered all questions, leaving some gaps in data saturation.

Recruiting participants was another challenge experienced in the development of this study. As people with intersex variations are conditioned to keep their diagnoses secret (or subsequently, experience shame due to this secrecy) it was difficult to find participants willing to share their stories. Further, finding these participants is problematic as there are no registries or access to registries for intersex variations. Due to the above, recruitment was therefore made via intersex variation support groups and word of mouth within the intersex community.

Some participants were also deterred by the wording (‘intersex’ rather than more pathologising terms such as DSD or ‘variations of sex characteristics’) and did not associate with the term and subsequently, did not feel they were relevant to this study. This extended to some support organisations who did not associate themselves with the term ‘intersex’ despite being a diagnosis involving a variation of sex characteristics. It is possible that some groups may fear the stigma attached to ‘intersex’ or, as they may not necessarily result in ambiguous external genitalia, may therefore not associate themselves with this group. Whilst some may express concerns that recruiting via support groups may potentially allow for skewed data, results are synonymous with other studies who had an array of recruitment strategies, such as Jones, et al. (2016). Jones, et al. (2016), where the term ‘congenital variations in sex characteristics (Intersex/DSD/hormonal, chromosomal or other biological variations/conditions)’ was used which contributed to engaging in a wider and relevant audience compared to this study. For example, Jones, et al. (2015) identified over 30 variations amongst the 272 participants Australia-wide; this study only identified 14 (not including the three participants who did not know their intersex variation) variations of the 74 participants who answered that question.

This recruitment method, despite currently being one of the larger international studies, still resulted in a small sample size. A small sample combined with the diversity of the lived experiences of people with intersex variations means that these results may not necessarily reflect the experiences of *all* people with intersex variations. More narratives from a wider range of lived experiences should be explored. Whilst this study had ample room for qualitative responses, more narratives should be explored via interviews. Despite the use of online programs to facilitate communications, interviews were difficult to obtain for this group due different schedules and time zones, as well as participants being concerned about anonymity, thus, not coming forward for interviews. It is possible that too much time had passed between the survey and interview commencement and that participants may have lost interest as they did not respond to follow up emails requesting an interview time.

‘Intersex’ as a category is difficult to place as is sometimes reflected in biomedical studies, sociology, gender studies, or as part of the LGBTI umbrella. This results in limited funding opportunities for this area of study which in turn, may make some avenues of recruitment (for example, paid advertising, press releases, etc.) difficult. Most support groups identified were mostly in Western countries, meaning that most of the data from this study is reflective of experiences in Western systems of healthcare and other institutions, as most participants came from Australia, USA, Canada, and the UK. Language used may also have been a barrier to accessing nation-specific groups. This left a large gap in results from eastern countries or other culturally-specific regions. Different recruitment strategies should be employed in future studies to obtain data on these regions, which may reflect different cultural values on sex, gender and sexuality.

Whilst there are benefits to retrospective studies from an adult audience, there are some negatives. As some participants are older, their experiences may reflect practices that are no longer the norm; even the youngest participant reflected on practices that were occurring 20 years ago. This makes it difficult to assess current practices in healthcare. However, whilst there has been some progress in healthcare practices for people with intersex variations, there are still incidences in the media of surgical intervention happening globally (Simonette, 2018).

8.8 Implications

8.8.1. For hospital administrators

Some participants noted that they were assigned a particular sex at birth, but that they were later assigned a different sex, or their birth certificate reflected a different sex. At times, this can be a barrier to some intersex people either accessing certain healthcare or it can be difficult to change in the future. Care needs to be taken when recording a sex for a child, as well as how children may be sexed. Further, there needs to be a simpler process for changing recorded sex so that if need be, an intersex person may change their sex marker at will.

8.8.2 For doctors and other medical staff

Participants expressed concern over the lack of education for health professionals, including doctors and mental healthcare workers. Intersex variations need to be taught at both an undergraduate and postgraduate level for doctors and psychology students in order to achieve a better understanding of the normal diversity of sex characteristics. Having better educated staff means that medical staff and mental healthcare workers will be able to better support people with intersex variations in the future.

Another primary concern was over the nature of their unsolicited treatments and secretive nature on health records, particularly whilst participants were still children or adolescents. Participants were seldom given the opportunity to make fully informed decisions about their own bodies or treatment processes. Similar findings are supported by the Australian study of intersex participants by Jones et al. (2016). These experiences have resulted in a population of patients who are largely traumatised and angry towards medical staff for how they have been treated in the past. The repercussions of these unwanted interventions cannot be ignored, particularly as ceasing these normalising treatments has been called upon in reports on torture and the rights of the child by the United Nations (United Nations, 2012). The results from this study show that people with intersex variations want to be actively involved in their treatment, if they choose to seek it. Parents may or may not be involved in decision-making as advocates, however not all parents are advocates for their children.

A strong message that comes from these data is the need for consent for any surgical intervention, medical intervention, and the need to be involved decision-making process regarding their bodies. The *Decision-making principles for the care of infants, children and adolescents with intersex conditions* policy in Victoria (Department of Health, 2013), Australia is a step in the right direction towards positive intersex care, however it does not foreground the need for consent. Further, it does not specify which intersex variations may medically require intervention for survival; this non-specificity leaves room for medical teams to make their own decisions, including surgery for aesthetic purposes which is not recommended. Additionally, this document suggested, even in the title, that decisions must be made – these treatments should be presented as *options*, rather than *having to decide* on a treatment. Therefore, with the knowledge of these data, this policy needs to be updated to reflect the urgent need for consent and choice.

Participants of this study expressed a need for better handover processes from adolescent to adult care for their intersex variation management. Often, people with intersex variations cease receiving care once they turn 18 and struggle to find appropriate services that are well versed in intersex needs and subsequent management. This means that medical staff need to be better prepared for handover services while the intersex participant is still under adolescent care.This process should be introduced slowly to build trust with the patient's new doctors. This will minimise intersex patients having to repeat and educate each new doctor and will ensure a smoother handover process. Further, this means that intersex patients will have access to healthcare professionals that are well versed in not just their individual care, but overall in intersex variations.

8.8.3 For mental health providers, professionals and support groups

Given that intersex is an umbrella term that covers a wide range of variations, being a person with an intersex variation can be a very subjective experience, even within their own community. Participants expressed a broad spectrum of sexualities, identities and sexual behaviours in this study. Further, some participants expressed engaging in non-heteronormative, pleasurable sex. However, most of the treatments they were exposed to were to prepare them for living in a two-sex binary society to lead heteronormative adult lives, including PIV sex. Therefore, these data suggest that mental health and social support privileging the present essentialist model of sex, gender, and sexuality that is imposed medically and socially on people with intersex variations does not fit their true identities, sexual behaviours and experiences, or sexualities. Therefore, this means a different model of care needs to be applied to sufficiently care for this population including to better assist their needs in healthcare, education, and relationships within families.

Another consideration in mental and social support provision is how some intersex people do not fantasise about their own bodies in their own sexual fantasies due to experiencing shame. Whilst there is some theory on the relationship between shame and sexual fantasy, this does not accurately describe the disconnect in the relationship between their fantasy-self and their actual-self. Further, there is currently no existing literature that has explored this disconnect specifically for people with intersex variations. This relationship is similar to that of internalised homophobia and punishing sexual fantasies (Sullivan, 2003), however it stems from a different stigma from being differently bodied or from trauma. As there is no term that describes this disconnect between body and fantasy selves, there is subsequently no research in this area. As this experience involves internalising a corrective bias over intersex bodies, a proposed term for further related mental and social health research and discussion is the ‘internalised corrective bodily bias’; describing this disconnect between bodies and fantasised selves.

8.8.4. For schools and staff

School experiences were diverse, however there were instances of bullying for some physical differences in schools. Participants often gravitated towards other outcasts or excluded themselves from school activities. Therefore, more policies and staff training surrounding inclusion may be beneficial for schools, teachers, and administrative staff. Activities that involve segregating classes by sex should be avoided, and more inclusivity in physical education and science classes to discuss sex diversity should be implemented. This study found that negative experiences worsened from primary school to high school. Therefore, more support needs to be available for intersex students, particularly around puberty when secondary sex characteristics from intersex variations may begin to occur.

8.8.5 For families

Findings from this study show that parents were often given inadequate information regarding treatment options, the nature of the intersex variation of their child, and long-term repercussions of some treatments. Complications or secrecies that evolved from these treatments impacted the relationship between children with intersex variations and their parents. As a result, people with intersex variations often foster a lot of anger towards their parents, ongoing medical complications and experience shame over their intervened bodies.

Families also need to be held accountable for decisions they are making for their children. More importantly, parents need to be supportive of their children with intersex variations, particularly as familial support and acceptance were considered one of the most valuable (Snapp et al., 2015). Findings from this study show that children with intersex variations often experienced enforced gender roles from institutions of power, including parents. Therefore, as imposed gender roles and expectations had a high impact on intersex children, parents instead need to support and nurture the development of their children, including allowing them to express and explore their gender freely.

8.8.6 For researchers

Both the literature review and results from these data highlighted some gaps in research. As previously mentioned, there are no existing studies on sexual fantasy and the intersex population. This is likely due to the dehumanising approach that clinical data tends to take when conducting research on intersex populations. When seeking comparable data for intersex and families, only one study (Jones, 2017) was found. More research needs to be conducted in this area to gain a better understanding of the dynamics between people with intersex variations and how they develop and navigate complex relationships including relationships with family, friendships and relationships.

Given the disparities between sexual identity, sexual desire and sexual experiences found in this study, researchers should also ensure they explore and consider these areas separately. This is supported by Morales Knight & Hope (2012).

Despite the diverse characters amongst intersex participants, researchers should not assume that intersex participants necessarily waiver from their assigned sex and gender. Questions in research surrounding the topics or fluidity of gender should therefore be optional to avoid conflict with participants.

During the stages of quantitative research, some categories of responses were collapsed in order to give more weight to statistical results to find significance. Whilst this is a normal part of quantitative data analysis, this does mean that some information is lost. As this was a mixed methods study, qualitative analysis was also conducted which allowed the researcher to capture more detail from these responses. This illustrated how voices can be lost in quantitative data analysis. Therefore, there needs to be more qualitative or at the very least, mixed method research on lived experiences of intersex populations to fully explore and understand feelings, attitudes and experiences of this population.

When comparing the findings from school experiences with results from Jones (2017), the participants in this study did not particularly reflect on relationships with school staff, school policies, or learning difficulties. A more thorough investigation of these experiences should be explored in future studies and should cover a wider range of questions regarding school experiences and relationships such as the examples seen in Jones (2017).

Capturing specific data about intersex variations is a difficult process. This is particularly due to participants either misunderstanding what intersex is, as well as the evolving names of some intersex variations (for example, how pAIS used to be called ‘male pseudohermaphroditism’). Further, as the word ‘intersex’ still carries stigma, some people (and support groups) with particular intersex variations prefer not to be associated with this term and prefer to be identified as nothing more than a medicalised condition. As this study largely recruited from support groups, this meant that some subgroups of intersex were not captured. Further, as ‘intersex’ is sometimes experienced as an identity, this may also be misconstrued by some participants. Therefore, asking participants if they ‘identify as intersex’ who do not use the term as an identity and may misinterpret the question as asking about identities rather than asking about diagnoses of their sex differences.

As established in this study and others (Morales Knight & Hope, 2012), there are differences between sexual behaviours, sexual desires, and sexual identities. This study deliberately left these discussions open to capture a broader range of data regarding sexual experiences and sexual fantasies. However, particularly due to the small numbers of this study, not all participants chose to discuss sexual identity as part of this, leaving a gap in quantitative data analysis for sexual identity. Therefore, these different aspects of sex should be explored separately.

Further, conducting research on populations that experience trauma may take an emotional toll on researchers. Future researchers should consider vicarious trauma training. This training may assist in developing compassion fatigue resiliency which can minimise stress and prevent vicarious trauma, compassion fatigue, or emotional burnout (Potter, Pion & Gentry, 2015).

8.9 Moving Forward

8.9.1 Better policies and training for medical staff

All medical practitioners need to be fully trained in understanding intersex variations, in not only their undergraduate and postgraduate courses, but from training or policies at their places of employment. Medical practitioners need to understand that not all intersex patients will seek treatment for their aesthetic physical differences (Jones et al., 2016).

This training should also cover how to respectfully respond to intersex bodies. This includes understanding how to respond to an intersex body respectfully and neutrally and gaining consent from the patient regarding any practice relating to their person such as gaining consent before engaging in any physical exams or tests (regardless of the age of the patient), gaining consent before sharing any information (including viewing) of the patient’s body with colleagues, or making assumptions about sexuality or gender of the patient which may otherwise lead to particular heteronormative treatments (for example, suggesting vaginal surgeries to accommodate their future husband’s penis).

Intersex patients need to be involved in their own treatments and partner with medical staff to be a part of the process to make informed decisions about their bodies. Further, risks of all treatments need to be clearly communicated to all patients, and their families (if required). Additionally, intersex patients need to be counselled on their rights to disengage from treatments or not receive treatments initially in order to exercise their right to fully informed consent.

Whilst multidisciplinary teams are often used when it comes to the management of intersex variations, these conversations are still held behind closed doors, away from parents, where decisions are often already decided by professionals (Davis, 2015a). Multidisciplinary teams should consider inviting intersex patients or if they are too young, their parents, into these conversations to fully involve them in the process. Further, these teams should also involve a mental health professional to ensure that not only clinical views are considered, but the potential effects on mental health that some interventions may have are also considered. By involving intersex patients and if welcomed or necessary, their parents, into these meetings will give further transparency as to whether or not a medical or surgical procedure is necessary.

Further, health professionals and hospitals need to develop policies to ensure there is a better handover process when it comes to adolescent to adult care for people with intersex variations. There is minimal existing research on the nature of this handover of care, thus, different approaches need to be trialled and evaluated to determine the most appropriate method of delivery. A handover process from adolescent to adult care would foster better relationships between the intersex community and health professionals. Ideally, this would mean that people with intersex variations can get referred over to health professionals who specialise in ongoing care for intersex adults and prevent the need the for intersex patients to continuously educate each doctor, specialist or mental health professional they encounter. This handover process should be introduced slowly to build trust between the intersex patient and the new practitioners assisting in their care.

Given the benefits found for peer support groups, government funding should additionally be considered along with legislative changes. This added assistance to continue or promote these programs could have long term benefits to the mental health of those with intersex variations.

As this is a retrospective study on life experiences, there is an understanding that these processes and treatments have begun to slow down internationally. Despite this, there are still cases of non-consensual surgical intervention occurring. However, there are currently no existing guidelines for treatment for intersex children globally and non-consensual surgical intervention continues. There needs to be legislative change to ensure that harmful non-urgent, irreversible procedures cannot legally occur without a patient's consent and are postponed until they are able to make their own fully informed decisions, if they decide to pursue interventions at all.

Additionally, these policies need to be tested and evaluated to determine how effective these new policies may be. Policy models need to be developed with reference advisory groups consisting of intersex community members. Models need to be developed and tested on how consent may be more involved in intersex healthcare, this may involve further involvement at certain ages, or investigating different models of age appropriate consent. This will improve the management of intersex variations in the future and will ideally ensure that future intersex generations will not share the same trauma and negative experiences associated with older and current intersex generations.

8.9.2 Reform in school policy and training

Given the amount of bullying in schools for physical differences towards students with intersex variations, it is recommended that schools develop policies to protect intersex students against bullying and discrimination. Given the isolation some students mentioned in physical education classes, sex education lessons should be re-developed to be more inclusive of the diversity of sex differences. This would not only be more inclusive to the individual but may aid in normalising intersex variations as a natural, diverse part of sex development which in turn, may minimise bullying for differences from their peers. Guidelines should be developed to train school staff regarding the support and disclosure surrounding intersex variations, including the training of school counsellors to be more aware of intersex variations. Further, schools should minimise gendered practices in the classrooms such as dividing students into boy/girl teams as this promotes exclusion for both intersex and transgender students. Similar recommendations are also supported by the Jones, et al. (2016) study on Australian individuals with intersex variations.

8.9.3 Families

Parents need to better support and nurture children with intersex variations. This includes allowing children to express their gender freely without condemning any behaviours that do not fall outside of the two-sex binary. Exploring this is a part of natural play and allows for children to get a better understanding of their own identity which can help them make informed choices about their body in the future. Further to this, parents need to include their children in the decision-making process when it comes to determining treatments and interventions (if any) about their own bodies. Children need to not only give consent, but informed consent; they must be made aware of any and all risks associated with any kind of treatment, particularly if it is irreversible. As parents are not always advocates for their children's' choices, parents should only be involved if the child chooses to have their involvement.

Parents may also benefit from seeking support from outside sources such as peer support groups. Peer support groups can help not just families find others who are sharing the same experiences but exposing intersex children to others with biological sex differences may allow them to also find peers and feel less isolated in their variations. Being around others with intersex variations may also help to normalise the understanding of sex diversity in society which may allow for them to feel less marginalised by others.

8.9.4 Researchers

Whilst there are numerous clinical studies exploring intersex, there needs to be more qualitative and social research on this population. Further, these clinical approaches are often conducted without the input of members of the intersex community. This reflected the historical lack of collaborative involvement with intersex people which in turn, has led to a contentious relationship between the intersex community and researchers as a result of the concerning history of this relationship. Future research must utilise a reference group of members from the intersex community to ensure that the study will be ethically sound, is developed with input from the intersex community, and to ensure that language used in the study is appropriate.

Greater care needs to be taken when capturing intersex data. There are large gaps in capturing intersex data in studies of LGBTI youth as a result. As discussed, participants may misinterpret questions about intersex to be identity based rather than diagnoses based. If researchers are aiming to include people with intersex variations, useful questions to capture these data may be examples such as '*Please list any intersex variations you have been diagnosed with* _________'. As there is still some stigma around the word 'intersex', this can also be substituted with 'variations of sex characteristics'. It is recommended that examples are used to give further information to participants so that they have a greater understanding of the question. For example, this may look like '*Please list any variations of sex characteristics you have been diagnosed with (e.g. Congenital Adrenal Hyperplasia, Androgen Insensitivity Syndrome, Klinefelter Syndrome, etc.)* ___________'. This gives a clear example of what is meant by the question and those who are applicable can describe information they are willing to share so this information can be identified in any reporting on the study. The diagnoses entered will then need to be clarified by the researcher to ensure they are actual intersex variations and may need to be updated to the most recent terminology used for consistency to avoid confusion in reporting.

To avoid further confusion, ensure that examples are used when capturing separate data on sex and gender. For example, '*Please describe your gender (e.g. woman, man, agender, genderqueer, etc.)* ___________'. This will ensure that data regarding their sex and their gender identity will be recorded separately for later reporting. Both the literature review and the findings from this study identified gaps in some key areas of intersex studies and highlighted the importance of exploring the following:

- Knowledge of intersex variations by health professionals and mental health professionals;
- Potential models of healthcare proposed by people with intersex variations;
- Further exploration of the complex relationships between people with intersex variations and families;
- Investigations into school policies for intersex students, including inclusion in sex education and/or science programs;
- Exploring connections between self-esteem, body image, and sexual fantasy for people with intersex variations; and

- Further qualitative studies exploring sexual satisfaction for people with intersex variations (rather than clinical studies).

Whilst most of the above suggestions are based on using a critical or post-modern lens to question the status quo of healthcare, education and research approaches, there is value in exploring this population through other lenses. As some participants in this study required access to other medical services, or had concurrent disabilities, some literature describes a higher prevalence of disabilities in this population (Jones et al. 2016). As such, there may be some benefit to using Post-modern Crip Theory or Critical Disability Studies lenses. This may be useful for exploring how these labels impact or are challenged by this community and their access to services or citizenships, as well as exploring expectations around sexuality. This study largely reflects on Western approaches to healthcare and lived experiences. Exploring different cultural perspectives and experiences via different lenses, such as Southern theory would allow researchers to challenge the universalism in existing social theory, and shed light on intersex experiences (which in some cultures, are often paired with trans) in places like Australasia (brotherboys and sistergirls; kwolu aatomwol [Herdt, 1990]), India (Hirja) (Habib, 2013; Lal, 1999), South Africa and Latin America (guevedoche) (Connell, 2007).

A variety of stakeholders need to undertake the further work necessary in multiple systems to ensure that the challenges experienced in these systems are overcome in ways that meet the values and needs of the intersex community and individuals. There are core issues faced by people with intersex variations including inappropriate intervention and consent processes; having incorrect assumptions made about gender, sexuality, sexual behaviours;

and difficulties of navigating relationships and trust for others, which potentially may begin at a young age where it would be unfair to hold them responsible for making change. This research has proposed several recommendations that could assist healthcare providers, education providers, families, and researchers to reform practices and support provision for individuals with intersex variations. Central to these recommendations are challenging the existing paradigms of heteronormative gender essentialism, and the critical valuing of bodily autonomy and the empowering of intersex bodies. This international study together with previous country specific research suggested that the critical approach outlined has the potential to create more positive outcomes, involvement, and lived experiences for future generations of intersex populations in Australia and other nations with similar models of institutional power.

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Appendices

Appendix A

Intersex Adult Questionnaire

Short answer demographic questions

1. What is your age? ___

2. What is your education level?
   a) High school __
   b) Trade (e.g. Certificate/Diploma) __
   c) Some tertiary undergraduate (Bachelor) __
   d) Completed tertiary undergraduate (Bachelor) __
   e) Postgraduate (Grad Diploma/Masters/PhD) __

3. What is your:
   a) Occupation:
   b) Country of birth:
   c) Country of residence:

4. Do you currently have a partner?

5. What sex were you assigned at birth? ___________

6. If you know your chromosome status please indicate which:
   XY___, XX___, XXY___, XXX___, other ___

7. Did you receive an intersex diagnosis? Y __ N __ (*If No, please skip to the Childhood section starting at question no. 1)*

8. At what age did you receive the diagnosis _____
9. What was the diagnosis? ____________________
10. Who gave you the diagnosis? ____________ I don't know __
11. I was diagnosed via:
    a) DNA test __
    b) Physical examination __
    c) Ultrasound __
    d) Other:

e) I don’t know __
My diagnosis changed from: ____________ to __________, re-diagnosed at age: ___.

12. Would you like to be contacted for an interview for a case study? Y/N
If yes, please provide your email address: _____________________________

Please provide as much information as you can for each question.

Childhood

Interventions

1. Did you receive surgical interventions in infancy and/or childhood? Y __ N__
*(if **No**, please go to question 2)* If **yes**, how did this affect you and how did you feel about it?
Do you feel the surgery was appropriate ___
Do you feel the surgery was inappropriate ___
Comment:____
____
____
_

2. If no, reflecting on this as an adult, do you wish you had received surgical intervention as an infant? Why?
____
____

3. Did you receive any other form of treatment for your intersex variation as a child? *(mark all that apply)*
hormone treatments __ dilation __ counselling __ further surgeries __ medication: __
other: __________

4. What kind of ongoing support did you receive from health services during childhood and adolescence? *(Mark all that apply)*

General practitioners __ surgeons __ endocrinologists __ counsellors__
psychiatrists__ urologists__ gynaecologist__ other: _________

5. What kind of support do you think was most important for your parents?
____

6. Do you know if your parents were fully informed by health professionals about your intersex variation? Yes __ No__ I am unsure___
Comment:____
____
____
_

7. If you were fully informed about your intersex variations, did you have concerns for your future?
Yes __ *(please describe below)*
No__
I do not feel like I was fully informed about my intersex variation *(please describe below).*
Comment:____
____
_

8. What more would you have liked to know growing up?
____

Rearing

9. How did you feel about how you were raised?
I was raised as a boy __ girl __ gender neutral __
It felt appropriate. Y/N It felt inappropriate. Y/N
Comment:____
____
____
_

10. Who made this decision?
    a) Parents
    b) Physician
    c) Both
    d) I did
    e) Other: ______

Was this satisfactory? Explain.____
____

11. If you had any siblings, were they treated similarly with gender rearing?
All of the time ___ Most of the time ___ Some of the time ___ Rarely ___

12. How do you feel about your parents’ decisions regarding your intersex variations? (e.g. the gender they raised you as, what they did and did not disclose to you regarding your intersex variation, etc.)
    Comment:____
    ____
    ____
    _

School and friendships

13. In *primary/elementary school*, how would you describe your *feelings* about your intersex variation?
    a) How did you experience and express these feelings?
       Explain.____
       ____
       _
    b) Felt to be part of a group; among friends. Yes___ No___
    c) Felt different, somewhat alienated. Yes___ No___
    d) Was popular. Yes___ No___

14. *In primary/elementary school*, how would you describe your *relationships*?
    a) Was a loner. Yes___ No___
    b) Had about the average number of friends. Yes___ No___
    c) Had more friends than average. Yes___ No___
    d) Was often teased for being ‘different’. Yes___ No___
    e) Had a few close friends. Yes___ No___
       Friends were mostly: Boys ___ Girls ___ Both ___

    Please comment on your childhood feelings and relationships during primary/elementary school.
    Comment:____
    ____
    ____
    _

15. In *high school*, how would you describe your *feelings* about your intersex variation?
    a) How did you experience and express these feelings? Explain._________________
    ____
    b) Felt to be part of a group; among friends. Yes___ No___
    c) Felt different, somewhat alienated. Yes___ No___
    d) Was popular. Yes___ No___

16. In *high school*, how would you describe your *relationships*?
    a) Was a loner. Yes___ No___
    b) Had about the average number of friends. Yes___ No___
    c) Had more friends than average. Yes___ No___
    d) Was often teased for being ‘different’. Yes___ No___
    e) Had a few close friends. Yes___ No__

f) Friends were mostly: Boys ___ Girls ___ Both ___

Please comment on your childhood feelings and relationships during high school.
Comment:____
____
____
_

17. Did you feel comfortable dating during your teens? Yes___ No___
Were you sexually active?
Yes ___ No ___
Comment:____
____
____
_

Adulthood

18. Describe your gender you are currently living as.
____

19. Does this differ to the gender you were raised? *(if No, please skip to Q.30)* Not Different __ Very Different __ How?
____
____

20. At what age did you *begin* to think that instead of being the gender you were raised, you should have been another gender?
At age ___ .
Not applicable, I have not thought that. ___

21. At what age did you firmly decide you wanted to transition to another gender?
At age ___ .
Not applicable, I have not thought that. __

22. If you changed your gender identity, what steps did you take to develop this?
Comment:____
____
____
_

23. Are you planning on receiving any additional support or treatment in the future? *(tick all that apply)*
Hormone replacement therapy __ surgery __ pharmaceuticals ___ counselling ___
other: _______________

24. As an adult, did you choose to seek mental health support? If yes, how would you describe this experience?
Comment:____
____
____
_

25. Do you feel you currently have sufficient healthcare management regarding your intersex variations? (e.g. sufficient specialists, ongoing support, ease of access to information, etc). How has this level of care changed since childhood?

26. How do you feel the management and support of both adults and children with intersex variations could be improved?

27. Reflecting as adult, what support do you think would have helped you as a child?

28. Reflecting as an adult, what support do you think would have helped your parents/family when you were a child?

29. What impact has your experience as a child with an intersex variation had on you as an adult?

Relationships:

30. How would you describe your current relationship with your family? Has it changed since you were a child?
Comment:____
____
____
_

31. As an adult, how would you describe your *feelings* regarding your intersex variation?
Feel to be part of a group; among friends. Yes___ No___
Feel different, somewhat alienated. Yes___ No___
Am popular. Yes___ No___

32. As an adult, how would you describe your *relationships*?
I am a loner. Yes___ No___
I have about the average number of friends. Yes___ No___
I have more friends than average. Yes___ No___
I am often teased for being ‘different’. Yes___ No___
I have a few close friends. Yes___ No___
My friends are mostly: Men ___ Women ___ Both ___

Please comment on your current feelings and relationships as an adult.
Comment:____
____

____
_

33. As an adult, have you been comfortable dating? Yes__ No__
    Comment:____
    ____
    ____
    _

Sexual Satisfaction

34. Are you able to reproduce without any known issues or complications?
    Yes, naturally. ___ Yes, with medical assistance. ___ No. ___ I am unsure. ___

35. Please describe your sexual experience.
    Comment:____
    ____
    ____
    ____

36. Do your sexual fantasies differ from your existing experiences?
    Comment:____
    ____
    ____
    ____

37. Do you feel that any surgical intervention you have received as an individual with an intersex variation has affected your sex life?
    Comment:____
    ____
    ____
    _

Other:

38. Is there anything else you would like to add?

Thank you!

Thank you so much for participating in our intersex mental health survey, by sharing your experiences with us we can further the knowledge of previous intersex management in order to facilitate change. We understand that recalling these experiences may be traumatic and have included a brief list of support websites and lines should you need to seek counselling or further support:

OII Australia
www.oiiaustralia.org.au

AIS Support Group Australia

http://home.vicnet.net.au/~aissg/

Bodies Like Ours

http://www.bodieslikeours.org

Intersex Society of North America (Accord Alliance)

www.isna.org

Lifeline 13 11 14 (24 hour support - Australia)
https://www.lifeline.org.au (online counselling available)

Kids Help Line

http://www.kidshelp.com.au/grownups/getting-help/who-else-can-help/helpful-links/help-lines.php

Depression Understood (UK)

http://www.depression-understood.org/information/ukcrisisline.htm

The Trevor Project (US)

http://www.thetrevorproject.org

Appendix B

Discipline of HIV, STI's and Sexual Health
Faculty of Medicine

ABN 15 211 513 464

Mandy Henningham / Dr. Spring Cooper
Chief Investigator / Supervisor

Western Sydney Sexual Health Centre
Level 4, Jeffery House
162 Marsden St, Parramatta
NSW, 2150
Australia

Email: mhen4620@uni.sydney.edu.au
Web: http://www.sydney.edu.au/

Born This Way: The long term psychological effects of non-consensual surgical intervention during infancy or childhood on individuals with intersex variations.

PARTICIPANT INFORMATION STATEMENT

(1) What is the study about?

You are invited to participate in a study of the long term psychological effects of surgical and medical intervention during infancy or childhood on individuals with intersex variations. This study aims to gather more information about the management of people with intersex variations in order to improve management in the future. This study will also investigate the sexual satisfaction of individuals with intersex conditions in order to gain more information about the psychosexual repercussions of non-consensual medical and surgical interventions.

(1) Who is carrying out the study?

The study is being conducted by Mandy Henningham and will form the basis for the degree of Doctor of Philosophy (Medicine) at The University of Sydney under the supervision of Dr. Spring Cooper, senior lecturer in HIV, STI's and Sexual Health.

(2) Who can participate in this study?

- People who are aged 18 years and older
- Individuals who have (at some stage in their lives) been diagnosed with an intersex variation

(e.g. AIS, CAH, ambiguous genitalia, etc.)

- Individuals ***who have had*** surgery of some description relating to their intersex variation (e.g. mastectomy, gonadectomy, clitorectomy, recession of the clitoris, etc.)
- Individuals ***who have not had*** surgery of some description relating to their intersex variation
- Individuals who are able to read and understand English

(3) What does the study involve?

- Audio/video taping (if applicable), questionnaires, surveys, and interviews via phone or email (subject to availability of the participant) Any on site interviews will occur at*: Western Sydney Sexual Health Centre, Level 4, Jeffery House 162 Marsden St, Parramatta*
- The questionnaire and/or interviews will cover questions regarding your past and present experiences. This includes discussing your experiences of medical and surgical interventions as well as sharing your emotions and feelings throughout these times. Questions regarding your current mental health will be asked in addition to questions relating to your levels of sexual satisfaction and desire.
- There may be some risk of experiencing anxiety or other post-traumatic stress disorder (PTSD) symptoms such as depression, flashbacks or nightmares from recalling previous events and emotions that you have experienced.
- Should this occur, seeking counselling or support may be advantageous. Below is a list of some support lines and groups that you may find helpful.

(4) How much time will the questionnaire take?

The time allocated for questionnaires largely depends on how much information you share, but may range from 20-60 minutes.

(5) Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with The University of Sydney.

You may stop the interview or survey at any time if you do not wish to continue, the audio/video recording will be erased or email conversations deleted and the information provided will not be included in the study.

Being in this study is completely voluntary and you are not under any obligation to consent to complete the questionnaire/survey. Submitting a completed questionnaire/survey is an indication of your consent to participate in the study. You can withdraw any time prior to submitting your completed questionnaire/survey. Once you have submitted your questionnaire/survey anonymously, your responses cannot be withdrawn.

(6) Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants.

A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

(7) Will the study benefit me?

There are no direct benefits from the study; however it may raise awareness of the issues faced by the intersex community. This study will have future impacts on the development of management on people with intersex variations.

(8) Can I tell other people about the study?

We would encourage you to discuss this project with others**.** Anyone who is interested in this project can contact Mandy Henningham (*mhen4620@uni.sydney.edu.au*)

(9) What if I require further information about the study or my involvement in it?

If you would like to know more at any stage, please feel free to contact Mandy at her email address: *mhen4620@uni.sydney.edu.au*

(10) What if I have a complaint or any concerns?

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

This information sheet is for you to keep

-

Further Support Information

Thank you so much for considering to participate in our intersex mental health survey, by sharing your experiences with us we can further the knowledge of previous intersex management in order to facilitate change. We understand that recalling these experiences may be traumatic and have included a brief list of support websites and lines should you need to seek counselling or further support:

OII Australia
www.oiiaustralia.org.au

AIS Support Group Australia
http://home.vicnet.net.au/~aissg/

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Intersex Society of North America (Accord Alliance)
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Lifeline 13 11 14 (24 hour support - Australia)
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Kids Help Line
http://www.kidshelp.com.au/grownups/getting-help/who-else-can-help/helpful-links/help-lines.php

Depression Understood (UK)
http://www.depression-understood.org/information/ukcrisisline.htm

The Trevor Project (US)
http://www.thetrevorproject.org

Appendix C

Facebook advertisement

THE UNIVERSITY OF
SYDNEY

‘The long term psychological effects of non-consensual surgical intervention during infancy or childhood on individuals with intersex variations.’

If you were born with an Intersex variation (CAH, AIS, etc) please participate in this study to contribute to a better understanding of how to improve the management (including physical and mental health) of individuals with Intersex variations throughout development. *(Please read the information sheet prior commencing the questionnaire*)