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"Wiser and Wider": An Analysis of DSD Treatment Protocol in the Netherlands and Practitioner and Patient Attitudes Towards Medical Care

Mel Ferrara
SIT Study Abroad

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Ferrara, Mel
Academic Director: Kopijn, Yvette
Advisor: Verkerke, Vreer

Muhlenberg College
Gender and Sexuality Studies and Philosophy/Political Thought

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Abstract

The main objective of this study is to assess current medical practices in the Netherlands for the treatment of disorders of sexual development (DSD) through interviews with both medical practitioners and individuals diagnosed with these conditions. Data was obtained qualitatively through personal interviews with a pediatric endocrinologist, pediatric urologist, ethicist, and four men who have been diagnosed with Klinefelter's Syndrome. This study examines how institutional protocol aligns with individual practitioner's perception of ideal treatment as well as their own conceptions of sex and gender. This data is juxtaposed with the personal experiences and perspectives of several men diagnosed with Klinefelter's Syndrome in an attempt to provide a more holistic understanding of medical best practices. It is concluded that, in regards to DSD treatment teams, there have been several strides to meet the guidelines of the Consensus Statement of 2006, however there could be more efforts to incorporate a patient-centered model. Treatment of Klinefelter's Syndrome, on the other hand, lags very far behind that of specialized DSD medical care in regards to being care-focused.

Table of Contents

Introduction pg. 4

Historical Background

- Medical Paradigm Shifts in the Treatment of Intersex/DSD pg. 5
- Klinefelter's Syndrome pg. 10

Methodology

- Participants pg. 12
- Interviews pg. 13
- Positionality and Bias pg. 14
- Language pg. 15

Literature Review pg. 18

Results and Discussion

- Approach and Perspectives of Medical Practitioners
  - Intra- and Inter-institutional Cooperation pg. 23
  - Surgical Treatment pg. 24
  - Pre-natal Diagnosis and Treatment pg. 26
  - Consent, Disclosure, and Agency pg. 28
  - Sex and Gender in the Dutch Context pg. 30
- Patient Experience
  - Self-perception pg. 32
  - Experiences with Medical Practitioners and Treatment pg. 34

Conclusion

- General pg. 37
- Limitations pg. 37
- Continued Research pg. 39

Appendices

- Appendix I pg. 40
- Appendix II pg. 42
- Appendix III pg. 47
- Appendix IV pg. 49

References pg. 52

Introduction

Intersex is the marker ascribed to individuals whose biological sex is ambiguous, neither strictly female or male genetically, anatomically, hormonally, or some combination thereof. Statistically, intersex conditions, or disorders of sexual development (DSD), are fairly common, affecting about 1 in every 100 live births (Williams, 2002). To date, there are dozens of recorded types of DSDs, some of which result in variances that often remain unnoticed until adolescence or adulthood without some type of genetic testing, such as Klinefelter's Syndrome. On the other hand, several of these conditions can manifest externally, and thus are noticeable at birth, such as Congenital Adrenal Hyperplasia (CAH) or Androgen Insensitivity Syndrome (AIS).

Medical approaches to the treatment of intersex conditions/DSD has become a site at which three different frameworks have been contextualized. The concealment-centered model, the original standard of treatment developed during the 1960s, is notable for its almost exclusive focus on implementing physical and social norms through surgical procedure. Later, the Consensus Statement of 2006 released by the American Academy of Pediatrics proposed several changes to the dominant model of treatment. This includes: (i) the implementation of a multidisciplinary team for treatment, which includes elements of psychosocial support, (ii) a more "cautious" approach to sexual reassignment surgeries (SRS), and (iii) increased, open communication with patients and their families, especially in regards to decision-making (Lee et al., 2006). Still today, many advocates propose an even more patient-centered or care-focused model that is centered on the agency of the patient in making decisions about his or her own body.

This study is an effort to understand which model(s) of intersex/DSD treatment are followed by medical institutions in the Netherlands, particularly as there has been no specific research on the implementation of the Consensus Statement. Furthermore, this study examines how practitioners' perceptions of institutional protocol align with their personal understandings of sex and gender, questions that lie at the core of this discourse. In the second part of the report, this information is juxtaposed with an analysis of a series of interviews conducted with men who have been diagnosed with Klinefelter's Syndrome and who have therefore undergone medical treatment and interacted with practitioners first hand. In putting their personal experiences and perspectives in conversation with current Dutch medical discourse, this report aims to provide a more holistic understanding of best practices for DSD medical care.

Historical Background

Medical Paradigm Shifts in the Treatment of Intersex/DSD

For the past several centuries, the intersex body has been a site of fascination, observed, and often exploited, by curious eyes seeking to understand a variation of one of the Western world's most fundamental social markers: biological sex and, analogously, gender. While also critiqued in the everyday or lay sphere, the "phenomena" of the intersex body has been largely regulated by a series of societal institutions, such as religion, legislation, and medicine. During the late nineteenth century, medical interest with the intersex then understood as hermaphroditic body manifested into a desire to uncover these individuals' "true sex" amidst a system of binary sexual norms. According to Alice Dreger, a large number of hermaphroditic subjects began to be recorded by practitioners during this time, namely in France and Britain; she explains that this most likely was due to an increased number of people being seen by doctors and the rise of the field of gynecology (Dreger, 1999). In response to this sudden influx of case studies, many medical experts sought to develop a system by which individuals could be categorized as "male," "female," or "true hermaphrodite," largely in an effort to minimize this last ambiguous, and thus threatening, group.

New systems of nomenclature and taxonomy were developed in accordance with this aspiration of eradicating the existence of the "true hermaphrodite." Scholar Hilary Malatino, for instance, claims that the popularization of the terms "male and female pseudohermaphroditism," used to describe bodies that are predominantly that of one sex while exhibiting some physical features of the other, was merely an effort to try to fit as many individuals as possible within the established sexual binary (Malatino, 2009). Opening up the definition of what is male and what is female still was seen as a safer option than disrupting the dualistic system itself. Ultimately, it was the approach of British physicians George F. Blacker and Thomas William Pelham Lawrence (1896), expanding on the taxonomical work of German physician Theodor Albrecht Edwin Klebs, that spawned a new era of systematically categorizing intersex bodies according to their reproductive organs (Malatino, 2009).

In what Dreger coins as the "Age of Gonads," Western medicine relied on observing the presence of ovaries and/or testicles in clearly determining an individual's "true" sex. She describes:

> Henceforth, no matter how manly a patient looked, even if he had a full-sized penis, no vagina, full beard, and a reputation for bedding down (and satisfying) young maidens, if

> he had ovaries, he would be labeled as female - in this case a "female pseudo-hermaphrodite." No matter how womanly a patient looked, no matter if she had a vagina, fine and rounded breasts, a smooth face, and a husband she loved, if she had testes, she would be labeled a man - in this case a "male pseudohermaphrodite" (Dreger, 1999).

Unless it was determined by means of microscopic verification that an individual possessed both ovarian and testicular tissue, the label of "true hermaphrodite" was not used in diagnosis, again demonstrating the staunch effort to eliminate or at least minimize the social existence of total ambiguity. Additionally, the sole focus on gonadal organs in assignment suggests the social importance placed on reproduction □ regardless of actual viability □ in designating sex. Ultimately, the "Age of Gonads" prevailed for about twenty years until 1915, with the development of increased medical technology and the work of British physician William Blair Bell, who questioned the limitations of looking solely at gonads in establishing sex. In a case study of an individual with AIS, while upholding the sex binary, he suggested a more expansive set of characteristics to analyze: "Since it is now possible to demonstrate that the fact that the psychical and physical attributes of sex are not necessarily dependent on the gonads, I think that each case should be considered as a whole... the sex should be determined by the obvious predominance of characteristics, especially the secondary, and not by the non-functional sex-glands alone, for this is neither scientific not just" (Dreger, 1999). This notion of looking at several physical factors is similar to the popular method of assigning sex to infants with ambiguous genitalia in current Western medicine based on several characteristics, such as chromosomal, gonadal, and hormonal features. Up until the turn of the twenty-first century, however, there was an intermittent period in which this was not the case and where the gender of an infant with ambiguous genitalia was determined by means of a measurement of his or her phallus and capacity for "proper penile function" (Fausto-Sterling, 2000).

With the exception of the coining of the term "intersex" by endocrinologist Richard Goldschmidt in 1916, the next major shift in medical approaches to intersex bodies did not occur until the mid-twentieth century with the work of psychologist John Money and one of his most popular case studies, that of John/Joan. John/Joan □ who's real name is David Reimer □ was himself not an intersex person; rather, at eight months old, Reimer was castrated after a botched attempt at circumcision through cauterization. Damaged beyond repair, the remainder of his penis was removed and his genitalia reconstructed into a functional vagina as per the suggestion of Money, who believed that the child could then be raised as female (ISNA, 2008). Money postulated that

gender did not have an essential source and that instead nurture was the sole determiner of gender identity on the basis of psychosexual development. Central to this psychosexual development was (1) genital appearance and (2) gender role inscription (Chittenden, 2011). According to Money, newborns are psychosexually neutral at birth and have a semi-mutable gender identity up until the age of two (Chittenden, 2011). The differentiation of gender identity occurs through social programming on the basis of one's physical reality. According to Money:

> You attain your gender identity/role in much the same way you attained speech. In fact, the parallel with language illustrates the way gender identity/role develops. You were born wired for language, so to speak, but not programmed for any particular language. You couldn't have learned to talk unless you'd been born with the mouth, vocal cords, ears, and brain pathways to accommodate language, but these were not enough. There also had to be the releasing of stimulus of an environmental example, and it had to come at the right time in your life (Money, 1975).

Thus, through the metaphor of language, Money presents a sort of dialectical relationship between the body and social inscription, claiming that one cannot be successful in forming an individual's gender identity if it is existing in exclusion of the other. Just as the mouth is useless without linguistic exposure and vice versa in the production of language, the genitalia of an individual does not have gendered meaning without the cultural influence of social roles. Money applied his theories on gender development from the John/Joan case to instances of intersexuality. He postulated that, first, patients must be rid of their ambiguous genitalia, as the absence of a clear penis or vagina would only cause confusion and psychological distress during psychosexual development. Yet this physical reality in itself is not enough, and an individual's sexed body must be coupled with the rigid teaching of appropriate social gender roles as rooted in a traditionally dimorphic conception of manhood and womanhood. Furthermore, both of these factors must be present before they reach the age of 18 months to 2 years, the end of this period of psychosexual neutrality. After this point, changing one's gender is pathological (Fausto-Sterling, 2000).

With the publication of the John/Joan case study, many contemporaries lauded Money for his revolutionary theories on the nature of gender role and gender identity development. In actuality, David Reimer's life story was largely tragic. Money falsely claimed that "Joan" had properly adjusted to being a girl although she had eventually failed to follow-up, but psychologist Milton Diamond uncovered the reality of the situation when he located Reimer. After discovering that he had in fact been born male, Reimer, never having identified as a girl, eventually underwent

sexual reassignment surgery and transitioned to living as a man (Kessler, 1998; ISNA, 2008). He struggled with the psychological trauma of Money's experimentation, and, having had depression throughout his life, ultimately committed suicide at the age of 39 (Walker, 2004). Later, in 1970, psychiatrist Bernard Zuger publicly critiqued Money's theories on intersexuality:

> "The data from hermaphrodites purporting to show that sex of rearing overrides contradictions of chromosomes, gonads, hormones, internal and external genitalia in gender role determination are found unsupportable on methodological and clinical grounds. Conclusions drawn from the data as to the adoption of such assigned gender role and the psychological hazard of changing it after very early childhood are shown not to be in agreement with other similar data found in literature" (Fausto-Sterling, 2000).

In spite of the publication of Diamond and Zuger's research and the revelation of Reimer's story in the documentary *As Nature Made Him*, Money's influence continued to dominate the discourse on intersex management. In her 1998 report, Kessler explains, "This [Money's] theory is so strongly endorsed that it has taken on the character of gospel. 'I think we [physicians] have been raised on the Money theory,' one endocrinologist said'" (Kessler, 1998).

Influencing the so-called concealment-centered model of treatment,[1] Money's theory prevailed for decades without significant institutional critique. In 2006, however, the American Academy of Pediatrics published the "Consensus Statement on the Management of Intersex Disorders." A composition comprised of the input of 50 international experts, the document functions as the contemporary framework for medical management of intersex conditions, here referred to as disorders of sexual development (DSD). The document elaborates on five fundamental guidelines for practitioners:

> Optimal clinical management of individuals with DSD should comprise the following: 91) gender assignment must be avoided before expert evaluation in newborns; (2) evaluation and long-term management must be performed at a center with an experienced multidisciplinary team; (3) all individuals should receive a gender assignment; (4) open communication with patients and families is essential, and participation in decision-making is encouraged; and (5) patient and family concerns should be respected and addressed in strict confidence (Lee et al., 2006).

There are three important shifts in perspective delineated by these experts in regards to the use of a multidisciplinary team, sexual reassignment surgery, and psychological care:

(1) Multidisciplinary Team: The Consensus Statement emphasizes the importance of an interdisciplinary team in providing treatment for DSD. They list several positions that should be included in an ideal team, given the institution's resources and developmental context:

1 See Appendix III

"endocrinology, surgery, and/or urology, psychology/psychiatry, gynecology, genetics, neonatology, and, if available, social work, nursing, and medical ethics" (Lee et al., 2006).

(2) Sexual Reassignment Surgery: Money claimed that surgery should always be performed between three months and one year after birth in order that a child be properly perceived as either male or female. Additionally, for females, he claimed that earlier surgery is needed to avoid traumatic memories of "castration" (Kessler, 1998). While authors of the Consensus Statement still identify SRS as the appropriate method of treatment in many cases, they claim that several factors such as physical and psychological surgical risk should first be considered and minimized. They state that surgery should serve functional as opposed to cosmetic outcomes, especially in the preservation of sexual tissue. While hypospadias should be consistently corrected, in cases of clitoromegaly, only more severe virilization should be surgically corrected in infancy. Still, it is referenced that the American Academy of Pediatrics advises early reconstruction on the basis that it is easier to avoid physical complications (Lee et al., 2006).

(3) Psychological Care: The Consensus Statement emphasizes that psychological care should be integral to treatment and that the service should be provided to both patients and parents. The document states, "This expertise can facilitate team decisions about gender assignment/reassignment, timing of surgery, and sex-hormone replacement" (Lee et al., 2006). A psychologist can provide support to parents and the child in making medical decisions. Additionally, a psychologist can help if a child appears to have a different gender identity than was assigned, even beyond the first 18 months that Money describes as the upper limit of gender assignment (Lee et al., 2006).

According to a statement released by the Intersex Society of North America (ISNA), the Consensus Statement involved significant developments to the medical model of intersex/DSD treatment, including an increased focus on psychosocial support and, relatedly, a more cautious approach to surgical treatment. That being said, the organization claims that these improvements are still limited and furthermore have failed to be fully implemented at any institution, lacking any mechanism by which to be instated (ISNA, 2008). In response to the Consensus Statement, Accord Alliance, progeny of ISNA, published "Clinical Guidelines for the Management of Disorders of Sex Development in Childhood" in hopes of promoting an even more patient-centered model of medical care. Specifically, they proposed the following standards:

1. Provide medical and surgical care when dealing with a complication that represents a real and present threat to the patient's physical well-being.
2. ...care provides should not seek to force the patient into a social norm (e.g. for phallic size or gender-typical behaviors) that may harm the patient.
3. Minimize the potential for the patient and family to feel ashamed, stigmatized, or overly obsessed with genital appearance; avoid the use of stigmatizing terminology (like "pseudohermaphroditism") and medical photography; promote openness (the opposite of shame) and positive connection with others...
4. Delay elective surgical and hormonal treatments until the patient can actively participate in decision-making about how his or her own body will look, feel, and function...
5. Respect parents by addressing their concerns and distress empathetically, honestly, and directly
6. Directly address the child's psychosocial distress (if any)
7. Always tell the truth to the family and the child... (Accord Alliance, 2006)

Klinefelter's Syndrome

Klinefelter's Syndrome affects 1 in every 500 individuals, mostly male assigned, and is the most common chromosomal disorder. It is characterized in part by "gynaecomastia, small, firm testes, hypogonadism, and a high level of FSH (Radicioni et al., 2010). The history of Klinefelter's Syndrome is in part shared with that of other intersex conditions, particularly during the 19th century, before individual disorders of sexual development were distinguished. While the manifestation of different physical features among patients were recorded, it would likely be difficult to differentiate some of the earlier case studies according to the conditions that they describe, all of them instead being referred to under the generalizable label of "hermaphrodism." In this report, the history of Klinefelter's Syndrome will be recounted beginning with when it was first defined by physician Harry F. Klinefelter in the 1940s. During his residency under Dr. Fuller Albright, Klinefelter worked on the case studies of eight men with "a syndrome characterized by gynecomastia, aspermatogensis without aleydigism, and increased excretion of follicle-stimulating hormone" (Klinefelter, 1985). Though initially thought to be an endocrine disorder, the condition, now known as Klinefelter's Syndrome, was discovered to be genetic about fourteen years after it's original description was published when two groups of researchers discovered extra chromatin mass or chromatin positivity in the buccal mucosal cells of these

patients. Subsequently, Patricia Jacobs and John Strong discovered the presence of an additional X chromosome in chromatin positive patients as a result of nondisjunction or anaphase lag, resulting often in a karyotype of 47, XXY (Klinefelter, 1985).

An important component of Klinefelter's Syndrome's history is it's frequent association with psychosis and criminality. John Money, for example, frequently affiliates the two in his work, both explicitly and implicitly. In *Sex Errors of the Body*, he writes:

> Mentally, males with Klinefelter's syndrome are peculiar people. They seem to have a special, nonspecific proneness to mental deficiency to schizophrenia. A large number of them, if not all, who are not more severely afflicted, have what may best be characterized as an inadequate personality. Though they are typically very low-powered in sexual drive, paradoxically many of them manifest psychosexual behavior disorders (Money, 1968).

Without any data to support these findings, Money presents a stigmatizing characterization of men with Klinefelter's Syndrome, accordingly calling into question their social desirability. Similarly, in a later supplement to *The Handbook of Sexology*, Money chooses to represent Klinefelter's Syndrome solely by the case study of a 19-year-old man in solitary confinement who had been institutionalized since the age of 14, a largely sensationalistic example (Money, 1991). Still today, there are several studies being conducted to analyze any correlation between Klinefelter's Syndrome and criminality.[2] Although some of his past work suggests otherwise, in his 1985 report, Klinefelter's own observations refute such claims: "Mental deficiency, manic depressive psychoses, and schizophrenia seem not to occur more commonly in this syndrome than in controls; most of these patients work regularly, and lead normal lives except for the inability to procreate" (Klinefelter, 1985). Thus, often baselessly, Klinefelter's Syndrome has been not only pathologized but largely demonized, having a profound impact on the perception of the condition by both affected individuals and society at large.

Methodology

Participants

For this study, two groups of participants were interviewed: practitioners and individuals who have been diagnosed with a disorder of sexual development (DSD). In regards to the former group, recruitment occurred through email. In total, I emailed twenty individual

2 For example, the article "Criminality in men with Klinefelter's syndrome and XYY syndrome: a cohort study," (Stochholm et al., 2012)

practitioners involved in DSD diagnostics and treatment and three department secretaries. Practitioners contacted were from a variety of disciplines, namely endocrinology, urology, gynecology, genetics, and psychology. Practitioners contacted were working at five medical institutions in the Netherlands: VU University Medisch Centrum (Amsterdam), Universiteit Leiden Medisch Centrum (Leiden), Radboud University Medisch Centrum (Nijmegen), Academisch Medisch Centrum (Amsterdam), and Erasmus Medisch Centrum (Rotterdam). Of these institutions, practitioners from three institutions were unable to participate or did not respond to my emails. All practitioners from one institution refused to participate in the project.

In total, I was able to secure interviews with three practitioners from two medical institutions: a pediatric endocrinologist (Institution A), pediatric urologist (Institution B), and an ethicist (Institution B). Both the pediatric endocrinologist and pediatric urologist were asked questions about their institution's specific treatment protocols for DSD as well as their personal perspectives. Although the ethicist I interviewed is affiliated with a medical center, his interview was less directly focused on specific institutional protocol. The participants' names and institutions will be kept anonymous in this report as indicated in their consent agreement. This decision was made in hopes of allowing for more open and honest responses from the participants without fear of negative backlash for themselves or their institution.

The second group of participants for this research project were individuals who have been diagnosed with a disorder of sexual development (DSD). The multitude and diversity of intersex conditions can result in more divergent interactions between affected individuals and the medical community. Because of this, I was interested in interviewing two groups of people: those who have been diagnosed with Congenital Adrenal Hyperplasia (CAH) and those who have been diagnosed with Klinefelter's Syndrome. There are three ways in which these groups differ that specifically interested me in regards to their experiences and perspectives:

(1) Gender: Almost all individuals with Klinefelter's Syndrome are considered male on the basis of the presence of a Y chromosome, the most common karyotype for Klinefelter's being 47, XXY. In terms of CAH, however, affected individuals can be designated female or male at birth based on whether the are XX or XY. Unlike in cases of Klinefelter's, CAH is not characterized by a deviation from standard sex chromosome karyotypes and instead is the result of malfunctioning of enzymatic function. Thus, interviewing both men with Klinefelter's and men and women with CAH could reveal

how the experience of intersex individuals differ on the basis of their assigned gender.

(2) Age of diagnosis: Although earlier diagnosis has become more common in the past several years because of improved medical technology, most individuals who are aware that they have Klinefelter's are not diagnosed with the condition until after pubertal onset, often during adulthood. Individuals with CAH, however, are often diagnosed during infancy (in more severe cases, immediately after birth). The way intersex individuals have interacted with the medical community would largely differ based on their age of diagnosis, as could their self-perception.

(3) Treatment received: Except in some cases of hypospadias and gynecomastia, most men with Klinefelter's Syndrome do not receive surgical treatment for their condition. On the other hand, many girls with CAH who are born with ambiguous genitalia undergo SRS during infancy, childhood, and/or adolescence. Perspectives on medical treatment could largely differ between these two groups on the basis of this factor alone.

To find participants, I contacted two organizations suggested on the website of the Nederlands Netwerk Intersekse/DSD: the Bijniervereniging NVACP and the Nederlandse Klinefelter Vereniging. The former is an organization for individuals affected by adrenal disorders, including CAH. The latter is a support group for men with Klinefelter's as well as their partners and families. I did not receive a response from Bijniervereniging NVACP. I communicated via email for several weeks with the Nederlandse Klinefelter Vereniging (NKV) about my research and their organization. I was invited to attend an event of theirs to interact with their members, to achieve a better understanding of their group's objectives, and to explain my research. With the assistance of NKV organizers, I was able to interview four men from the organization for this study. As with practitioner's, the identities of the men will remain anonymous (provided names are pseudonyms) and any of their identifying information will be changed in this report.

Interviews

For this study, I performed personal interviews with the seven participants in person or via Skype at the interviewees' convenience. Participants were informed of privacy, anonymity, and confidentiality protocol before the start of the interview and provided their written or verbal consent. Interviews occurred during one session and lasted for the duration of thirty to sixty

minutes. Interviews differed on the basis of the participant group.[3] In terms of practitioners, the pediatric endocrinology and pediatric urologist were first asked questions about their experience as a medical provider as well as their institution's protocol for the treatment of DSD. Subsequently, they were asked about their perspectives on these treatment policies at their institution, Dutch policies and culture, and their personal opinions on sex and gender. The questions asked to the ethicist deviated from those asked to medical professionals and were more centered on the philosophical concerns involved in DSD management and protocol development. The men from NKV that I interviewed were asked about their personal experience having Klinefelter's Syndrome, particularly in regards to their interaction with the medical community. They were asked questions about their opinions about the medical management of DSD.

Positionality and Bias

I am a third-year student at Muhlenberg College (Allentown, Pennsylvania) majoring in Gender and Sexuality Studies and Philosophy/Political Thought. For the past several months, I have been living and studying in Amsterdam through the School for International Training (SIT). I have only come to learn about the Netherlands within a limited time frame, and thus my broader observations about Dutch culture must be understood with this in mind. Being an American researcher in some ways maintains my position as observer in spite of efforts to become participatory in Dutch culture because of the way my consciousness and perceptions have been fundamentally shaped by my own cultural context. In some ways, however, this is a benefit because it is often the case that "outsiders" can be more observant about a given culture than it's own members, who themselves are by it so ingrained and sculpted. My limited linguistic understanding of Dutch as well as the fact that the interviews for my research were performed in English have had an effect on communication with my participants and my interpretation of their remarks. In this regard, while included, I am being cautious in analyzing certain rhetorical choices made by the participants, such as the use of certain words, because they may be less indicative of a more subliminal opinion and more the result of the language barrier.

One of the main factors in regards to my positionality that has an effect on myself as a researcher is my own sexual and gender identity. In terms of my biological sex, I am a dyadic (or non-intersex) female. Thus, in interviewing men with Klinefelter's, it has been extremely important to me to gain the trust of my participants, allowing them to share openly with me their

3 Corresponding interview guides for these groups can be found in the Appendix IV of this report.

stories without a fear of exploitation or objectification. Although I am female and often read as a woman, I identify as genderfluid and am a part of the queer and trans/GNC communities. As my own gender identity is non-binary, my theoretical framework is largely deconstructive. Neither entirely essentialist nor social constructivist, I believe gender, sexuality, and biological sex are separate though interrelated identities that are spectral as opposed to binary. I strongly identify as an activist, specifically working in queer and intersex advocacy. In terms of the latter, I align with patient-centered approaches to medical care, including the delay of cosmetic genital surgery until the patient can verbally consent. As there has historically been tension between certain groups of the activist and medical communities, I recognize that there may be a hesitance of practitioners in participating in this study. While it is of course impossible to isolate my identity as an advocate from myself as a person, especially in interviewing practitioners, I aim to be conscious of any potential biases that I may have in regards to particular forms of medical treatment, looking not at all to judge the professionals themselves, but instead to gain a critical understanding of current medical discourse and protocol.

Language

In the Consensus Statement of 2006, it was suggested that there be a shift in nomenclature used to describe what had been understood largely as intersex conditions:

> Terms such as 'intersex,' 'pseudohermaphroditism,' 'hermaphroditism,' 'sex reversal,' and gender-based diagnostic labels are particularly controversial. There terms are perceived as potentially pejorative by patients and can be confusing to pracitioners and parents alike. We propose the term "disorders of sex development" (DSD), as defined by congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical (Lee et. al, e488).

Correspondingly, the use of the term disorders of sex development (DSD) has become popularized, particularly within the medical context. Still, there remains a debate as to whether or not the term DSD is appropriate. Critiques of the term specifically question the use of the word "disorder" and whether or not this implicitly medicalizes individuals' identities. For example, intersex activist and scholar Morgan Holmes claims that the label DSD "has not met its stated objective of destigmatizing the 'intersex' label... but instead produces "a problematic understanding of morphological variation as disease" (Holmes, 2009). This conversation can be related to a similar debate existing within trans* discourse surrounding the use of the terms "gender identity disorder" (GID) or "gender dysphoria" within the medical context, with many

claiming their use is a pathologization of individuals' gender identities. Recognizing both sides of the debate over the terminology of DSD, the Intersex Society of North America (ISNA) offers their own position:

> Over the past year we have begun to use the term "disorders of sex development," or DSD, in place of "intersex" in these [medical] contexts. It is not our intention to make intersex an entirely medical issue. But we are addressing people working in a medical context. We have found that the word DSD is much less charged than "intersex," and that it makes our message of patient-centered care much more accessible to parents and doctors. Our aim is to meet them where they are. Intersex itself is not a disorder, rather a variation. But Congenital Adrenal Hyperplasia, for instance, is an inherited disorder affecting adrenal function... "Disorder" refers to the underlying cause, not intersexuality itself, and certainly not the whole person." (ISNA, 2008).

In other words, ISNA supports using the term "DSD," specifically in the medical context, as this nomenclature allows for a fundamental degree of mutual understanding between advocacy and medical communities. The use of the term is an action of providing access to appropriate medical care. They claim that there is a degree to which conditions such as CAH, AIS, and Klinefelter's Syndrome are forms of disorders that require medical intervention. They qualify, however, that this does not mean the identity of having a variant biological sex itself should be pathologized. It can be inferred from this claim and that of other thinkers such as Holmes that the experience or political placement of some individuals with a DSD could be more aptly understood using the term "intersex."

In regards to my own study, I have debated extensively over whether or not to use the term "intersex" or "disorders of sexual development," in my report. This decision became even more complicated when I discovered that the use of DSD is even more popularized in the Dutch context than in American discourse, with some of my interviewees having not even have been familiar with the word "intersex." That being said, I have decided to use an approach similar to that of the ISNA, using both of the terms not interchangeably but side-by-side. I will be using the term "disorders of sexual development" in discussing matters more specifically related to medical protocol, including my interviews with medical professionals. I will also use "DSD" in instances where the men I interviewed used the term. At the same time, however, in the parts of my analysis focusing more on identity and body politics, I will also use the terms "intersex individuals" and "intersex conditions." Of course, I recognize from the beginning that this method may have its own problematic features. First of all, not all individuals with DSDs identify as being intersex. Secondly, there is no strict binary existing between one's experience

inside and outside the medical context. Thus, this approach is still in need of development. Therefore, I offer apologies if the use of my terminology is perceived as offensive or inaccurate at any time during this paper. While imperfect, I find it the most appropriate method to use at this point.

Literature Review

I was unable to locate any previous literature specifically or even distantly focused on the impact of medical treatment on the psychosocial development of individuals with Klinefelter's Syndrome. A 2004 report by Geschwind and Dykens claims that while there are reports pertaining to the linguistic and cognitive development of individual's with Klinefelter's, there is a

significant lack of non-anecdotal data on their social and emotional development. The researchers include a pilot study of 15 subjects between the ages of 16 and 64 who had been diagnosed with Klinefelter's Syndrome, focusing on the components of this underdeveloped data. They utilized three measures: (1) the Reiss Profile of Fundamental Goals to assess motivations, (2) the Young Adult Self-Report to examine internalization of emotional symptoms and externalization of behavioral problems, and (3) the Thematic Apperception Test to identify internalized difficulties. Results indicate that subjects share dominating motivations of family issues and social contact, with minimal concern towards social prestige, independence, the desire to seek vengeance, and the avoidance of physical pain. The frequency of the subjects internalizing symptoms was significantly higher than the frequency of externalizing behaviors. Furthermore, internalized difficulties were identified as romantic conflict (71%), death or loss (71%), sadness or emotional upset (64%), family conflict (57%), empathy with others (50%), shirking responsibilities (50%) and exploitation/trauma (50%) (Geschwind and Dykens, 2004). In their report, Geschwind and Dykens did not include a more extensive analysis on potential causes of their results. In relation to my study, several specific features are of considerable interest. The strong emphasis on familial and social (excluding prestige) concerns may be the subjects' response to the experience of disclosing his Klinefelter's Syndrome to family and/or peers; it could also be a result of feeling "different" from peers at different points in life. More relevant to my core research question would be an analysis of the high rate of internalized feelings of exploitation and trauma by men with Klinefelter's Syndrome and whether or not these are at all derived from their experience with medical treatment.

Another report that highlights the psychosocial development of individuals with Klinefelter's Syndrome is that of Diamond and Watson (2004). In addition to describing various physical attributes of the condition, the authors also make several claims regarding learning and personality considerations. In regards to learning, they claim that there is an increased risk of learning and behavioral disorders in boys with Klinefelter's Syndrome, however they claim that these tend to be minor and that individuals with Klinefelter's tend to have an average to above-average IQ. Diamond and Watson characterize most boys with Klinefelter's as "shy, passive, quiet, immature, and dependent," and state that the onset of puberty may result in "low self-esteem, anger, frustration, or depression," and less sexual interest than their peers. They explain that these boys score significantly lower on the masculinity scale on the Bern Sex Role Inventory

and often perceived themselves as being less masculine. They also claim, however, that the frequency of gender change in men with Klinefelter's is unknown. There is also no demonstrated significant increase in the prevalence of homosexuality in men with Klinefelter's as had been suggested by earlier studies. (Diamond and Watson, 2004). Again, Diamond and Watson's report does not look into the potential causes of these psychosocial features in terms of a posteriori or experiential influence. Instead, they only focus on potential biological causes, in keeping with their largely essentialist approach to psychosexual development.

More reports discussed the psychological concerns of the parents than those of individual's with Klinefelter's Syndrome. One such report was a qualitative study of fifteen mothers performed by Bourke et al. (2014). While focused on parents, this report includes useful information about the treatment of Klinefelter's that could also have a significant impact on patients. In relation to the efficacy of medical care, all parents reported having received incorrect, false, outdated, or only "worst case scenario" information from their health-care professional (HPC) (Bourke et al., 2014. Similarly, another report about parental counseling by Girardin and Van Vliet explains that it is important to inform parents that there is a lot of misinformation available on the Internet that the stereotypes men with Klinfelter's as mentally retarded and less masculine, all of which could have a negative impact on their perception of their child (Girardin and Van Vliet, 2011). In terms of parental response, subjects described that, after initial relief, they experienced concern, confusion, sadness, and depression as they struggled to grasp the ramifications that this diagnosis could have on their child, specifically in terms of sexuality, masculinity, and fertility (Bourke et al., 2014). Both of these reports are interesting when one considers the effects that misinformation and increased parental concern about these social factors could have on children with Klinefelter's. The researchers suggest that increased training about and awareness of Klinefelter's Syndrome by healthcare practitioners, specifically regarding its non-physical features, could improve the process of both diagnosis and post-diagnostic counseling for parents (Bourke et al., 2014).

Most articles about the medical care of Klinefelter's Syndrome focus on the physiological efficacy of treatment. In discussing age of diagnosis, however, some also include psychosocial analysis. In their article on the advantages of early diagnosis, Radicioni et al. (2010) do focus primarily on physical and cognitive concerns, however they also consider emotional and social concerns. The researchers delineate the positive aspects of diagnosis and treatment on the basis

of age level: prenatal, neonatal, infancy, childhood, puberty, and adulthood. They conclude that earlier diagnosis is associated with the greatest amount of benefits, as it allows for early intervention in responding to potential physiological, cognitive, and psychosocial concerns. Currently, the rate of early diagnosis of Klinefelter's Syndrome is extremely low, and about 75% of individuals are never diagnosed at all. In this regard, the researchers suggest that medical practitioners must have increased awareness of the various symptoms of Klinefelter's and associated diagnostic strategies. This applies not only to specialists (i.e. pediatricians, gynecologists, and fertility specialists), but also to general practitioners who may interface with affected individuals (Radicioni et al., 2010). In addition to the benefits of diagnosis, however, the study also discusses some potential complications that could arise. Prenatal diagnosis, for instance, is currently associated with an extremely high rate of pregnancy termination (70%) that is often linked to the parent's social and cultural background, local laws, and the genetic counseling strategy (Radicioni et al., 2010).

A 2011 report by Herlihy et al. discusses diagnostic ages with slightly more emphasis on psychosocial concerns. Researchers claim that while diagnosis of Klinefelter's Syndrome could result in some immediate benefits for infants and children, it could oppositely have potentially harmful effects on the psychosocial development of infants and teenagers. For infants, the study suggests that diagnosis could increase parental anxiety and hypersensitivity, in turn negatively affecting the child. During the teenage years, which are sighted as already "tumultuous," diagnosis could result in lower self-esteem or sense of identity as well as social ramifications such as bullying, stigmatization, and discrimination (Herlihy et al., 2011).

While not specifically discussing a case of Klinefelter's Syndrome, a Dutch study by Slijper et al. (1998) analyzes the psychological development of 59 children being treated at Sophia Children's Hospital who are "female pseudohermaphrodites," "male pseudohermaphrodies," or "true hermaphrodites." In discussing psychological concerns, the report largely focuses on issues of psychosexual development, focally gender identity and gender role development (Slijper et al., 1998). Not directly analysed were other psychological and emotional concerns, such as conduct disorder, anxiety disorders, and depression in children who were not diagnosed with gender identity disorder (GID) or characterized as having deviant gender role behavior. Statistically, 39% of the children developed a severe general psychopathy, and of this subgroup, only 53% of patients and their families received immediate counseling

after diagnosis. The researchers conclude that immediate psychological care may be crucial to proper psychological development in intersex children (Slijper et al., 1998).

Another Dutch report reflecting on psychosocial and psychosexual aspects of DSD was composed by Cohen-Kettenis (2010). The researcher highlights gender assignment, information management and communication, timing of medical interventions, consequences of surgery, and sexuality as core concerns in these cases. Cohen-Kettenis offers several suggestions to address these issues:

> (1) gender assignment: Mental health evaluation of parents is crucial to understand their ability to adapt to the diagnosis of their child and therefore act in his or her best interest. In this regard, there is currently a lack of screening tools, especially when considering the complex influence of parental, religious, and cultural factors. Additionally, DSD-specific programs of problem-solving skills for psychologists to provide parents with should be developed (Cohen-Kettenis, 2010).
>
> (2) information management: Current systems of disclosure methods for parents, children, and other involved individuals should be reevaluated with an accentuation on the impact of "the effects of timing, type of information (and potential interaction of the two), the best way of conveying information [,]... the influence of cultural, family and child..." and other contextual factors (Cohen-Kettenis, 2010).
>
> (3) psychosocial and timing aspects of surgery: Sexual consequences and goals of surgery should be discussed. Additionally, better educational materials, to be used in conjunction with counseling, should be provided to families. The development of systematic decision-making aids for DSD would be valuable. Finally, the efficacy of support groups in making surgical decisions should be explored in future research (Cohen-Kettenis, 2010).
>
> (4) sexuality: Because of an increased risk of sexuality-related problems, children with DSD require both medical and sexuality education in conjunction with private consultation of these matters with a mental health clinician (Cohen-Kettenis, 2010).

In summation, Cohen-Kettenis proposes that the development of DSD-specific education materials and treatment methods is important in the advancement of medical best practices for these conditions. Additionally, she claims that there must be more research performed on the psychological and social effects that medical treatment has on individuals with DSD (Cohen-

Kettenis, 2010). This last suggestion is fundamental to my research project.

A 2004 report by Creighton and Liao presents a more nuanced view on the subject of sexual reassignment surgery on intersex individuals. Recognizing that SRS is a key component to the dominant medical framework for the treatment of certain forms of DSD, the authors investigate some of the potential consequences of these procedures. In terms of satisfaction, they reference one report that claims 28-46% of vaginoplasty patients have unsatisfactory or poor cosmetic results not in keeping with their expectations. The authors do claim, however, that this question is not largely investigated. Perhaps more importantly, in terms of physical consequence, another case study found that 36-100% of women experience vaginal stenosis after vaginoplasty. Creighton and Liao also report that clitoral surgery carries a risk of damaging the neuroanatomy of the clitoris in a way could diminish sexual function, however they state that it is very difficult to research the sexological impacts of these procedures because of the discomfort many patients have in discussing these matters. Finally, the authors cite a controversial discussion of the psychological impact of SRS infancy. Although some reports state that patients who have received adequate medical and mental health care have "relatively positive 'personality functioning,'" other studies conclude that these procedures can have significantly negative effects on psychosocial development (Creighton and Liao, 2004).

Results and Discussion

Approach and Perspectives of Medical Practitioners

Appendix I is a table briefly juxtaposing the results of my interviews with two of the three practitioners in regards to treatment protocol and practice at their institutions.[4] In this analysis,

4 In addition to a pediatric endocrinologist and pediatric urologist, an ethicist was also interviewed. As we did not

practitioners will be referred to by their titles: pediatric endocrinology (Institution A), pediatric urologist (Institution B), and ethicist (Institution B). There are five key themes: (1) intra- and inter-institutional cooperation, (2) protocol for surgical treatment, (3) protocol for prenatal diagnosis and treatment, (4) consent, disclosure, and agency, and (5) perspectives on sex and gender in the Dutch context.

Intra- and inter-institutional cooperation

In keeping with the guidelines of the Consensus Statement of 2006, both institutions of the practitioners interviewed have a multidisciplinary DSD treatment team. In terms of included positions, both teams are composed of similar groups of practitioners: endocrinologists, urologists, gynecologists, geneticists, and psychologists. The pediatric urologist interviewed mentioned that an ethicist as well as a trained set of nursing staff are also directly involved at her institution. In his interview, the ethicist affiliated with Institution B described his role as being a source of reflexive guidance for medical professionals in protocol and treatment decision-making: "I'm not developing ethics as something which is added to normal care practice. I'm going- I'm trying to uh make transparent what is already there for ethical choices in order to uh let's say empower the professions to-to make their own ethical decisions (Anonymous, personal communication, April 30, 2014)." In other words, the ethicist does not perceive his role as didactic, but as more impartial.

When asked about the benefits of having a multidisciplinary team, the pediatric endocrinologist describes the system as being more functional when specialists are able to focus in on an aspect of treatment related to their expertise, all while maintaining communication about a patient with the other involved practitioners. Similarly, the pediatric urologist highlights communication as central to the functioning of the DSD treatment team: "We have a good team. We're uh- we're able to reach each other easily. We have um regular meetings um to discuss the patients and to discuss um like research or um future aspects, ethics, uh on DSD" (Anonymous, personal communication, April 25, 2015). Interestingly, both practitioners describe this beneficial communication as not extending beyond their individual medical centers. When asked about inter-institutional interaction, the pediatric endocrinologist claimed that discussions are mostly confined within his medical center, with the occasional exception: "So actually we do

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discuss much about the ethicist's institution's protocol, but rather broader ethical and philosophical concerns, his responses are not included in this table but will instead be incorporated into the analysis portion of this discussion.

the most ourselves, and sometimes we ask experience from elsewhere, eh? Just to talk things through, if you can imagine... Very, very difficult cases, eh, we asked him [an external specialist] also sometimes for his expertness" (Anonymous, personal correspondence, April 4, 2014). The pediatric urologist stated that, while it is slowly improving, there is not enough interaction between different hospitals. While both practitioners had a very positive view of their individual institution's DSD treatment protocol, she claimed that inter-institutional cooperation is the component of current practice that needs the most development: "...we think that in a small country like the Netherlands, it should be possible to make like more national protocols. As it is a multidisciplinary field, it's not so easy to organize um good communication between the groups... even if we don't agree on every point, I don't think that's a problem. We can disagree but still uh I think we should um- have some- a little bit more cooperation" (Anonymous, personal communication, April 25, 2015). Thus, while the implementation of a multidisciplinary team specialized in DSD treatment appears to have been successful at both institutions, further development is needed in fostering inter-institutional communication and cooperation.

Surgical Treatment

The issue of neonatal genital surgery is at the heart of discourse about intersex/DSD, largely because of its epistemological, ontological, and ethical implications, the last of which will be expanded upon in the section on consent, disclosure, and agency. Institutions A and B had divergent policies towards the use of surgical treatment, specifically on girls with DSD. According to the pediatric endocrinologist, approaches to surgery differ depending on whether the child is assigned male or female. In the case of the former, surgery is recommended when the child is younger: "If you have for instance um a male infant and it's under-virilized, eh, so it's underdeveloped, of course you want to do it [surgery] rather early. Because, um, it has to look normal of course when a child goes to school and yeah it's a good age to do surgery" (Anonymous, personal correspondence, April 4, 2014). Similarly, in cases of hypospadias[5], the pediatric urologist always operates to improve function. In regards to girls, the decision making process is much more complicated, and Institutions A and B have greatly different policies, largely based on divergent medical evidence. The pediatric endocrinologist, in most instances, does not recommend surgery for young girls because of the potential risk: " If you have for

5 Hypospadias is when the urethra does not run through the tip of the penis but rather just below the tip or along the shaft (Fausto-Sterling 52).

instance a child, a girl, eh, actual who is virilized be- mostly because congenital adrenal hyperplasia. Then we say well it is intersex but in fact it's cliteromegaly what you see. We want um we prefer not to operate it too early, because um you damage more than you do good to the child...the nerves in the genital area, you damage them." (Anonymous, personal correspondence, April 4, 2014). Additionally, he claims that pubertal onset alone may "correct" some of the differences, making surgery ultimately unnecessary. The pediatric urologist holds an opposing opinion, claiming that it is medically and psychologically more beneficial for the child to undergo surgery between 2-6 months: "They heal better. They have less complications... if you operate before one and a half years, then it seems that afterwards, when they're happy, when they have enough painkillers and they get some food, then they're fine and don't have bad memories about the surgery" (Anonymous, personal communication, April 25, 2015). She claims that a lot of evidence of surgery being physiologically harmful is based on earlier techniques, not those that are being used currently, and that the results of her surgeries will be clear in another 20 to 30 years. At Institution B, she claims that surgery is only not performed during infancy on girls if there is any question in regards to gender assignment, as with Partial Androgen Insensitivity Syndrome (PAIS).

In speaking about boys, the pediatric endocrinologist's language of the normalization of genitalia is here clearly linked to public space (i.e. the hypersexualized spaces of bathrooms or locker rooms[6]), instances where a child's penis may be seen by others and therefore judged. Similarly, one can consider social instances in which a girl or woman's sexual anatomy becomes critiqued, often in relation to (penetrative) sexual intercourse. An emphasis on public perception as opposed to private or self-perception suggests the way in which the interpretations of our personal bodies are extremely linked to social understandings of these bodies. In order to be perceived as abnormal, there must be a standard external to the self that dictates normalcy. Here, this standard operates at the permeable barrier of the medical institution (i.e. constructed anatomical edicts on normal genitalia and its deviances) and cultural understandings. This standard of "normal" can be externally enforced, but can also become internalized by the individual, as they begin to see their body as unusual without being told so in a specific instance. In addition to imposed regulation (as with surgery), he or she can begin to self-regulate the body

6 The notion of the men's bathroom or locker room as hypersexualized is in reference to the article "Female Masculinity" by Linda Alcoff.

in an attempt to achieve the norm and therefore access social security. Although other body parts of course are engaged in a similar dialectical relationship, there is a conflation of genitalia with gender, perceived masculinity or femininity, that results in an increased social, and often personal, pressure to "look normal."

In one of her articles, Roen approaches body deviance through a queer lens, making the following claim about surgical "correction" of intersex bodies:

> A queer reading of such surgical practices would suggest that the binary framework is a fantasy that can never be fully attained and that, as long as surgeons seek to (re)produce the reality of binary sexes, they inevitably keep producing queer embodied subjects. As Holmes writes, the irony of intersex surgery is that, rather than eliminating abnormality, such surgery *creates*...abnormality" (Roen, 2008).

In other words, in creating medical standards of "normal" genitalia on the basis of a binary understanding of sex and encouraging the alteration of such bodies to meet these standards, medical discourse produces deviance as opposed to recognizing natural spectral variance. Of course, such critique is not meant at all to demonize medical practitioners who provide genital surgeries. As the interviews reflect, central to the decision-making of both the pediatric endocrinologist and pediatric urologist is a concern as to what is in the best interest of the patient. Rather, this critique is intended to challenge broader social and institutional systems that structure our understandings of the sexed body in a way that make cosmetic surgeries appear necessary.

Prenatal Diagnosis/Treatment

In spite of their differing policies on surgical treatment, both Institutions A and B offer prenatal diagnosis and treatment of certain DSDs, both of which have been associated with certain controversies in intersex discourse. While prenatal diagnosis is often cited as being beneficial, allowing both practitioners and parents to prepare potential medical and psychological care before birth, it has also been associated with higher rates of pregnancy termination. In his interview, the ethicist discussed the proposed correlation between Klinefelter's Syndrome and a higher abortion rate:

> Uh that is assumed, but it's not clear yet in the Netherlands. I think also in other countries from Europe from the figures. But it is assumed that hear after 8 or 10 weeks of pregnancy that your child is healthy, but that it is Klinefelter's or will be not fertile, then lots of people say, oh oh I don't know what it is but take it away then. And that is of course something which the DSD community says, well *(pauses)* that's not *(pauses)* fair to the unborn child, because people should have knowledge about also how it is to be a Klinefelter. Uh what kinds of symptoms they might have (Anonymous, personal

communication, April 30, 2014).

There are several ethical implications that come into question. While of course in no way questioning a woman's right to choose or judging parents for making the difficult decision to terminate a pregnancy, the high rate of abortion associated with conditions such as Klinefelter's more broadly points to a way in which our society values certain bodies as more viable than others. The ethicist's observations also demonstrates the way in which fertility is highly regarded in such a way that some parents view it better for a child not to exist at all than to be a man unable to naturally produce children. Often, parents are not fully informed about Klinefelter's Syndrome or are presented with stigmatizing or aggrandized symptomatic information (Girardin and Van Vliet, 2010). What becomes evident then is that it is extremely necessary to provide more accurate information and counseling to parents whose child receives this prenatal diagnosis in order to equip them with the knowledge and tools necessary for decision-making. The effect of the social mentality behind the high abortion rate on an individual with Klinefelter's will be discussed later in this analysis.[7]

In terms of prenatal treatment, both Institutions A and B offer dexamethasome treatment, in which an expecting mother whose fetus may be at risk for CAH is administered the steroid dexamethasome to prevent potential masculinization of female genitalia (the treatment is discontinued if the child is discovered to be male)(Fausto-Sterling, 2000). Dexamethasome treatment is controversial because it is associated with several medical risks; in addition to a 1-2% increased chance of miscarriage, mothers may "retain fluids, gain a lot of extra weight, develop hypertension and diabetes, have increased an permanent scarring along abdominal lines, grow extra facial hair, and become more emotion"... and, for the fetus, negative effects may be "failure to thrive and delayed psychomotor development... [and] behavioral problems" (Fausto-Sterling, 2000). In spite of this, the pediatric endocrinologist states that the treatment is still offered at the request of informed parents because the benefits may outweigh the risks: "if she [the child] is severely virilized, it's quite a burden. So I think uh with respect to that, the uh benefits outweigh the risk, eh? It's- *(pauses)* I think it's difficult to deal with for many parents. Um and if you have yeah some side effect it it it will be excepted. Or it will be acceptable. Of course there are benefits and risks, and it's up to the parents eh to make the final decision" (Anonymous, personal correspondence, April 4, 2014). The fact that masculinized genitalia is

7 See the "Self-Perception" section beginning on page 32

seen as a potentially greater problem that some of the health complications listed again reifies the fact that Western culture is so intensely rooted in a binary system of sex and gender. Institution B offers dexamethasome treatment as well, but the pediatric urologist claims that this may be becoming less necessary as surgical technology improves: "our pediatric endocrinologist also has some doubt about it because afterwards...she says the results of surgery so- well most of the times, uh do we need to um take the risk of the use of dexamethasome in pregnancy? So um, we don't always do it" (Anonymous, personal communication, April 25, 2015).

Consent, Disclosure, Agency

The issues of consent, disclosure, and agency are multifaceted and linked to the extent to which parents and patients are involved in medical decision making processes. According to the Consensus Statement of 2006, it is important that parents are informed throughout the process about all aspects of their child's medical care and that they are integral in communicating with doctors as to which treatments are desired. Children should be informed about their condition in a step-wise manner as their age allows, and as they get older, they too should be involved in decision-making (Lee et al., 2006). Both the pediatric endocrinologist and pediatric urologist speak of the significant involvement of parents in decision-making processes at their institutions. Additionally, although she still advocates surgery during infancy, the latter discusses the stress that she personally puts on listening to the child's wishes when they are at a point where they can verbalize them:

> ...we do have rules in the Netherlands for that [consent]. And uh like there's um before 12 it's the parents that decide, and in between 12 and 16, they need to give both their consent. And that's espec- that's um if you propose a treatment. Some kind of treatment. And after 16, children are allowed to decide for themselves even if the parents do not agree. Um and we have a culture in which everybody can say what they want to say. So I take a child very seriously also when they are younger than 12 years old (Anonymous, personal communication, April 25, 2015).

Specifically, she cites the case of a child who was assigned male at birth (in China) who says that she is a girl and wishes to undergo sexual reassignment surgery: "...the child has a question to me that I need to make her a girl. And I find that strong wish of a child very important, so I'm not going to postpone it until she is 18. Because she made like- she explained [to] her mother with a movement like it- it needs to get off. So she- she really wants to have her physical appearance match with what she wants- what she feels she is" (Anonymous, personal communication, April 25, 2015).

The pediatric endocrinologist says that the issue of patient consent in childhood is becoming a more important issue, but that it is difficult because of the strong influence of parents in decision making, particularly before the patient is able to verbalize his or her desires: "when a child is born, eh you counsel the parents, and not the child. And um hopefully if you counsel, you are always thinking about what is best to the child, but there is a discrepancy because what is the best for the child, might not be the best for the parents, and they have to raise the child" (Anonymous, personal correspondence, April 4, 2014). He continues to say that what is medically less desirable may in fact ultimately be more psychological beneficial for the child because of his or he parents:

> "we have a few cases that surgery has been done even though it's- it's damaging. But you have to keep in mind that the parents have to deal with the child, and it could be better for the parents to have a child where you don't see anymore this as a neonate already. And yeah yeah of course is that bad for the child? Well maybe not. Because the child has to deal with his parents *chuckles* You do you see what I mean? Because it's quite complex of course (Anonymous, personal correspondence, April 4, 2014).

The major ethical concern underlying issues of consent and disclosure for patients is the ability to have agency over decisions related to one's body. According to Wilson and Reiner, "Although parents may give consent for surgery, there is increasing movement toward obtaining a child's assent to procedures, particularly those which, like most genital "reconstructive" procedures, are elective from a medical viewpoint. This means delaying surgery until we can take into account the affected individual's determination of his or her own gender" (Wilson and Reiner, 1999). Expanding upon the last line, it is not merely a matter of which gender the child ultimately identifies with, but how they would like to express their gender through their body. A child who identifies as a girl, for example, may not wish to undergo vaginoplasty or clitoral reduction, again challenging the general social notions of physical sex's relation to gender. Many theorists describe that performing surgeries on a child before he or she can consent sometimes causes psychological distress later in life: "Actions regarded as repair by doctors and parents are experienced as damage by the recipient. The mistrust and shame created by parental and medical deception is a further source of trauma" (Williams, 469). This dialogue, according to the ethicist, runs alongside that of parental agency:

> ...the problem of course is should we wait until the child can have their own consent. And then everything has to be checked whether or not uh dangers for infection or the outgrow of the genitals or something else, which might- which might occur all kinds of trauma in the child when it grows up. Yeah. And when all those things have checked and

> it is possible for a child to grow up as a DS- or an intersexed child in this case, then uh the discussion is, do we allow the parents or not to have it their way because they are in charge of the child (Anonymous, personal communication, April 30, 2015).

Thus, while the Consensus Statement of 2006 has been largely successful in incorporating parents, and to some extent patients, into the decision-making process, as opposed to the predominately practitioner-based protocol of the concealment-centered model, there is still more development needed in constructing institutional policies that more directly consider the multifaceted needs of the patient not solely in terms of their parent's decision-making. This could perhaps be achieved by incorporating the more patient-centered approaches proposed by "Clinical Guidelines for the Management of Disorders of Sex Development in Childhood," specifically the delay any elective or cosmetic treatments until the patient is old enough to provide his or her consent.

Sex and Gender in the Dutch Context

Last year (2013), Germany implemented a policy allowing infants to be registered as having an "indeterminate" sex, as opposed to being assigned female or male at birth. Although they are the first European country to do so, several others (Australia, Bangladesh, India, Nepal. and New Zealand) already have enacted similar legal measures to recognize the "third sex" (BBC, 2013). All three of the practitioners interviewed discussed their opinions on whether or not a similar policy could be implemented in the Netherlands and whether or not it would be beneficial. The pediatric endocrinologist had a negative opinion of these laws, believing that they are not a good way to manage gender ambiguity:

> I'd rather not have that, because I think it's- it's difficult to have a third gender. You um you have to assign a gender, just to make sure that a child is properly raised, eh. You have to treat a child as a boy or a girl and not as something else. That's-that's my opinion. And I think that it is even better to be wrong about the gender you assigned than to have a completely different gender (Anonymous, personal correspondence, April 4, 2014).

This response reinforces the notion of a sex and gender binary, although the practitioner later claimed, less traditionally, that it was not necessary for a person's gender to "match" what is normally considered the appropriate genitalia (i.e. not all boys must have penises and not all girls must have vulvas) and that gender roles and expression can be more fluid. More conditionally, the pediatric urologist stated that it is impossible to know at this time if it would be possible or beneficial to have a "third sex" category in the Netherlands, as it has yet to be tried. She related the introduction of another sex or gender option to the process of "normalizing" gay identity:

> When I grow up, I didn't know anyone who had two mothers, but my daughter was in a class with a child who had two mothers. And when you grow up in surrounding[s] where that's very normal, then, who cares? And so it could be that after a while, when everyone is used to a third sex, that everyone says, oh no that's not a boy or a girl, that's um, well give it a name. And then it could be that it's- that well it's accepted. I think now, in this time, people are not ready for it yet. I think the child would be unhappy (Anonymous, personal correspondence, April 25, 2014).

Such a response naturally leads to the consideration of how a "third sex" could be incorporated and normalized without putting children at psychological, social, and even physical risk, a question that at this time has no clear answer. Rather, it highlights the tense relationship between legal recognition and cultural security. Finally, the ethicist commented that there is no a priori reason why a third sex could not and should not be recognized:

> Most of these problems are quite, from a biological point of view, they are um uh the-the they are you should not be surprised for them to occur. Because the difference between a male person and let's say a female person is not 0 1 or 1 0 *uses hands to indicate a binary*. It is a continuum. So within the continuum, all kinds of different varieties could by nature um uh it's, I think within our society, it is still a problem that we try to see that as either or. You are a man or you are a woman. And that was- that was the philosophical problem which I started already in the early 90s, in order to say it's strange that people say, well I'm not this or that but I'm somewhere in between are not listened to, because they respond to their biological uh physiological behavior... But society, the law, and the like are saying you are either this or you are this. There's nothing in between. And that social structure duality I think is one of the big problems (Anonymous, personal communication, April 30, 2015).

He agrees that it could be a difficult policy to enact because the Netherlands is not as progressive as it believes it is in regards to matters of gender and sexuality: "...the Dutch culture even more than the German culture, when it comes to these matters [is] quite conservative. And uh we do not like to talk about these kinds of things. And there's um there's not so much openness. And uh we'd rather talk about rights but not about feelings" (Anonymous, personal communication, April 30, 2015). Thus, when one considers these questions, he believes that cultural context is crucial to philosophical understanding.

The pediatric urologist earlier had claimed that Dutch culture was characterized by openness, having effect on current DSD management in a way that allowed for dialogue. This greatly contrasts with the ethicist's explanation. When asked if a change in medical discourse could be a source of a paradigm shift in terms of perceptions of the body, he responded that this change would first have to occur in culture. Mostly, the ethicist cites the inability of the Netherlands to address the various psychosocial concerns of intersex individuals as stemming

from a very logistical, legalistic Dutch approach to problem-solving as opposed to one that is more ethical in the care-focused sense:

> But it is the fact that Dutch people like to make a legal procedure out of it. Um so we- we think that it is uh ethical or for other reasons the best thing to be open about it, and to have these kind of legal statures. And that kind of openness and that sort of willingness to say well it is a right and you are open to have it, that thinking in rules, ...it's too powerful to think that it could be changed by uh these kind of small minority groups in medicine. And um so it, the policy, it's better to gain acceptance and let's say to um use the emotional side for people to ask and respect also to ask for more attention to these problems (Anonymous, personal communication, April 30, 2015).

This analysis therefore reifies the notion that a purely legalistic change, such as a "third sex" documentation policy, is not inherently implausible in the Netherlands, but would need to occur alongside broader social shifts in understanding difference in order to be truly effective.

Patient Experience

The four men that I interviewed (Ruben, Luuk, Joost, and Hans), who have been diagnosed with Klinefelter's Syndrome, vary greatly in age, symptoms, treatment experience, and perspective. Their biographies can be found in Appendix II. There are two key themes that will be discussed in this analysis: (1) self-perception and external support systems, and (2) interaction with medical professionals.

Self-perception

Each of the men that I interviewed felt "different" at some point during their childhood, but neither they nor their parents and doctors anticipated that they had some type of genetic condition. Two of the men interviewed (Ruben and Luuk) stated that they felt a sense of relief to receive the diagnosis of Klinefelter's Syndrome because it finally provided an explanation for the difficulties that they had faced growing up. That being said, at some point in each of their narratives, all four men also expressed that this diagnosis resulted in struggles of self-esteem and self-acceptance. Two of the men, Ruben and Luuk, particularly struggled with their infertility, which is, as mentioned earlier, a socially valued component of masculinity. For Luuk, this insecurity largely is the result of his partners' responses to his diagnosis. For example, his ex-wife told their son that Luuk was not actually his father because he was conceived via sperm donation. In another instance, Luuk was involved in an altercation with his current wife when she used his infertility as an insult:

> Two years ago, she make me so angry. She said to me, 'you're fragile.' She said to me, 'you can't get any children, you have only seed (inaudible).' She said something, so I take

> her *makes a grabbing motion* And I think, okay, that was not okay. Because I killed her almost. This is not good...I walk a lot, and then I go to a psychiatrist, and I said no, this is not okay. We have to talk. We have to do something to get it... that anger out. But she still doesn't understand (Anonymous, personal communication, April 22, 2015).

Ruben and Hans both describe difficulties coming to terms with having Klinefelter's Syndrome because they said that social stigmas associated with the condition had an effect on their self perception. For Ruben, it was struggling with the common characterization of men with Klinefelter's as criminals that in part led him to visit a psychologist:

> ...I had an alcohol addiction, a- a gambling addiction, and a couple of more, so I went talking about it. And I don't know if it's- ... well the guy [H. Klinefelter]... he found a lot of Klinefelter's so he said, when somebody is a Klinefelter, uh a lot of them are not good for society. It's a story long long ago. Uh so well that's the reason why I uh went talking (Anonymous, personal communication, April 15, 2015).

For Hans, being diagnosed with Klinefelter's resulted in a period of burnout, and he still struggles with the social stigmatization of the condition. Specifically, he discusses abortion of fetuses with Klinefelter's Syndrome, relating this treatment of the body to the non-holistic approaches of current medical treatment:

> ...he [a friend] told me about a story about a woman she was pregnant at the 8 months. And uh she decided not to have the baby because of- the baby had this Klinefelter's Syndrome. And the doctors accepted. So they helped her to not having this child alive. So [my friend] told me, we are uh a kind of species we will not live forever because we are not-... It's legal to kill us in a way, you know?...in a way, I think the treatment, the testosterone treatment is also in a way like this you- you know. You should not treat people like... They should make much more work from that. And not just put us into medicine and that's it, you know (Anonymous, personal communication, April 23, 2015).

Joost, a former bookkeeper in his late seventies, states that it is the limitations caused by Klinefelter's itself and its associated difficulties that ultimately wears on him:

> when I *(pauses)* will have born again, I hope that it is without Klinefelter. Scoliosis, it is not lovely, but you can live with it. But Klinefelter, it gives a lot of trouble in your life. In my younger days, I didn't know. You function like you do. And you can only think, oh that boy- does that. I can't. I can't that, I can't that, I can't that. And that is not nice. So, to live again, please without Klinefelter's! (Anonymous, personal communication, April 24, 2015).

Each of these narratives demonstrate the ways in which a stigmatization of Klinefelter's as well as lack of understanding and social support has negative consequences on affected men's self-perception and ability to function. Of the men interviewed, only one stated that his family has been supportive throughout the process of his diagnosis and treatment, which he describes as having been crucial not only emotionally, but medically, as they have helped him perform

research on his condition not often provided by practitioners. The other men describe themselves as always having felt rather lonely or not understood by their families, partners, and or friends. All a part of the same organization[8], de Nederlandse Klinefelter Vereniging (NVK), each man has found membership beneficial at several points during his journey, whether it is to ask questions, share treatments, or discuss difficulties that he are currently facing. Joost explains:

> I think the most important things is in my opinion when you speak with uh people...who have the same as you. They are the people who knows the most about the ill- let's say illness. Normally I don't use such word, but then I must take the dictionary *chuckles* Because they can tell you what is happening... They can tell you uh what they are doing uh to find another job uh to do things work more nice. A doctor never can tell me that. He is only for recette. (Anonymous, personal communication, April 24, 2015).

Experiences with Medical Practitioners and Treatment

Only one of the four men (Luuk) says that he is satisfied with his interactions with medical practitioners and provided treatment. It is important to note that, in part because of the late age of diagnosis, most men with Klinefelter's Syndrome are treated by their general practitioner (or house doctor in the Dutch context) as opposed to regularly (or at all) seeing a specialist. This is true of all four of the men interviewed in this study. Luuk describes his current house doctor as being very respectful and interested in his care, open to his questions and willing to send Luuk to other specialists as requested. In comparing his current doctor to his first practitioner, who he describes as being unsupportive, Luuk points to a generational difference in their training: "The other one is younger and he sees more the- modern uh uh medicine. And the other one was from old school. He says, don't talk, just walk *chuckles*" (Anonymous, personal communication, April 22, 2015). It is quite plausible that DSD treatment approaches are linked to the time period in which the practitioner received medical training, particularly because of the temporally-linked shifts that have occurred in the related medical models (as with the release of the Consensus Statement in 2006). In future research, a question regarding the dates of when medical training was received by practitioners will be included in inquiry.

Several of the men report having information related to their medical status withheld from them. Strikingly, although Joost was administered a test at the age of 30 indicating that he had Klinefelter's Syndrome, the doctors never informed him of this diagnosis. It was only 20 years later, incidentally, that he learned of this. The doctor of his wife, who was receiving

8 Most of the men interviewed were not directed to the NVK by their practitioners, but rather through personal research or the recommendation of another party.

psychiatric treatment at the time, requested her files from the couple's shared practitioner. As both Joost and his wife shared both of their initials, the doctor received his information as well: "And he said [to my wife], here, look at the papers [indicating he had Klinefelter's Syndrome]. And my wife, she called me. And I called the doctor and said, send me that letter. Because I didn't know. And from that moment, I know that I have that syndrome. Because in the younger days, and some doctors still do at this time, they don't tell you anything" (Anonymous, personal communication, April 24, 2015). When Ruben was informed that he had Klinefelter's Syndrome, he was immediately started on testosterone without being told that a potential side effect was losing his limited fertility. It was only after he was retested some time later, discovering that he had no more viable sperm, that practitioners informed him of this possibility. He describes the experience:

> And I went there and I said hi. And he said hi. And that was it. And he opened my statue. And I saw the paper. And I saw the zero. I didn't say nothing. I said, 'well it was fun here, bye!' And I was gone because I was so pissed off. 'Cause I had in my mind -- it was in 2004. I thought, well it's going to be fine, because well there are some living seeds so there...And then there was none. So I said, how is it possible? And then he told me... So if they told me in uh in '98 that it was well coming, then I would have said, well I give you a lot of sperm, make the seeds, freeze them, and we'll- we'll find out later. But they didn't. So that's also the reason why I'm telling everybody who wants to know... 'cause I don't- well, I'm- *(pauses)* I kind of feel fucked. Because I thought well I want to have kids. I'd love to have kids (Anonymous, personal communication, April 15, 2015).

Ultimately, several men claim that practitioners cannot be trusted to provide information about Klinefelter's Syndrome. Some, as Joost describes, are not even interested in learning about the information themselves: "And he [my house doctor] said, I heard about it [Klinefelter's] when I studied, so I know the name. I know in what year it was found. But I don't know anymore. And I'm not interested. So. I had to look for myself" (Anonymous, personal communication, April 24, 2015). For that, many of the men rely on the NKV and research that they perform. Ruben finds it greatly important to share his findings with others. For example, he informs the parents of children with Klinefelter's Syndrome who come to meetings that they should freeze some of their son's sperm before he begins testosterone treatment. Ultimately, the practitioners' withholding of information from their patients indicate the extent to which informed consent and disclosure is not being valued in providing care.

Relatedly, several of the men describe interactions with practitioners in which they feel disrespected and not listened to. Many of the men say that their doctors minimize their

symptoms and do not look into treatment options. Joost, for example, describes the difficulties of getting his doctor to fill out forms so that he can receive medical testing:

> And there was many times that he said, that we don't because we've done it last year. And that is not necessary...because that's also researched by women. And I said, I have breasts! So, you look for it. And he said, we don't. So you get a paper to go to the doctor to the hospital things like that with a list *shows paper* to research. And I said eh in my home, I also have a pen. And when you don't cross that, I do it myself... So every year, it was almost a war (Anonymous, personal communication, April 24, 2015).

Hans explains that he believes that this lack of concern is linked to the Dutch medical mindset: "You can go to your doctor. You can say I have problem here. They send you back, and they say take a paracetamol and uh wait a bit and you'll be better soon, you know. If you tell them, okay, I really have here a problem. I need uh really help. Yeah, then they might go further. But sometimes also not so" (Anonymous, personal communication, April 23, 2015). In his own experience, he describes the frustration of his doctor being uninterested in considering alternative forms of treatment that are better suited to his body. After experiencing several negative side effects as the result of testosterone treatment, Hans performed some research and began to treat himself with different herbal substances, which he describes as being extremely effective both physiologically and mentally. When Hans tried to enter into a conversation about this with his practitioner, however, the latter was uninterested in researching the alternative:

> "When I told him yeah look, I take this. It's helping me. He said nothing. He said, okay... but he was not uh uh like giving applause or something like that... he said, if it's something for you, that's good, but uh I don't trust that. I don't like that. I said okay I trust this, you know, because it gives me a positive effect on my life. I can better handle my situation" (Anonymous, personal communication, April 23, 2015).

Currently, because of this interaction, Hans is not informing his endocrinologist that he is off of testosterone and still using herbal treatments. Although Luuk has not personally experienced it, he knows of other men who feel exploited and dehumanized by their practitioner, treated as an object of study instead of as a person receiving medical care. Each of the instances described suggest similar ways in which the agency of the men as participants in their own medical care was not respected by their practitioner. This in many ways reifies the binary subject/object relationship between doctor and patient that is characteristic of earlier concealment-centered, as opposed to care-focused, models of treatment.

Conclusion

In regards to DSD treatment teams, this study suggests that there have been many efforts

made to consider the proposed guidelines released by the Consensus Statement of 2006, such as the use of an multidisciplinary team, the employment of psychological care, and improved consent and disclosure policies, specifically in regards to parents. Still, there are alterations that can be made to the existing medical models to encourage more care-focused or patient-centered medical care. Specifically, this would involve further evaluation and consideration of where the patient currently is situated in regards to medical power dynamics, especially while he or she is unable to verbalize his or her consent in regards to treatment. Furthermore, there must be more social efforts to provide accurate information about DSD not only to patients and their families, but also to the general public, in an effort to help eliminate stigmatization of intersex and to deconstruct normative conceptions of sex and gender that create a distinction between "normal" and "other" bodies.

Currently, in the Netherlands, medical care for Klinefelter's Syndrome appears to be lagging far behind that of conditions treated regularly by DSD teams, particularly because of the lack of proper, specialized training being received by general practitioners. More supportive care, in which consent, disclosure, and agency of the patient is respected, is mandatory if ethical medical care is to be providing to these individuals. In addition to providing more education to prospective and current medical professionals about Klinefelter's Syndrome and other DSDs, it is also important to begin to create a network between the medical community and other resources, such as support groups, as currently these groups function independently. Ultimately, as can be best summarized in the words of Hans, medical care for Klinefelter's Syndrome and other DSDs still must become "wiser and wider" (Anonymous, personal communication, April 23, 2014).

Limitations and Suggestions

One of the largest limitations to this research project is the lack of diverse responses obtained on the basis of a small participant pool. Whereas my project was only able to consider three practitioners from two institutions, a better understanding of the current state of medical protocol and practitioner perceptions in the Netherlands would be achieved with a larger and thus more diverse set of participants.

Initially, the lack of positive response that I received from practitioners in regards to being interviewed was a bit surprising, specifically the open and resolute refusal of an entire institution to participate. In part, some of this limitation could be due to certain linguistic choices that I made as a researcher. In my email to practitioners, I described my research using

the terminology of "intersex condition" as opposed to "disorders of sexual development (DSD)." It was only through the interview process itself that I came to discover that the term "intersex" is outdated and often even not know within the Dutch context. Additionally, for those aware of the term, the rhetoric of "intersex" is often associated with activist efforts. Accordingly, my choice in using that word as opposed to DSD could have been perceived as positioning me within a community that is often in conflict with the medical world. Thus, a lack of understanding about my research project or a perception of researcher bias may have made practitioners less apt to respond to my interview request.

The scarcity of positive response by practitioners must be significantly observed in considering the current guarded positioning of the medical community in regards to these issues. For example, the institution who refused to participate responded that they had participated in another SIT student project[9] a few years ago and felt that the conversation had been exhausted. Recognizing that medical practice is not a stagnant entity that can be holistically understood at one temporal point, I believe that this institution's response may perhaps be more rooted in a fear of subsequent critique. In the future, this hesitance to participate in research could perhaps be partially addressed by both using the terminology of DSD and clearly stating confidentiality protocol in recruiting measures.

Another limitation of this project is the relationship between the medical practitioners interviewed and the particular subset of individuals diagnosed with a DSD, men with Klinefelter's Syndrome. In my recruitment, I reached out to medical center practitioner's are trained in working with patients with DSD. When my study ultimately came to focus on the experience of individuals with Klinefelter's, the *direct* relevance of these practitioner's work became more limited. As two of my practitioner interviewees work in pediatrics, they often do not interface with patients with Klinefelter's because of the average age of this condition's diagnosis. Additionally, most men with Klinefelter's are primarily treated by their house doctors, although they may also elect to visit specialists at a medical center. As a result, many of the treatment protocols discussed by the practitioners are not experienced by the group of men that I interviewed about their experience with medical treatment. This of course has an effect on the conclusions that can be drawn in regards to medical best practices on the basis of juxtaposing practitioner and patient experience. That being said, however, some fundamental ethical

9 In this project, participants and their institutions were not kept confidential.

questions -- such as consent and disclosure, agency, and medicalization of the body -- are still central to the experience and perceptions of both of these participant groups, still allowing for cross-analysis.

In future research, this limitation could be addressed in two ways. Firstly, it is necessary to additionally learn of the experiences and gain the perspective of individuals who have been diagnosed with DSDs other than Klinefelter's Syndrome, such as Congenital Adrenal Hyperplasia (CAH), Turner's Syndrome, and Partial Androgen Insensitivity Syndrome (PAIS) in regards to medical care. Because of the extensiveness of these groups and the associated complexities, this would have to occur in separate undertakings. Additionally, it would be useful to interview medical practitioners who are not directly affiliated with the treatment of DSD, namely house doctors, as many individuals who are diagnosed later in life are under these professionals' care.

Continued Research

In terms of my undergraduate work, this summer, I will be administering surveys to American medical practitioners involved in the treatment of DSD. The surveys will contain questions about their institution's protocol, their opinions on the protocol, and their experiences with burnout/vicarious trauma. Subsequently, after the completion of the study, I hope to juxtapose the results with those of this research project to analyze cross-cultural features of DSD treatment.

Further research is needed in several areas in regards to Klinefelter's Syndrome. First, it would be useful to garner information about general practitioners (house doctors): their knowledge-base of Klinefelter's, methods of treatment, and perspectives on the condition. This data is currently non-existed in a specialized study. Partly because it is diagnosed so late in life, there is extremely little psychosocial research on men with Klinefelter's Syndrome, almost all of which does not allow them to discuss their personal narrative. In order for any improvement ultimately to be made, medically or socially, their stories need an avenue by which to be told. Finally, as they are central to current decision-making processes for DSD treatment, further research is needed regarding parents of children diagnosed with these conditions about their experiences with and perspectives on medical care and sex and gender.

Appendix I

The following is table providing a comparative summary of interview responses by two of the

medical practitioners:

	pediatric endocrinologist (Institution A)	**pediatric urologist (Institution B)**
Did you receive medical training about intersex/DSD?	Yes, received training in medical school specifically about DSD	No, did not have any lessons on DSD in medical school
Is there interaction between institutions?	No, discussions and treatment are mostly confined within the institution. Occasionally, colleagues from different institutions are asked for advice about difficult cases.	No, there is not enough. Practitioners are working to arrange a better system, but it will take time.
Who composes the DSD treatment team at your institution?	Endocrinologists, urologists/surgeons, gynecologists, psychologists, clinical geneticist, laboratory endocrinologist	Pediatric urologist, pediatric endocrinologist, adult endocrinology, psychology, ethics, gynecology, genetics, nursing
What are the benefits of a multidisciplinary team?	Each team member specializes in a particularly area.	Different practitioners are able to discuss research and patients.
Is there a designated protocol for treatment?	Yes, but it's difficult because of the variety of manifestations. Mostly it's a guideline of important steps not to forget, such as consistent communication.	Yes, but it's difficult because of the variety of conditions. There is a protocol for infants with undefined sexes and also protocols for individual DSDs.
What is the process for sex determination?	Physical examination and ultrasound. Sometimes hormonal testing is needed. Diagnosis is made within a few days, but it can be a working diagnosis. Early diagnosis is important psychologically and legally.	Consultation with endocrinologist and an ultrasound. There is a protocol.
Have you had any patients who feel like they were assigned the wrong sex/gender?	Not yet at least, because this practitioner's patients are still young.	Practitioner discussed one case. Child was not assigned gender at this institution. Practitioner is planning to perform SRS even though the child is below the age of 18 because that is the child's wish.
What is the policy for consent and disclosure?	A psychologist is involved from the beginning, first to counsel the parents. Sometimes the psychologist is involved in the process later, when the child when he or she is old enough to understand. In this case, sometimes they are not given a full explanation, but one that is age-appropriate. This practitioner would recommend the use of a	Parents immediately are seen by a psychologist after the birth of a child with DSD. Children are provided with psychological support up until the age of 18 and even after if necessary. Dutch medical law dictates that a child between the ages of 12-16 must consent along with his or her parent for treatment. After the age of 16, it is the child's decision. This practitioner strongly

	psychologist, especially to make sure gender development is occurring normally. In terms of decision making, parents have a great deal of control, although patient agency is becoming more of a concern.	values the patient's wishes even before the age of 12, but will also still perform surgery on infants.
What is the recommended age for hormonal treatment?	11 for girls, 12 for boys (the ages of pubertal onset). There is some room to adjust based on height and parental pubertal history.	---
What is the recommended age for surgical treatment?	For girls, this institution tries to avoid surgery until the child is older, particularly because it may not be necessary. This is because surgery could have potentially bad physical consequences. For boys, surgery is performed in infancy, because there is little psychological risk.	Recommended age is 3-6 months unless gender is still in question. Surgery is seen as more physiologically and psychologically beneficial before the age of 18 months. Hypospadias is always repaired, often without the diagnosis of another DSD.
Does your institution provide prenatal treatment for DSD?	Yes, dexamethasome treatment is offered with the belief that the benefits, especially psychologically, can outweigh the risk of side effects. Ultimately, it is the parents' decision.	Yes. Prenatal diagnosis results in counseling with a social worker. Dexamethasome treatment is offered, but it is becoming less advised because surgery has such a successful outcome, making prenatal treatment not worth the risk.
What are the greatest strengths of your institution's protocol?	Meetings to keep practitioners up to date on research and patients. Parents do not have to travel to several institutions.	The standardized protocol can be used even when DSD specialists are not present. Protocol helps practitioners to avoid communication errors.
What are aspects of the treatment practices that need development?	Not in regards to institutional protocol. Practitioner believes that science needs a better way to accurately determine sex.	Better inter-institutional communication and cooperation.
Would it be beneficial to have a "third sex" category?	No, it would be difficult. Practitioner personally believes that proper identity development requires being a boy or a girl.	No, it would not be possible in the Netherlands at this time based on the current culture.
Does sexual anatomy have to match one's gender assignment?	No	No, it is not clear cut. But it is often important to the parent and even the child.

Appendix II

The following are brief biographies of the four men interviewed about their experiences having

Klinefelter's Syndrome:

Ruben

Ruben is a 39 year old nurse. He was diagnosed with Klinefelter's Syndrome at the age of 23. As a child, Ruben says that he was very active and did not realize for several years that something was wrong. As he got older, however, around the time of puberty, his friends began to get stronger while he did not. He also was very tired, and he had difficulties concentrating at school. Ruben often felt very angry and would sometimes feel like becoming violent. He went to a psychologist to discuss his feelings of being different. From the beginning, Ruben's family has been supportive of him, and they helped him research Klinefelter's Syndrome after he was diagnosed.

At the age of 23, Ruben's left breast began to grow. He visited his house doctor and discovered through a blood test that he had Klinefelter's Syndrome. He was also told that his testicles were very small because of this, and that, even though he could still foreseeable conceive children, he had a low sperm count. Ruben remembers being happy to receive the diagnosis insofar as he was "very happy to know what I- well, who I am." He felt relief in understanding the reason for many of the difficulties he faced growing up. Ruben was instructed to begin taking testosterone via a plaster. Some time later, the medical office lost his paperwork, so Ruben had to have his tests redone for their records. He found out that he was no longer fertile. Doctors informed him at this point that the use of testosterone could cause infertility. Ruben was furious that his doctors did not inform him of this before he started treatment because he could have frozen some of his remaining sperm for later use, especially as he always wanted to become a father. Ruben now tries to inform the parents of children with Klinefelter's about this possibility, encouraging them to freeze some of their son's sperm before he begins testosterone treatment. Ruben still uses testosterone; although he used injections for some time, he now prefers using gels because of the lack of "peaks."[10] He says that he sometimes uses more gel than prescribed in a dose if he has missed a couple of days of application, which his house doctor scolds him for.

Ruben states that being a nurse causes him difficulties sometimes because he "knows too much" and challenges his doctors. Ruben says that he has had to find out a lot of information

10 Injections can cause fluctuations of testosterone levels based on time of administration as opposed to the more gradual absorption characteristic of gels.

about Klinefelter's on his own, and he worries for some of the other men whose families may not be as active as his are in helping him to discover more information. He says, most importantly, he wishes doctors were aware of other services that they could offer to patients, such as support services like NKV.

Luuk

Luuk is 48 years old. He was diagnosed with Klinefelter's Syndrome at the age of 24. As a child, Luuk says that he and his family never knew what was wrong with him. He experienced difficulties with learning and concentrating in school. More troubling were his struggles with controlling his anger. He would often lash out physically at people and objects. As a child, he was taken to a psychologist to help him deal with these feelings, however no doctor even suggested that he could have a condition such as Klinefelter's. Luuk says that he has always not felt understood and has been rather lonely throughout his life, although he does not mind being alone. He says that he is a good actor in pretending to be comfortable and happy. He tries to use his own understanding of feeling lonely, angry, and different in a positive way to help others, such as his nephew, who has been diagnosed with autism.

At 24, Luuk and his wife at the time visited a fertility specialist because they were having difficulties conceiving children. Luuk was told that his sperm is not viable, but he was not given a reason for this at the time. He went to a university hospital, where he was diagnosed with Klinefelter's through a blood test. Luuk then went to his house doctor, who he describes as not being concerned, instead thinking that the diagnosis was "no problem" and that Luuk "need[ed] nothing." Luuk and his then-wife conceived twins with the use of donor sperm. One child passed away and the other was born prematurely. Luuk and his wife divorced, becoming distant over the grief of the loss of their one child. He says that his ex-wife told their son that he was not really Luuk's because he was conceived through donor sperm. Luuk was upset by the situation and took his son to a child psychologist to help him to understand. He says that this helped and that he and his son (now 15) have a very good relationship and can even joke about his conception. Still, Luuk has been very hurt by the claims of his second and current wife. He describes one instance in which she affronted him as being fragile and infertile, which resulted in him becoming violent with her. After this, Luuk realized that they needed help and began visiting a psychiatrist. Luuk's parents have also struggled to come to terms with his diagnosis, sometimes denying his infertility or saying that he is behaving like a victim. Luuk is able to talk

with some of this other family members and colleagues about his condition, but says that he is unable to talk about it with most people because they wouldn't understand.

Luuk says he now has had a very good experience with his new house doctor (who is also able to have him communicate with other doctors as needed). He says that this doctor is more trained in modern medicine while his old doctor was "old school." Luuk's doctor helped him determine the best treatment method for him: gels. Luuk feels respected by his doctor, who has told him that he can contact him at any time when he has questions. The doctor also will send Luuk for testing whenever he has concerns. According to Luuk, other men at NKV have had a different experience with their own practitioners, feeling as though they were being treated as a study object. He says that he does not feel the same way about his doctor and therefore would not change anything about his treatment.

Joost

Joost is a former bookkeeper in his mid-to-late 70s. He was diagnosed with Klinefelter's Syndrome at the age of about 50. Joost says that he never expected that he had any condition, even though he cites some differences between himself and other children growing up. These differences resulted in him being beaten up, which he describes as a very difficult experience, Other than being very thin, however, Joost says that he has not experienced some of the other symptoms that some men with Klinefelter's do throughout their lives, such as fatigue. He says that, just like "normal" people, men with Klinefelter's are all different.

At 30, Joost and his wife visited a doctor because of an inability to conceive children. After some tests, they were told that his wife was able to conceive, and that the chances were about one and a million. Joost was not told that he had Klinefelter's or that he was infertile. He was encouraged to come back to talk to the practitioners, but after several times, he stopped going because he says that the doctors were only asking him questions about his wife. Joost's wife had stayed in a psychiatric hospital for many years. When Joost was about 50 years old, his wife's doctor requested all of her medical records. As she and Joost share the same initials, the doctor received his medical information as well. It was at that point that Joost discovered that he had Klinefelter's Syndrome.

At this point, Joost visited his house doctor. His house doctor stated that he had heard of the terms "Klinefelter's" but did not know what it was and was not interested in learning about it. Joost discusses the many difficulties he has had with his two different house doctors, both of

whom are not familiar with Klinefelter's, do not want to learn about it, and do not listen to Joost when he requests different tests and treatments. Joost says that he is not able to switch doctors because of the healthcare system. His doctor did not help him figure out a treatment regimen for testosterone. Joost has been finding out most of his information from the NKV. After he was diagnosed, he and another member sat down and discussed a list that Joost had made about his potential symptoms, finding out that he shared about ten of them with other men with Klinefelter's. Joost says that the men in the group can understand him like no doctor ever could because of their shared experiences. Joost has a strong dislike of doctors, claiming that they have tunnel vision and do not listen.

Joost says that he does not discuss his Klinefelter's unless "it is useful." He told his younger brother that he has the condition, and his response was doubtful and invisibilizing. His younger sister was more interested. Joost says that Klinefelter's is not an illness, but a defect. He says that if he could be born again, his only wish is that he would not have Klinefelter's because it causes so many difficulties and limits what you can do.

Hans

Hans is 54 year old artist. He is originally from Germany but has been living in the Netherlands for about 17 years. He was diagnosed with Klinefelter's at the age of 32. As a child, Hans says that he had difficulties learning, but that this was not a red flag indicating that he may have had another underlying condition such as Klinefelter's. He was very quiet and did not have a lot of friends growing up. He says that he always felt as though something was missing, but never knew what this was. Hans claims that this sense of loneliness is something that he has come to deal with throughout his entire life. To cope with what he describes as a missing out on love, Hans struggled with alcoholism in his early adulthood. As he became older, he also struggled to figure out what his place in the world was, particularly in regards to his career. Many of these combined difficulties, including ultimately being diagnosed with Klinefelter's, led to his experiencing depression or burnout at several points in his life.

At the age of 32, Hans was having trouble conceiving a child with his partner and was subsequently diagnosed with Klinefelter's Syndrome. The situation was very difficult for him, as the relationship ended, his family was not very supportive, and he struggled with his own feelings of self-worth. For several years, Hans did not received any medical treatment for Klinefelters, both because he felt as if he wasn't showing symptoms and because he was having

difficulties coming to terms with the diagnosis. About ten years later, however, he started gaining a lot of weight, something abnormal based on his familial history. To help to halt these changes, Hans had his doctor prescribe him testosterone in the form of injections, however he experienced many negative side effects such as pain and hyperemotional feelings. He therefore stopped after about three months and began using gels for about ten years. About a year ago, he stopped using gels in favour of using different herbal treatments that he discovered. Hans says the herbs have been extremely helpful for him. He describes them as being a more holistic form of medical care which has had many positive effects on him both physically and emotionally. He doubts the effectiveness of testosterone treatment, claiming that it does not in fact prevent many of the conditions that it is supposed to, such as osteoporosis. When Hans informed his doctor that he has been taking herbs, he says that the doctor was not interested in learning more about them and merely said that it was Hans' decision but that he didn't trust it. Hans is currently still not taking testosterone, unbeknownst to his endocrinologist.

Hans is very upset by the treatment of Klinefelter's beyond just the ineffectiveness of testosterone. One thing that he finds very grave is the fact that prenatal diagnosis of Klinefelter's has lead to the abortion. He discusses one case in which a woman decided to terminate her pregnancy at eight months after discovering the fetus had Klinefelter's. Hans hopes that treatment for Klinefelter's will become "wiser and wider," looking for methods other than testosterone injections or gels. He also hopes that pracitioners will have more respect for the men they are treating and that parents will come to have a better understanding of their sons.

Appendix III

The following is a copy of "Shifting the Paradigm of Intersex Treatment," created by Alice

Dreger, Ph.D. for ISNA (2008):

Key Points of Comparison	Concealment-Centered Model	Patient-Centered Model
What is intersex?	Intersex is a rare anatomical abnormality which is highly likely to lead to great distress in the family and great distress for the person with an intersex condition. Intersex is pathological and requires immediate medical attention.	Intersex is a relatively common anatomical variation from the “standard” male and female types; just as skin and hair color vary along a wide spectrum, so does sexual and reproductive anatomy. Intersex is neither a medical nor a social pathology.
Is gender determined by nature or nurture?	Nurture. Virtually any child can be made into a boy or a girl if you just make the genitals look convincing. It doesn't matter what the genes, brain, hormones, and/or prenatal life are/were like.	Both, surely, but that isn't the point. The point is that people with intersex conditions ought to be treated with the same basic ethical principles as everyone else—respect for their autonomy and self-determination, truth about their bodies and their lives, and freedom from discrimination. Physicians, researchers, and gender theorists should stop using people with intersex conditions in “nature/nurture” experiments or debates.
Are intersexed genitals a medical problem?	Yes. Untreated intersex is highly likely to result in depression, suicide, and possibly homosexual orientation. Intersexed genitals must be “normalized” to whatever extent possible if these problems are to be avoided.	No. Intersexed genitals are not a medical problem. They may signal an underlying metabolic concern, but they themselves are not diseased; they just look different. Metabolic concerns should be treated medically, but intersexed genitals are not in need of medical treatment. There is no evidence for the concealment paradigm, and there is evidence to the contrary.
What should be the medical response?	The correct treatment for intersex is to “normalize” the abnormal genitals using surgical, hormonal, and other technologies. Doing so will eliminate the potential for parents’ psychological distress.	The whole family should receive psychosocial support (including referrals to peer support) and as much information as they can handle. True medical problems (like urinary infections and metabolic disorders) should be treated medically, but all non-essential treatments should wait until the person with an intersex condition can consent to them.
When should treatments designed to make a child's genitals look "normal" be done?	As soon as possible because intersex is a psychosocial emergency. The longer you wait, the greater the trauma.	ONLY if and when the intersexed person requests them, and then only after she or he has been fully informed of the risks and likely outcomes. These surgeries carry substantial risks to life, fertility, continence, and sensation. People with intersex conditions should be able to talk to others who have had the treatments to get their views.
What is motivating this treatment protocol?	The belief that our society can't handle genital ambiguity or non-standard sexual variation. If we don't fix the genitals, the child with an intersex condition will be ostracized, ridiculed, and rejected, even by his or her own parents.	The belief that the person with an intersex condition has the right to self determination where her or his body is concerned. Doing “normalizing” surgeries early without the individual’s consent interferes with that right; many surgeries and hormone treatments are not reversible. The risks are substantial and should only be taken if the patient has consented.
Should the parents' distress at their child's condition be treated with surgery on the child?	Yes, absolutely. Parents can and should consent to “normalizing” surgery so that they can fully accept and bond with their child.	Psychological distress is a legitimate concern and should be addressed by properly trained professionals. However, parental distress is not a sufficient reason to risk a child’s life, fertility, continence, and sensation.
How do you decide what gender to assign a newborn with an intersex condition?	The doctors decide based on medical tests. If the child has a Y chromosome and an adequate or “reconstructable” penis, the child will be assigned a male gender. (Newborns must have penises of 1 inch or larger if they are to be assigned the male gender.) If the child has a Y chromosome and an inadequate or “unreconstructable” penis according to doctors, the child will be assigned a female gender and surgically “reconstructed” as such. If the child has no Y chromosome, it will be assigned the female gender. The genitals will be surgically altered to look more like what doctors think female genitals should look like. This may include clitoral reduction surgeries and construction of a “vagina” (a hole).	The parents and extended family decide in consultation with the doctors. This approach does not advocate selecting a third or ambiguous gender.The child is assigned a female or male gender but only after tests (hormonal, genetic, diagnostic) have been done, parents have had a chance to talk with other parents and family members of children with intersex conditions, and the entire family has been offered peer support. We advocate assigning a male or female gender because intersex is not, and will never be, a discreet biological category any more than male or female is, and because assigning an “intersexed” gender would unnecessarily traumatize

		the child. The doctors and parents recognize, however, that gender assignment of infants with intersex conditions as male or female, as with assignment of any infant, is preliminary. Any child may decide later in life to change their gender assignment; but children with intersex conditions have significantly higher rates of gender transition than the general population, with or without treatment. That is a crucial reason why medically unnecessary surgeries should not be done without the patient's consent; the child with an intersex condition may later want genitals (either the ones they were born with or surgically constructed anatomy) different than what the doctors would have chosen. Surgically constructed genitals are extremely difficult if not impossible to "undo," and children altered at birth or in infancy are largely stuck with what doctors give them.
Who should counsel the parents when a child with an intersex condition is born?	Intersex is a psychosocial emergency that can be alleviated by quick sex assignment and surgery to reinforce the assignment. Professional counseling is suggested but typically not provided. Peer counseling is typically not suggested or provided.	Intersex is a community and social concern requiring understanding and support. Counseling should begin as soon as the possibility of intersex arises and/or as soon as the family needs it. Professional counselors trained in sex and gender issues, family dynamics, and unexpected birth outcomes should be present. Families should also be actively connected with peer support.
What should the person with an intersex condition be told when he or she is old enough to understand?	Very little, because telling all we know will just lead to gender confusion that all these surgeries were meant to avoid. Withhold information and records if necessary. Use vague language, like "we removed your twisted ovaries" instead of "we removed your testes" when speaking to a woman with AIS.	Everything known. The person with an intersex condition and parents have the right and responsibility to know as much about intersex conditions as their doctors do. Secrecy and lack of information lead to shame, trauma, and medical procedures that may be dangerous to the patient's health. Conversely, some people harmed by secrecy and shame may avoid future health care. For example, women with AIS may avoid medical care including needed hormone replacement therapy.
What is wrong with the opposing paradigm?	Parents and peers might be uncomfortable with a child with ambiguous genitalia. Social institutions and settings like locker rooms, public restrooms, daycare centers, and schools will be brutal environments for an "abnormal" child. The person with an intersex condition might later wish that her or his parents had chosen to have her or his genitals "normalized".	The autonomy and right to self determination of the person with an intersex condition is violated by the surgery-centered model. In the concealment model, surgeries are done without truly obtaining consent; parents are often not told the failure rate of, lack of evidentiary support for, and alternatives to surgery. Social distress is a reason to change society, not the bodies of children.
What is the ideal future of intersex?	Elimination via improved scientific and medical technologies.	Social acceptance of human diversity and an end to the idea that difference equals disease.
Who are the proponents of each paradigm?	John Money and his followers, most pediatric urologists and pediatric endocrinologists, and many gynecologists and other health care practitioners.	Intersex activists and their supporters, ethicists, some legal scholars, medical historians, LGBT activists, feminists, and a growing number of clinicians.

Appendix IV

The following are two sets of interview guides utilized in this study:

Interview Guide for practitioners

Initial Questions: Exploring decision to enter field

- How did you become interested in becoming a (insert career title here)?
- In medical school/your training, did you receive lessons on DSD? If so, can you describe what this instruction entailed?
- How did you decide to specialize/ begin to work with patients with DSD?
- In the Netherlands, is there any interaction between medical practitioners from different institutions in regards to discussing work with patients with DSD? If so, can you describe some of the conversations that arise in these discussions?

Institutional Protocol:

- Does your institution have a designated protocol for the treatment of DSD? If so, can you please tell me about that protocol?

** In this section, make sure to discuss the following aspects of treatment:

    - Do and, if so, how do medical practitioners work together in providing treatment for intersex patients? Is there a specific team or is there less interaction between practitioners?
    - How is gender determined for children with DSD at your institution?
    - At what age is hormonal treatment recommended? At what age is it performed?
    - At what age is surgical treatment recommended? At what age is it generally performed?
    - Does your institution engage in pre-natal treatment of DSD (i.e. dexamethasone treatment of CAH)?
    - What is the policy surrounding consent and disclosure?
    - What is the policy surrounding psychological care?

- How do you think the Dutch health care system has an impact on DSD treatment?

Personal Perspective on Treatment

- Are there any specific aspects of your institution's protocol that you strongly agree with?
- Are there any aspects of your institution's protocol that you disagree with or believe need further development?

** At this point, various components of the listed treatment questions can be discussed

  - medical team
  - age of treatment
  - consent and disclosure
  - psychological care

Personal Perspective on Sex and Gender

- From the experience you have as a practitioner, do you think that there is a difference between biological sex and gender? Please explain.
- Do you believe that it is important for children to be raised as girls or boys? Why?
- Do you think that it is necessary that intersex children have "female" or "male" anatomy in order to be raised properly as girls or boys respectively? Why?
- To what extent do you believe intersex individuals have control over their own sexual and gender identity based on current medical practices, and how do you feel about that?

Interview Guide for patients

Initial Questions: Establishing Rapport

- Could you please tell me a little bit about yourself? Where were you born and when? Into what family were you born?
- Describe what it was like for you growing up. What kind of child were you? What are some of the best memories you have about your childhood? Do you also remember any challenges?

Discovering Being Intersex

- How old were you when you first discovered that you had Klinefelter's Syndrome?
  - How did you come to learn of it/how much were you told about it?
  - How did that affect you at that age?
  - Did it change the way you perceived yourself?
- Who in your family/friend group was aware that you had Klinefelter's Syndrome? What was their response?

- How did this affect you?

Treatment

- Have you received any treatment for Klinefelter's Syndrome?
  - How old were you when this began?
  - How would you describe your experience with receiving/ not receiving treatment? What were some of the challenges, if any?
  - Did your parents discuss treatment with you? If so, what was that like?
  - Do you still receive any treatments today? Why/why not? Do you feel as though it is a choice?

Perspectives on Treatment

- Based on your experiences, what is your opinion on medical treatment for Klinefelter's Syndrome?
- Is there anything you would change about the way treatment works?
- Do you think receiving/no receiving medical treatment has had an effect on how you see yourself? Why/why not/ how?

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