Department of Political Science

Chair of Bioethics

Sex Reassignment Surgery on Newborns: Old Approaches and New Ethical Perspectives.

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In queste poche righe -le più difficili dell'intero elaborato- voglio condensare dei ringraziamenti speciali, per le persone senza le quali la mia vita sarebbe meno riuscita e certamente più grigia:

i miei genitori, Claudio e Stefania, che hanno investito moltissimo sulle mie capacità e di cui soprattutto non so elencare in poche righe gli innumerevoli pregi e l'amore smisurato che mi donano;

i miei nonni e i miei zii, persone meravigliose che mi hanno accompagnato in ogni fase della vita;

Leonardo, l'amico senza il quale i momenti più belli della mia vita avrebbero perso parte del loro significato ed i momenti più oscuri sarebbero stati insopportabili;

Ester e Giulia, le mie più care amiche, con cui ho condiviso i momenti più delicati della mia esistenza e che mi hanno permesso di essere parte della loro;

Isabella, che ha abbracciato ogni mio difetto senza giudicarmi e con cui sono cresciuta nonostante fossi già maggiorenne;

Marta e Sabrina, compagne di una vita con cui sono legata indissolubilmente;

Michela, Rossella e Riccardo, che mi regalano meravigliosi momenti di spensieratezza e felicità, anche al bar sotto casa.

ABSTRACT

The aim of this paper is to focus attention on the management of individuals presenting an atypical development of sexual characteristics, that cannot be classified in the traditional binary paradigm as female or male. The main focus will be on the treatment of intersex newborns with such atypical features, especially on the basis of core bioethical principles: autonomy, informed consent, bodily integrity and information disclosure. The issue of sex reassignment surgery, seen both from a historical and pragmatical point of view, will have its implications analyzed in order to assess whether it is ideal and morally acceptable to be performed on infants. Interviews of both parents' and intersexed individuals will be included to provide real life experiences, useful to comprehend some of the long-term aspects of the surgeries' outcomes and how intersex conditions impact on affected individuals and their relatives.

1 An Overview

1.1 What is Intersex?

The atypical development of sexual characteristics can refer to external genitalia, internal reproductive organs, hormones, genes or chromosomes; intersex conditions can be either external or internal.[i] Due to the different characteristics that the atypical development can determine, some intersex variations are diagnosed prenatally, some at birth and others might be discovered once the affected individual is in his or her adulthood (at puberty or while trying to conceive).[ii] Chromosomes are responsible for the determination of an individual's sex, as males have XY chromosomes and females have XX chromosomes.[iii] Genital characteristics, both internal and external, start developing after the first six weeks of the embryonic development.[iv] In genetic male cases, the Y chromosome carries the instructions that will determine the development of the gonad, resulting in a testicle. The creation of a testis is extremely complicated and goes through numerous steps that must have a precise order and if any of the parts of this procedure is missing or appears in the wrong order, the process will arrest and an ovary will be formed instead.[v] In that case, the observed chromosomes will be XY, but the individual might present ambiguous genitalia, as hypospadias; split scrotum that reminds female reproductive organs or an extremely underdeveloped penis.[vi] In other cases, in which the testes are correctly formed, they need to produce testosterone and the anti-Mullerian hormone.[vii] The former is a male hormone that will determine the development of the penis and that will also help the correct formation of the whole organ, as it will cause the connection of scrotum and penis and formation of the tube through which sperm is carried; the latter is a hormone that causes the disappearance of the primitive fallopian tubes and uterus.[viii] Until the production of male hormones done by the functional testicular tissues, the embryo will present a sort of rudimentary crasis of both a male and female reproductive structure, therefore presenting both the Mullerian and the Wolffian ducts.[ix] Because of the presence of high levels of testosterone in a genetic male, the Wolffian ducts will internally start developing into male reproductive organs and the anti-Mullerian hormones will make the Mullerian ducts regress.[x] Around the third month post-conception males develop the external appearance of reproductive organs and testicles descent into the scrotum shortly before birth.[xi] In females individuals, seen the lack of the anti-Mullerian hormone, fallopian tubes and uterus keep developing resulting in a womb[xii] and the absence of testosterone will cause the external structures to be characterized by the presence of clitoris and labia, as the inherent property of the fetus development

is oriented toward the female sex.[xiii] When some sort of problem during the sexual differentiation occurs it determines an atypical development that can present itself either as internal or external.[xiv] Intersex variation can vary, some are defined as chromosomal variations and occur when individuals are not born with the classical XX or XY chromosomal configuration, presenting variations as: XXX, XXY, XXXY, XYY, XYYYY and XO (in this case there is just one chromosome).[xv] The most common chromosomal variations consist in Klinefelter syndrome and Turner syndrome. The former is a condition that affects men, causing them to have one Y chromosome paired with at least two X chromosome; the latter affects females, leading to the presence of only one X chromosome.[xvi] Gonadal variations, as the name might suggest, affect testicles and ovaries. The outcomes of these kind of variations consists in the presence of ovotestes (a mixture between ovaries and testes); the presence of one testicle and one ovary; the presence of one working gonad (either a testis or an ovary) and a streak gonad.[xvii] Gonadal variations might determine a condition names Swyer syndrome (or complete gonadal dysgenesis) causing affected individuals to present XY chromosomes, but with a missing the segment of the Y chromosome that determines sex, leading to the absence of working testes and a female appearance of the fetus that will be lacking of a uterus or ovaries.[xviii] This condition is usually diagnosed at puberty.[xix] Hormonal variations are instead linked to the production or detection of male hormones, causing fetuses to not fully develop.[xx] As an example, compete androgen insensitivity syndrome in genetic males determines the incapacity for the fetuses to process male hormones produced by the testicles, letting the fetus' default female development to occur but without the correct formation of female internal organs.[xxi] Conversely, genetic females are affected by the partial androgen insensitivity syndrome that causes the virilization of external genitalia in various degrees, depending on the severity of the condition.[xxii] Hormonal variations also include 5-alpha reductase deficiency and congenital adrenal hyperplasia.[xxiii]

1.2 Terminology

The first word used to describe individuals with atypical sex development traits was hermaphrodite. This term clearly refers to a Greek mythology character, Hermaphroditus, son of Hermes and Aphrodite. Salmacis, a water-nymph, fell in love with him and expressed the desire to never be separated from him and the Gods merged the two of them into one body with both male and female characteristics.[xxiv] Seen the etymology of the term, it is easy to deduct how this word carried mythological associations, leading to a dehumanization and stigmatization of the intersexed newborns, making it easier to advocate for non-consensual and non-urgent surgery treatments performed on them.[xxv] The Intersex Society of North America (ISNA) explained how, beside their main goals, the association aims at removing the stigma that the word «hermaphrodites» carries and

that has led many intersex people to feel pain and shame.[xxvi] The Consensus Statement on Management of Intersex Disorders, published in 2006 by Hughes et al., addresses the matter of terminology, stating «A modern lexicon is needed to integrate progress in molecular genetic aspects of sex development» and suggesting that the chosen lexicon should be sufficiently descriptive and understandable for patients.[xxvii] In this statement it is underlined how some terms (intersex, pseudohermaphroditism, hermaphroditism) are perceived as pejoratives by patients and the expression "disorders of sex development" (DSD) is proposed as an umbrella term able to enclose all the variations from the traditional conception of male and female.[xxviii] In said paper other options are proposed: 46,XY DSD instead of undervirilization of an XY male or undermasculinization of an XY male; 46,XX DSD instead of overvirilization of XX female or masculinization of XX female; ovotesticular DSD instead of true hermaphrodite; 46,XX testicular DSD instead of XX male or XX sex reversal; 46, XY complete gonadal dysgenesis instead of XY sex reversal.[xxix] Terms like «normal» or «natural» are generally used referring to the binary norm, characterized by absolute female and absolute male and it is important to understand to what extent such normality is culturally and socially imposed.[xxx] Moreover, defining an intersex body as deviant seems to reveal the tendency to ignore the fact that there have bene different historical cases, creating a precedent for the expansion of the binary concept of normality.[xxxi] Scholars as Diamond and Sigmudnson prefer the use of words as «atypical» or «less frequent» and they argue that intersex conditions should be considered biological varieties and not a deviation from the norm.[xxxii] When referring to the intersex realm, it is important to define terms such as gender and sex.[xxxiii] The former refers to the societal context of man and woman, the latter is about the biological distinction between male and female.[xxxiv] The differentiation of these two expressions leads to the subsequent differentiation between sexual and gender identity, respectively indicating the way individuals perceive themselves as biological male or female and how the society identifies them, wither as a man or a woman.[xxxv]

1.3 Common Variations

Congenital Adrenal Hyperplasia

Congenital Adrenal Hyperplasia (CAH) describes a group of disorders that derive from defective adrenal steroidogenesis, with a deficiency of the enzymes that are needed to control the production of cortisol and therefore determining an overstimulation of the adrenal cortex.[xxxvi] This condition starts impacting on individuals when the external genitals, of both the male and female fetuses, have not yet completed their development.[xxxvii] Excessive androgens are produced because of the deficiency or total lack of an enzyme, also determining a lowered production of cortisol.[xxxviii] In a developing XY individuals this increased number of male hormones (androgens) does not lead to an

atypical development of the external genitalia, as the body would have been produced such hormones anyway.[xxxix] In a XX person, as the female fetus does not receive male hormone whatsoever, the production of such hormones will determine an appreciable variation in the external appearance.[xl] It is important to note that virilized genitals can derive from the mother's use of virilizing medication or the occurrence of a virilizing tumor, but more commonly the cause of virilized genitalia in female individuals is congenital adrenal hyperplasia,[xli] more precisely the deficiency of the specific enzymes caused by this condition. [xlii] CAH occurs when part of the genes needed to control the production of adrenal enzymes do not work correctly, determining a variation in the genes' structure[xliii] resulting in the external virilization of the genitalia.[xliv] Such variation can be caused by different types of malfunctions: part of the DNA structure could be missing (deletion); part of the DNA could be added (insertions); there might be an alteration of the DNA, determining an error in the amino acid produced (point mutations); part of DNA structure is recombined with other different genes (recombination).[xlv] The most common enzyme deficiency is 21-hydroxylase deficiency, others are 3ß-hydroxysteroid dehydrogenase and 11ß-hydroxylase deficiencies and oxidoreductase deficiency, resulting in a virilization of affected female fetuses and an under-virilization of affected male fetuses.[xlvi] In both males and females affected by CAH, the formation of testis and ovaries goes as planned, resulting in internally functioning reproductive organs: males will have the connection between the scrotum and the penis, allowing sperm to travel as it should; females' eggs will be able to reach the womb, seen that the tubes will have their full functionalities. [xlvii]

Salt-wasting Congenital Adrenal Hyperplasia (SWCAH) – 21-Hydroxylase Deficiency

In a XX person the SWCAH determines an appreciable virilization of the external appearance, ranging from a slightly enlarged clitoris,[xlviii] to a clitoris enlarged to the extent that it will seem a penis, also presenting swollen and fused labia similar to a scrotum.[xlix] In some cases, when there is a point mutation the total absence of the gene that codes for the protein that makes the enzyme 21-hydroxylase occurs, determining a salt-wasting crisis in both female and male newborn that can put their life at stake.[l] A salt wasting crisis (or adrenal crisis) is a life threatening complication that causes weight loss, vomiting, poor feeding and dehydration; if not treated immediately by physicians, the infants can suffer a shock and die.[li] The 21-hydroxylase deficiency caused by point mutation can also cause a decreased activity of the enzyme production to about 10-15% and therefore not necessarily causing a salt-wasting crisis or changes to female external genitalia.[lii] The occurrence of a salt-wasting crises in a female leads to the CAH diagnosis, leading to a surgery or hormone treatment with the aim to feminize the virilized genitals. On the other hand, if a female newborn does not experience a salt-wasting crisis the pathology often remains undiagnosed because the infants seem to be male and genetic testing at birth is not practiced as a routine, they will be treated as males.[liii] Regardless of the

degree of external virilization all girls affected by CAH have a vagina, both externally and internally.[liv]

Simple Virilizing Congenital Adrenal Hyperplasia (SVCAH) – 21-Hydroxylase Deficiency

The difference between this type of CAH and the salt-wasting one lies the degree of loss of the 21-hydroxylase enzyme, which instead of being totally absent has a decreased activity.[lv] The affected individuals, which usually do not present a salt-wasting crisis at birth, present noticeable symptoms when they are five or six years old including: faster growth and early puberty; increased body hair; body odor; acne; greasy hair.[lvi] The aforementioned symptoms might lead to a CAH diagnosis if no genitalia ambiguity is found at birth, but in many cases females may present ambiguous genitalia ranging from mild to severe, determining clitoromegaly or a mini penis.[lvii] In affected males the excessive production of androgens will not affect the formation of the genitalia, apart from a hyperpigmentation of the scrotum and postnatal virilization.[lviii]

Late-Onset Congenital Adrenal Hyperplasia (LOCAH) – 21-Hydroxylase Deficiency

Mentioned only for the sake of thoroughness, this type of CAH does not usually determines genital virilization, as the loss of the 21-hydroxylase activity is way less significant than the other forms of CAH.[lix] The main symptoms appear before or at puberty[lx], determining hirsutism; irregular menstruations or amenorrhea; deepened voice and muscular build in females; premature balding in males; accelerated growth.[lxi] The treatment for this condition, in its mildest forms, consists in the administration of estrogens with the aim of regulating of the production of testosterone; while in more severe cases steroids drugs as hydrocortisone are prescribed in order to administer hormone levels and prevent the excessive production of androgens.[lxii]

11-Hydroxylase or CYP11B1 Deficiency

The 11-Hydroxylase deficiency is the second most common type of CAH. The external physical manifestation of this condition is similar to the one observed in salt-wasting congenital adrenal hyperplasia, while internally there is an increase in adrenal androgens.[lxiii] Conversely to SWCAH 11-hydroxylase deficiency will not cause a salt-wasting crisis in affected individuals, but they will be suffering from salt and water retention and a rise in blood pressure, which might lead to serious consequences as mini strokes.[lxiv] This kind of deficiency can have milder or more serious symptoms, depending on its severity: in females it could determine the virilization of the external genitalia ranging from clitoromegaly to a phallus-looking clitoris; in males it could cause postnatal virilization and scrotum hyperpigmentation.[lxv]

CYP17 Deficiency

The effects of this uncommon form of CAH are quite dramatic, seen that the lacking enzyme is present both in adrenal grands and gonads.[lxvi] This deficiency can be either partial or complete, determining

low or absent adrenal and gonadal sex hormones and the individual will be cortisol deficient.[lxvii] In females it will determine unaltered external genitalia and the inability for ovaries to produce estrogens, making the puberty unlikely to happen. In males, as the testes are unable to produce testosterone, the external genitalia will be underdeveloped or will not develop at all determining ambiguous genitalia.[lxviii]

3ß- HSD 2 Deficiency

Just like the aforementioned deficiencies, the 3ß-HSD can present as mild or severe, depending on the degree of the loss of the functions of the enzyme.[lxix] At birth, this deficiency can cause various complications, as: failure to grow; salt-wasting crisis; hypoglycemia and adrenal crisis.

46XY patients will be affected by under virilization, varying from a micro-penis or a penoscrotal hypospadias to completely female-looking genitalia.[lxx] On the other hand, 46XX individuals can present a normal looking vagina, an enlarged clitoris, or a partial labial fusion. The milder forms of this deficiency can determine, in older patients, symptoms as hirsutism, irregular menstruations or primary amenorrhea.[lxxi]

Congenital Lipoid Adrenal Hyperplasia (lipoid CAH)

This deficiency is considered the most severe form of CAH and the defect mainly lies in the steroidogenic acute regulatory protein (StAR), causing an accumulation of cholesterol that destructs the adrenal glands, testes and ovaries. The majority of patients experiences a total loss of such regulatory protein, experiencing an adrenal crisis within the first month of life, regardless of their gender.[lxxii] 46XY patients have undescended nonfunctioning testes, which are located in the abdomen or groin; 46XX patients experience normal period and early menopause, as they can compensate the lack estrogen independently from StAR linked pathways, but they will experience an ovary failure on the long period.[lxxiii] When the StAR activity is not completely absent, but reduced to 10-25%, the symptoms occurs in childhood or adolescence causing spontaneous puberty and premature menopause in females and adrenal insufficiency with reduced cortisol and aldosterone in males.[lxxiv]

P450 Oxidoreductase Deficiency (POR)

As the other analyzed deficiencies, it is important to understand that there are different degrees of manifestation of the P450 oxidoreductase deficiency.[lxxv] The diagnosis is usually done when the individuals are still newborn.[lxxvi] Most of the individuals affected by POR present skeletal abnormalities and poor skull bones growth later in life.[lxxvii] While the outcomes visible on a male patient may vary from a small penis to a penoscrotal hypospadias, female patients present ambiguous genitalia at birth, even though there is no progressive virilization as the other forms of CAH seen that the adrenal androgens level are low or normal.[lxxviii] It has been noticed how some women carrying a fetus affected by POR experience temporary discomfort as hirsutism, acne and deep voice.[lxxix]

Androgen Insensitivity Syndrome (AIS)

The Androgen Insensitivity Syndrome (AIS) is characterized by a dysfunction of the androgen receptor, resulting in a hormone resistance[lxxx] and it affect only fetuses that are genetic males; 70% of cases derive from an inheritance from the infant's mother, while the remaining 30% cases have no known cause.[lxxxi] As the male fetus fails to respond to the hormones (androgens) produced by his own testes, the ones that should be determining a development of fully formed male reproductive system, the infant will have a female or ambiguous genitalia, depending of the severity of AIS.[lxxxii] This condition can be classified as complete, mild or partial, according to the severity of the androgen insensitivity.[lxxxiii] As with complete insensitivity (cAIS), the XY infant present a sex reversal and a female phenotype, therefore despite testosterone concentration exceeding the normal adult male range,[lxxxiv] these individuals do not develop a penis nor a scrotum, presenting underdeveloped Wollfian ducts and female-looking genitals instead.[lxxxv] The diagnosis is predominantly elaborated at puberty, once the patients present primary amenorrhea[lxxxvi] or when there is presence of inguinal hernia that actually contain undescended testes.[lxxxvii] AIS can also be discovered prenatally if there is a dissimilarity between the mapped karyotype and the sex detected on ultrasound or when the infant seems to be affected by a hernia, which actually contains a testicle. In some rare cases the diagnosis has been made for adults, mainly because of infertility.[lxxxviii] Individuals affected by partial androgen insensitivity syndrome will not have completely female looking genitalia, but due to the partial response to the androgens the external appearance of genitalia will be ambiguous.[lxxxix] Such ambiguity can vary from being externally almost indiscernible from female genitalia, but with undescended testes and a short vagina, to an hypospadic but apparently male genitalia, presenting scrotum and descended testes.[xc]

5-Alpha Reductase Deficiency

The 5-alpha reductase deficiency affects only genetic male, as it causes the impossibility to correctly convert testosterone in dihydrotestosterone (DHT), causing the fetuses to have correctly developed testes but not being able to prosecute the male features development.[xci] At birth, internal structure is typically male, testes are fertile but fail to descend[xcii] and can be abdominal, inguinal or labial.[xciii] At puberty, since there is usually an increase of testosterone production, some sort of penis development occurs, together with sperm production (if testes are intact), axillary hair growth, voice lowering and increased muscle mass[xciv]. At birth, affected newborns present a small penis that reminds of a clitoris with the scrotum looking like vagina's labia majora.[xcv] Severely undermasculinized individuals present a short and blind-ended vagina and are subsequently raised as females, but once they reach puberty they will not menstruate and due to the morphology of the vagina penetration results as impossible.[xcvi] In order to avoid the masculinization that might occur at puberty, some doctors suggest

gonadectomy and hormonal treatment also to be consistent with the female nurture given to the child, while post-puberty feminizing genitoplasty is performed together with estrogen therapy.[xcvii] Gonads will not be removed and the child will be reassigned as male if there is a switch towards a male role, taking into account the fact that the penis will not satisfy the culturally imposed standard of adequacy and that phalloplasty will be recommended.[xcviii] This change hardly happens, but there are not sufficient studies to determine if the gender identity change derives from the environment (such as male privileges), from hormonal prenatal programming or a combination of these two.[xcix] Operated patients that have been raised as females are infertile, on the contrary unoperated genetic males have low sperm volume and do not ejaculate but modern fertility techniques make reproduction viable.[c]

Gonadal Dysgenesis

Gonadal dysgenesis can affect both 46,XY and 46,XX individuals and it can present in its complete or mixed form.[ci] The complete form is characterized by the growth of non-working gonads, while the mixed form determines a formed functioning gonad (testis or ovary) and an underdeveloped gonad.[cii] The complete form causes the gonads to form atypically, leading to the complete absence of ovaries, testes or presence of ovotestes (a type of gonad containing both ovarian and testicular tissue) or underdeveloped, non-working gonads (or streak gonads).[ciii] As a consequence, there is no production of male or female hormones and therefore genetic male will present a female phenotype, while females will have a clitoral enlargement at birth and not experience puberty.[civ] In general individuals affected by this pathology are phenotypically similar to the ones affected by the Tuner syndrome.[cv]

Klinefelter's Syndrome

Klinefelter's syndrome, as well as the Turner one, are usually categorized as an atypical development of external genitalia, but it is important to notice that many affected individuals, their support groups and clinicians that work on such cases state that those syndromes are specifically related to males and females and not with intersexual individuals.[cvi] These conditions will be analyzed anyway, with the idea of taking in account every opinion on intersex and every facet of this umbrella term.[cvii] As this kind of condition does not determine any genital ambiguity, newborns affected by Klinefelter are labeled and raised as males.[cviii] This syndrome can determine different signs, listed below: tall; small testes; gynecomastia in late puberty; broad (or gynoids) hips; sparse body hair; signs of androgen deficiency.[cix] The symptoms might vary from infertility (due to azoospermia) to osteoporosis or sexual dysfunctions.[cx] There is a high frequency of patients presenting less clinical features, one of the reasons why the KS is often undiagnosed or diagnosed in late adult life, this tendency leads to severe long-term complications and a more difficult clinical management.[cxi] This syndrome was firstly discovered in 1942, when a group of clinicians guided by Dr. Klinefelter published a report concerning nine men that presented: enlarged breasts; sparse facial and body hair; small testes and

inability to produce sperm.[cxii] Years later, in 1959, these men affected by the Klinefelter syndrome were discovered to have an XXY genotype, presenting an extra X chromosomes comparing to the classic XY.[cxiii] It is important to note how the analysis was conducted: it was based on the terms of symptoms manifest, rather than on an examination of a broader statistical sample examined in order to determine who -within said sample- presented the aforementioned chromosomal anomaly.[cxiv] The criteria chosen by Klinefelter et al., emphasizing on the seemingly male physical characteristics, seems to undervalue the feminine ones such as developed breasts and exiguous body and facial hair excluding beforehand the possibility for the syndrome to be some kind of female-oriented intersex.[cxv] Being affected with Klinefelter's syndrome sometimes determines the occurrence of various comorbidities: diabetes, metabolic syndrome, osteoporosis; cardiovascular diseases and hypogonadism.[cxvi] Even though only a few of the males affected by KS syndrome develop noticeable hypogonadism, those individuals need a lifelong testosterone treatment.[cxvii] A testosterone treatment might also be needed shortly after puberty, as it could be crucial for a complete masculinization, muscle development and prevention of osteoporosis.[cxviii] Such treatment could be also helpful in order to reduce some symptoms that seem to derive from Klinefelter Syndrome, as learning disabilities that often lead to the need of a special education and tiredness.[cxix]

Turner Syndrome

As it was early mentioned the Turner syndrome is not perceived, by many individuals affected by it, as an intersex condition. The executive Officer of the Turner Syndrome Support Society, based in UK, emphasizes on the fact that women dealing with this condition refer to themselves as females, while Dr. Fausto-Sterling defines the syndrome as a type of intersexuality and as an unusual chromosome composition.[cxx] The Syndrome was named after an American endocrinologist, Dr. Henry Turner, who discovered it in 1938.[cxxi] This condition affects only women and can be referred to as congenital ovarian hypoplasia, derives from the partial or complete non-functionality of one of X chromosomes.[cxxii] The main observed characteristics are: short stature; short neck; broad chest; genu valgum; nail dysplasia;[cxxiii] low posterior hairline; urinary tract anomalies; low-set ears.[cxxiv] Individuals affected by Tuner Syndrome might have a higher risk of being affected by cardiovascular and autoimmune diseases. As a proof of this, the mortality rate for patients is three times higher than the one of the unaffected population and cardiovascular complications occur in 41% of the affected individuals. The more common cardiovascular abnormality consists in heart valve disease, but aortic dissections and aneurysm are quite common as well seen that young people with TS have a smaller aortic diameter than usual[cxxv]. Females affected by the Turner syndrome can present behavioral and emotional problems and the severity seems to be linked to the parental origin of the well-functioning X chromosome: the ones with the maternal chromosome seemed to struggle more than the ones with

the paternal X chromosome.[cxxvi] An estrogen treatment, which is generally administered around the age of 12, is needed with the purpose of inducing puberty and to prevent osteoporosis.[cxxvii]

1.4 Frequency and Data

Data on atypical development of external genitalia might sometimes differ, mainly because there are no exact guidelines for the diagnosis of some intersex conditions and no univocal conception of male and female.[cxxviii] As a proof of this, Chase states that the cases in which genitalia are so ambiguous that doctor cannot determine a precise sex for the baby are 1 in 2000, while Blackless suggests a rate of 1 in 50 births with 1-2 in 1000 receiving a sex reassignment surgery.[cxxix] Dr. Anne Fausto Sterling, taken as a data source by the Intersex Society of North America, refers a rate of 1 in 1500 to 1 in 2000.[cxxx] In South African culture the birth of an intersexed child is perceived as a bad omens or a curse to the community as a whole, leading an infanticide operated by midwives.[cxxxi] There is no clear data in this phenomenon and it difficult to understand how often it occurs, but an independent study done in the rural area of South Africa reported that 88 out of 90 traditional midwives have killed babies presenting ambiguous genitalia. Other cases of infanticide (or attempted infanticide) have been reported in Uganda, Kenya and China.[cxxxii] Data deriving from a worldwide screening comprehending almost 6.5 millions of newborns shows how classical CAH occurs in 1 in 13,000-15,000 live births.[cxxxiii] In its Late-Onest form, it affects 1 in 66-1000 individuals.[cxxxiv] Of the affected newborn the 75% experience an adrenal crisis (or salt-wasting crisis).[cxxxv] Deficiencies in 21-hydroxylase, in its non-classical form, can be considered one of the most frequent autosomal recessive disorder in humans as it is reported that the incidence in the heterogeneous population of New York is 1 in 100 individuals.[cxxxvi] This form of congenital adrenal hyperplasia seems to be prevalent in certain populations: in the Askenaki Jewish population 1 of 27 newborns are affected by it and there are 1 in 3 individuals that are healthy carriers.[cxxxvii] Cases of CAH deriving from the CYP11B1 deficiency are way less, ranging from the 5% to the 8% of all cases and occurring in 1 on 100,000 births. It is more commonly found in in some North African populations, but there are no precise records.[cxxxviii] Blackless et al. estimate that complete AIS occurs approximately in 1 in 13,000 apparently female births, while the partial AIS is estimated to be recurring one-tenth as commonly.[cxxxix] But on the other hand, there are different sources suggesting dissonant rates as 2-5 cases in 100,000 in male individuals for the complete androgen insensitivity syndrome and a rate of 5-7 in 1,000,000 live births for the partial syndrome, as reported by an article published on the International Journal of Surgery Case Report.[cxl] While Minto estimated Complete AIS to occur between 1 in 13,158 and 1 in 40,800 births and Ahmed suggests the rate to be around 1 in a range between 20,000 and 64,000 births.[cxli] Statistics vary as some scholars make the cases proportion considering the whole population, while others only

consider genetic males, as this disease does not affect genetic females.[cxlii] The Klinefelter Organisation, based in United Kingdom, affirms that 1 in 1,000 male infants present an XXY karyotype but both the Klinefelter's Syndrome association (UK) and the Klinefelter Syndrome and Associates (US) suggest a 1 in 500-1000 frequency.[cxliii] Regardless of the exact number the classical Klinefelter Syndrome occurs in 80-90% of the cases, affecting moreover infertile males (3-4%).[cxliv] Even though KS is the most frequent detected sex chromosomal anomaly, it remains undiagnosed in approximately 75% of the patients with the majority of diagnosis delivered in adulthood.[cxlv] Both Turner Syndrome Society of the United States and the Turner Syndrome Support Society in U.K. sustain that said syndrome occurs approximately once in every 2,000 female births.[cxlvi] On the other hand the Magic Foundation, a non-profit organization created to assist families with children affected by chronic or critical disorders,[cxlvii] suggests that the occurrence is less frequent: Turner's syndrome takes place in one on 3,000 births; 98% of the pregnancies with said syndrome abort spontaneously; 10% of the fetuses spontaneously aborted are discovered to be affected by TS.[cxlviii] What was considered as the "classic" karyotype linked to the Turner Syndrome (45,X) was found only in 45% of the patients, while the other ones had a mosaic karyotype as 45,X/46,XX or 45,X/47,XXX.[cxlix] It must be noted that the true frequency of the syndrome is not known, as many patients with mild phenotype might be undiagnosed.[cl]

2. Intersex Treatment and Dilemmas

2.1 History

Looking back at the sixteenth to the eighteenth century -the period in which disorders of sex development started to generate a relevant debate- we discover how jurists based the determination of a person's sex only on medical experts' opinion rather than taking in account intersexed adults' affirmations about their sex, shaping a juridical conception that clashed with actual biological findings of that time.[cli] The scientifical point of view shifted around the eighteenth century and started emphasizing emphasizing on the differences between man and woman, rather than on their similarities.[clii] Some scholars, as Laqueur, sustain that such change in the medical perspective led to the two-sex model of the human body and underlining the differences between male and female became crucial, even though many discoveries of that time showed how both sexes' reproductive organs derived from the same embryonic structure.[cliii] The general conception relied on the notion that the person taken into account had to be treated according to what was considered his or her prevailing sex, in order to correctly adhere to the norms it imposed such as marriage, civic status and property ownership.[cliv] The development of medicine around the nineteenth and the early twentieth century brought to light the existence of intersex individuals, which were not objects of sex

reassignment surgery as there was not the possibility to do that and from many historical findings they seemed to live happy and productive lives.[clv] Jorge Daaboul, an American pediatric endocrinologist, while delivering a brief speech for the American Association for the History of Medicine reflected on how studying the history of intersex taught him that what we perceive as «normal» and necessary is just a historical artifacts.[clvi] While the modernization of medicine was occurring in the Western Europe, around the end of the nineteenth and the early twentieth century, the interest towards bodies that showed signs of disorders of sex development quickly grew, as the physicians were interested into growing their knowledge of human body and its functions.[clvii] What drove such interest to the matter during the Victorian Era was perceiving it as a social threat and the challenges intersex posed to the sexual boundaries in the society and what was perceived as «the norm».[clviii] Further studies done in the nineteenth century led to the elaboration of two classification systems for what was still defined as «hermaphroditism», one was done by the French anatomist Geoffroy Saint-Hilaire and James Young Simpson, a British obstetrician.[clix] Saint-Hilaire's classification relied on the theoretical assumption that a person could be defined truly male or female if the sexual organs' six segments -previously identified and considered as essential by the anatomist- were entirely male or female.[clx] If said segments resulted as combined within one individuals, that person was considered as intersexed.[clxi] He considered the intersex condition as an abnormal overdevelopment or underdevelopment of sexual characteristics and he used to classify individuals basing on what they were lacking or what they were exceeding of.[clxii] Not many years after that, in the late 1830s, Young Simpson divided intersexed individuals in «spurious hermaphrodites» that presented some characteristics of the opposite sex and in «pure hermaphrodites», if they had both male and female features, a nomenclature that persisted until a complete renewal in 2006, when a new one was proposed.[clxiii] The former classification could also include clinical manifestations such as prolapsed uterus and enlarged clitoris when referred to a female individual and hypospadias and penis fusion to the scrotum if the subject was a male.[clxiv] Up until the second half of the nineteenth century there was not a broad consensus on which markers undeniably determined a certain sex, as it was difficult to identify exclusive traits of both sexes: some women menstruated, others not; some men ejaculated a some other did not, while some women did.[clxv] In 1876 a different type of taxonomy was proposed by Klebs, a German pathologist, still presenting categories as «pseudohermaphrodite» and «true hermaphrodite».[clxvi] The difference from previous studies relied on the method used by Klebs, who proceeded using an analysis of gonadal tissue and on the presence of ovaries or testes.[clxvii] Following Klebs' classification, a «pseudohermaphrodite» would be an individual defined as male or female by the gonads, but with mixed external anatomy, especially the reproductive organs; while a «true hermaphrodite» presented both testicular and ovarian tissue.[clxviii] «Pseudohermaphrodites»

could be either masculine if they had testes but presented male genitalia, or female if they had ovaries with male genitalia.[clxix] It was believed that gonads were the trait that determined an individual's sex, but since in the nineteenth century there was no technology to detect ovaries or testes an unquestionable diagnosis could be made only with an autopsy, while living people were examined only by palpation.[clxx] In some cases, due to gonadal ambiguity or malformation, the diagnosis was uncertain even after death.[clxxi] What was useful of the gonadal classification was that it allowed physicians do preserve the clear distinction between male and female and therefore it did not challenge the roles deriving from the traditional binary sex and gender distinction.[clxxii] At the beginning of the twentieth century, because of the scientifical development and the attenuation of masculine and feminine boundaries, it became increasingly important to root gender theories in biology.[clxxiii] Until the middle of the twentieth century, surgical interventions on intersexed individuals were uncommon and professionals were oriented towards the understanding and the classification of this phenomenon, taking in account only the male/female distinction.[clxxiv] The binary model taken in account by professionals has been considered as unmistakable, even though both human and animal biology showing how it should not have been considered as a universal axiom.[clxxv] Many intersexed individuals remained undiagnosed for different reasons: the prevalence of midwives instead of male doctors during deliveries and the lack of visible anomalies in intersexed newborns, since the assigned sex was based on the external appearance of genitals.[clxxvi] In 1902, a Dutch gynecologist underlined how sex could not be determined only basing on the external genitalia, delivering a strong critique to the tendency of performing rudimentary surgeries to remove the organs that were considered as incongruous to the assigned sex.[clxxvii] For that physician, proceeding without taking in consideration different aspects of the individuals' personality and considering only the genitals' suitability for reproduction and the gonadal makeup did not mean proceeding in the patients' best interests, but rather forcing them to live in a chosen sex.[clxxviii] The perspective from which professionals were approaching to this type of cases was switching from gonadal sex to the attempt to determine the «best sex» and there was a growing consciousness regarding this subject, that started to impact on the medical field.[clxxix] Within the first twentieth century decade, the English surgeon William Blair Bell understood how the gonads and the genitals were not the only markers responsible for sex determination, a procedure that should be done with particular attention towards secondary sex characteristics.[clxxx] This model, as many others of that time, aimed at annihilating physical ambiguity, a necessity that led to a considerable interest towards endocrinology, which promised an undeniable medical explanation for it.[clxxxi] The early endocrinologists started to isolate certain hormones secreted by the gonads, considered responsible for the sexual differentiation and for human behavior.[clxxxii] Therefore, the attention passed from ovaries and testes to the hormones they produce:

estrogen for females and testosterone for male, which scientists believed to be exclusive of one sex or another.[clxxxiii] Ten years later, around 1921 it was discovered how such hormones were present in both males and females, but in different amounts.[clxxxiv] The result of the discovery of different sex signifiers concurred to show how researchers and doctors operated in a great degree of uncertainty when treating intersexed individuals, but even if some treatments were highly debated, an increased in the use of corrective surgery occurred.[clxxxv] Hugh Hampton Young was one of the first doctor offering corrective surgeries in the United States, when such treatments were still uncommon.[clxxxvi] He was the head of genitourinary surgery at the Johns Hopkins at the end of the nineteenth century and in 1937 he published the first treatise on different types of intersexuality, provided with an analysis of forty-five patients.[clxxxvii] This publication included step by step explanations of the surgical techniques Young was using to treat ambiguous genitalia since the mid-1930s, comprehending a surgical treatment he used to slow down the virilization of CAH in female patients before such disease was fully theorized by clinicians.[clxxxviii] Young used to assess whether a patient was male or female taking in account different markers: gonadal tissue and evidence of the normal hormonal function shown by personality traits and sexual desire.[clxxxix] In the late 1940s, the psychological factors were taken in consideration and started to compete with the conception of gonadal sex.[cxc] Many theories were elaborated in the first half of the twentieth century as the ones aforementioned, as a proof of how there were no unifying theories or principles for the treatment of intersex people and it seemed that advances in sciences were determining a gradual complication of the matter.[cxci] Moreover, the notion of psychological sex determined a deep anxiety in clinicians as there was the possibility that it could clash with the surgically assigned sex.[cxcii] A systematic model that included psychological and biological variables was elaborated around 1950s by John Money and his colleagues, taking in account both psychosexual orientation and the expected physical development at puberty in intersexed individuals.[cxciii] For the first time there was a link between different fields (psychology, endocrinology, surgery), leading to the wide adoption of the protocol.[cxciv] Money started criticizing the gonadal sex determinations as he thought that no single factor could unequivocally determine the individual's psychosexual differentiation and identity, arguing that surgeries relying only on gonads did not give the right credit to the psychological traits of intersexed person and the future pubertal physical development.[cxcv] Money analyzed more than two hundred cases from 1895 to 1951, with his findings leading him to think that psychoanalysis incorrectly established a link between mental pathologies and intersexuality.[cxcvi] Of the many cases he studied, there were only a few individuals that presented psychosis or neurosis and moreover, it seemed that most people accepted their sex of rearing even if they had physical contradictions, but still Money was oriented towards minimizing the contradictions as much as possible by the use of hormonal and surgical intervention.[cxcvii] In 1951,

Money was invited to join the first interdisciplinary team for intersex treatment, founded by the pioneer regarding congenital adrenal hyperplasia doctor Lawson Wilkins.[cxcviii] Wilkins' team included two members of the psychiatry department, John and Joan Hampson, Howard Jones, a young gynecologic surgeon and Money, who became the first pediatric psychoendocrinologist.[cxcix] Money, together with the Hampsons, wrote different articles in which they sustained the importance of nurture in the determination of what they defined as «gender role», that in their perspective meant the attitudes of individuals that determine a male or female classification.[cc] They also argued that the gender-role was determined by different variables: chromosomal, gonadal and hormonal sex; secondary sex characteristics; external genital appearance; internal genital morphology; sex of rearing; gender role.[cci] They considered the reared sex as more determinant than the biological variables and when paired with surgical and hormonal treatment, the intersexed child would have surely avoided incongruous physical development with the assigned gender.[ccii] Money elaborated an innovative protocol, firstly because he offered a multidisciplinary approach for intersex treatment and secondly because his theories were backed by a solid data collection.[cciii] In order to guarantee a successful treatment of patients, Money and his colleagues recommended the physicians' intervention in the first few weeks of the newborn's life, resulting a well-established gender role at the age of two and a half.[cciv] The surgical reconstruction was recommended in infants that had ambiguous genitalia, choosing the assigned sex depending on how viable was to reconstruct male or female characteristics and the operation was advised for two main reasons: to avoid the parents' doubts regarding the child's sex and to ensure the young patient best development in relation to the assigned sex.[ccv] On the other hand, if the difficulty of recreating a male or female resemblance was approximately the same, the gonads would have been taken in account, as they are an indicator of pubertal development and fertility.[ccvi] In cases such as adults or older children the suggestion was to maintain the sex of rearing if the patient did not request for a sex reversal.[ccvii] The first arguments against Money were delivered by the anatomist Milton Diamond, who sustained that gender was firstly determined by biological factors and that hormonal exposure was responsible for its determination.[ccviii] In 1965 Diamond published one of the many essays in which he criticized his opponent's approach, labeling the idea of the undetermined sexuality at birth as erroneous and proposing the idea that every human is born with a precise sexuality, shaped by hormones.[ccix] Conversely to Money's opinion, Diamond considered the role of the environment as it could not modify what he defined as «inherent sexuality» determined by biological factors, as androgens and estrogens.[ccx] In 1972 Money published a book in which he presented what will later become famous as the «John/Joan case» regarding a boy who had his penis destroyed during a circumcision, leading the surgeons to perform a sex reassignment operation as the available technology did not allow for a penile reconstruction.[ccxi] Approximately six years later,

Money stated that the success of the treatment was a clear proof of the prevalence of nurture over nature and even if the patient did not have any intersex condition his case was extremely relevant for the publicity of intersexuality.[ccxii] Years later, the long-term outcomes of the case took a significant part in determining the Money's protocol crisis and served as a strong argumentation in Diamond's favor.[ccxiii] Up until the 1990s the mentioned protocol dominant in the medical field, but different changes started to challenge it: deeper understanding of the subject by both the society and physicians; movement for the acceptance of diversities related to gender, sexuality and bodies; the elaboration of principles of medical ethics; health care personnel losing part of his authority.[ccxiv] Moreover, people treated with Money's protocol were adults and started to inform themselves about their condition, with some of them perceiving the received therapies as harmful for their physical and psychological health.[ccxv] That perception has been the starting point for many movements founded with the idea of save other people from the pain and discomfort those people had to go through.[ccxvi] Another opponent of Money's theory, pediatric urologist and child psychiatrist William Reiner, sustained the idea that gender assignment is not alterable, regardless of what the medical personnel can do and it is wrong to assume that gender identity can be socially or scientifically modified.[ccxvii] This theory derived from his experience in the management of a rare birth defect, cloacal exstrophy, which caused the failure of the sealing of the abdominal wall together with a short and sometimes split penis, undescended testes and extremely severe hypospadias.[ccxviii] These children were not intersexed, but since the surgery for recreating male phenotype was almost impossible, most of the affected genetic males were assigned as girl.[ccxix] In 2000, Reiner presented his studies basing on a sample of thirty-three males of which 26 were affected by cloacal exstrophy and the remaining ones affected by other defects that were reassigned as females and treated at the Johns Hopkins.[ccxx] Of all thirty-three individuals nineteen switched back to a female identity, leading Reiner to advocate for a strong biological link with gender identity and sexual orientation, stating how gender identity is not a matter of environment.[ccxxi] Distancing from what had been the traditional practice for forty years, Diamond and Sigmundson proposed the effect of prenatal androgens as a marker to decide which gender should be assigned to an intersex newborn, as infants exposed to prenatal androgens were destined to grow up with a male typical sexuality and behavior.[ccxxii] The two scholars suggested that XY infants with micropenis, 5-alpha, Klinefelter's syndrome or the less severe androgen insensitivity should be reared as males, as well as 46,XX affected by congenital adrenal hyperplasia.[ccxxiii] Reiner agreed with them, stating that males affected by a micropenis should be raised as males, justifying this choice with the brain's masculinization.[ccxxiv] What was problematic with this kind of recommendations was the lack of a large empirical study, as Diamond was making his assumptions basing on the David Reimer's case and on studies involving rodents, while Reiner 1997 had not yet completed his research on

cloacal exstrophy.[ccxxv] Another challenge to their theory consisted in the inability to test the extent to which the infant is exposed to prenatal hormones, as the assessment could be done only via hormone samples taken right after birth and the degree of masculinization of external genitals, which theoretically should have been represented the brain's masculinization.[ccxxvi] An assumption which was later scientifically disproved, showing how it is difficult to find precise markers of gender assignment.[ccxxvii] Founded in 1993 by Bo Laurent, the Intersex Society of North America aimed at giving support to intersex people and challenging the traditional medical protocol for newborns' treatment.[ccxxviii] The idea that they were going against was the sacrifice of sexual pleasure and psychological health in order to create «normal» bodied heterosexual children, usually leading to shame and physical problem.[ccxxix] By the end of the 1990s, as scholars started to advocate against early sex reassignment surgery, the intersex movement's influence started to grow.[ccxxx] By the early years twenty-first century Money's treatment paradigm was seen as something that led to mutilation and disrespect of patients' consent.[ccxxxi] In 2001 the British Association of Paediatric Surgeons Working Party acknowledged, in a statement, how the protocols were based only on early diagnosis and emphasized on the need of a multi-disciplinary treatment and recommended a psychological support for both the intersexed child and the family.[ccxxxii] More importantly, they recommended the delay of cosmetic interventions in a post-pubertal period to allow the child full sexual development and allow for the possibility of a at least partial understanding of the consequences associated with such treatment.[ccxxxiii] Scholars advocating against cosmetic surgeries on infants have somehow shaped a new perception of this procedure, which has been even defined as violating of important human rights.[ccxxxiv] All this advocating translated into more factual changes, for example Malta was the first country banning cosmetic genital surgeries[ccxxxv] and Germany has followed the example in 2021.[ccxxxvi]

2.2 Sex Reassignment at Birth

The president of the androgen insensitivity syndrome Support Group base in Australia states stated more or less 25% of newborns have ambiguous genitalia and many of those have been, since the 1950s, undergoing sex reassignment surgeries and the subsequent hormone therapy.[ccxxxvii] Follow-up researches on the long-data outcomes of surgeries are quite limited and many of the existing ones have vague details regarding sexual functions, defining it as adequate or satisfactory.[ccxxxviii] The birth of an intersexed child determines the creation of a team of specialists in different fields and some specialized hospitals have a permanent team, while in other cases it is assembled ad hoc.[ccxxxix] Such teams generally include a pediatric endocrinologist, pediatric surgeon or urologist, a geneticist, a gynecologist and sometimes a psychologist or a social worker.[ccxl] The endocrinologist's point of view is of key importance to direct the intersex management and it is the first point the team starts from.[ccxli]

As an example, an adrenal disorder that determines atypical genitalia might not be recognized as those are extremely rare and the role of the endocrine team is central both for the detection and the treatment.[ccxlii] The endocrinologist will be responsible of explaining parents the expected growth and fertility issues and on the on the long term will be the one to administrate the endocrine replacement during puberty.[ccxliii] A gynecologist is required to give the team information regarding the sexual function and fertility on the long term, giving parents relevant details on the problems that they might encounter during the child's puberty.[ccxliv] The surgeon (pediatric surgeon or urologist) is needed for the evaluation of the child's condition together with the endocrinologist. These two physicians will analyze the detailed family clinical history, searching for any relevant information; will do an examination of the genitalia to assess their external appearance (penis dimension, number of orifices, labioscrotal and anal assessment); evaluate the gonads' size and assess their degree of development.[ccxlv] Once that all the evaluations are done, they must discuss their findings with the parents in a way that is comprehensible for them and they should explain terms that might result as unclear.[ccxlvi] Sometimes surgeries are not accepted by parents, or delayed until the patient is mature enough to take a weighed decision, but when the surgery is performed the ultimate responsibility relies on the surgeon.[ccxlvii] The psychologist presence is needed for the information disclosure procedure, since parents might need to elaborate the information they are given and their fears. Moreover, the involvement of such professionals aims at de-pathologizing atypical genitalia and at making parents understand the personal and social challenges their child might need to face instead.[ccxlviii] Traditionally, it was the penis size driving the gender assignment, way more than genital morphology in cases of female infants, leading to them being assigned as females regardless of the severity of genital masculinization.[ccxlix] This tendency demonstrates two underlying ideologies: the privilege of masculinity and the stronger social criteria to define a virile male.[ccl] In many cases in which there was a genetic male with a small penis the decision was oriented more towards the female rearing, regardless of their true maleness as the main concern was the future ability to perform sexual intercourse.[ccli] In 1980 different criteria for penis' "acceptability" had been elaborated creating different standards for a micropenis ranging from less than 2.5 centimeters to less than 1.5 centimeters, depending on the scholar analyzing the case.[cclii] The introduction of a written criteria (even if those were not all the same) could have been seen both as a safeguard from arbitrary assessments and as a way of enforcing rigid gender ideals, which also did not take in account that the newborn's phallus size does not necessarily predicts the adult phallus size.[ccliii] The contemporary scientifical point of view emphasizes on the importance of the harmony of different markers such as chromosome, hormones and genes and even though those are not considered as the only features that determine our gender, there is a global agreement that they contribute in a significant way,

overshadowing the concept of rearing over nature.[ccliv] When the decision for the operation has to be taken in the neonatal period different indicators are taken in account: the internal sex (biological and genetic characteristics of the individual); external sex (based on the size of the genital tubercule, vaginal opening and palpable gonads); functional sex (the expected reproduction capability and potential ability for sexual intercourse); social sex (how society will mirror the individuals).[cclv] More specifically: probe karyotyping in order to detect X and Y chromosomes; abdomino-pelvic ultrasounds; hormones assessments (testosterone, anti-Mullerian hormone, 17-hydroxyprogesterone).[cclvi] All of those screenings can lead to a functioning diagnosis within 48 hours, except for the karyotype screening that takes several days.[cclvii] Molecular screenings are currently limited by their cost and accessibility, but also because they lack a strict protocol for quality control.[cclviii] Moreover, it must be taken in account that if surgical reconstruction occurs in the neonatal period will need a refinement during puberty.[cclix] The current surgeries' purpose is preserving the organs' sensibility and the techniques adapted for this new need, evolving from the amputation of the whole clitoris or its burial to preserve as much tissue as possible to a clitoral reduction that aims to preserve the glans and the neurovascular bundle.[cclx] The surgery also aims to facilitate future reproduction in the cases in which it is viable; avoid future urinary tract infections deriving from an atypical anatomy; avoid late virilization at puberty in individuals raised as female; reduce the risk for gonadal cancer; avoid fluid retention in vaginal or uterine cavities.[cclxi] Vaginoplasty is usually performed paired with the clitoral reduction, but its timing and nature depend on the patient's condition.[cclxii] Women affected by congenital adrenal hyperplasia require a well-functioning vagina in order to permit the menstrual flow; 46,XY females will need it only for sexual intercourse; women affected by adrenal insensibility syndrome might present a short ended or absent vagina (vaginal agenesis) or a normal length vagina.[cclxiii] It must be noted that in vaginal agenesis cases it is recommended to use vaginal dilators before proceeding with a surgery and 78% of the patients using them reported a regular sexual function, but when this does not happen surgery is the next route.[cclxiv] Another attempt of avoiding surgery consists in a prenatal hormonal therapy administered in congenital adrenal hyperplasia cases, reporting successful results when the therapy started before week six of gestation, leading to a significant reduction of the enlarged clitoris.[cclxv] It is important to note that potential side effects of administered steroids are still discussed.[cclxvi] Clitoral reduction has been improved since there had be a deeper understanding of the nerves of that area, leading to a more precise reduction of the genital tubercule. Even if there have been sensible improvements to the surgery, advocates of a more delayed operations state that there is still a chance for a damage of the clitoral sensibility and that this kind of procedure is irreversible.[cclxvii] Unfortunately, adult patients still report loss of sensation, pain and scarring.[cclxviii] Patients experience sexual insensitivity that might

lead to a lack of arousability, often mistaken for low libido, but the most frequent problem is the fear of rejection that might lead to an unhealthy relationship with sexual intercourse. Some people avoid intimate relationship at all because of this fear and a sex therapy might be needed to soothe psychological problems.[cclxix] Most of the techniques for clitoral reduction involve the removal of a segment of the corpora cavernosa and some surgeons prefer to conceal it around the vaginal opening, thinking it might be needed in case the patient decides to switch to male identity.[cclxx] Once the removal has been performed, the clitoris is relocated.[cclxxi] For the reconstruction aiming to a male resemblance, there are three main steps, the first one consisting in degloving the genital tubercule to assess the hypospadias degrees and therefore the length of the urethra to be reconstructed, evaluating the size of the genital tubercule and the availability of the foreskin tissue.[cclxxii] After this first step, surgeons proceed with a urethroplasty (which can be performed with different techniques) and end the operation with the penile skin shaft refashion.[cclxxiii] The complexity that the phalloplasty entails should be considered and must be disclosed to parents, moreover unrealistic expectations should not be fostered.[cclxxiv] In patients presenting testis, if those are not removed, there might be a cancer occurrence after puberty. Male gonads can be partially or totally removed, but if the patient and the medical personnel decide not to do it the testis will require regular examination by ultrasound scans or biopsies.[cclxxv] The higher risk of tumors is detected in cases of positive gonadal dysgenesis and PAIS with intra-abdominal gonads, while a lower risk (<5%) is found with pathologies like ovotestes and CAIS.[cclxxvi] The remaining Mullerian pouch in male assigned patients can be removed in order to avoid urinary tract infections, stone formation or cyclic pain, such removal can be performed either with an open surgery or laparoscopically. Conversely to the remaining testis, Mullerian remnants have rarely determined cancer.[cclxxvii] Vaginoplasty and phalloplasty carry different burdens. The former can determine potential scarring and numerous modifications before any sexual activity is viable, together with a risk of neoplasia in cases of neo-vagina reconstructions; the latter is way difficult to perform and highly depends on the availability of erectile tissue and the severity of hypospadias and might also determine urological difficulties.[cclxxviii] Recently, with the Consensus Statement on Management of Intersex Disorders published in 2006, the switch occurred in the medical field has been made obvious as physicians have started to minimize the range in which the feminizing surgery for infant is suggested.[cclxxix] The narrowing of the patients eligible for the forgery has happened because there is a lack long term follow-ups of performed operation, especially there are almost no data da prove that said procedure increases the patients' quality of life or soothe parents' distress about their intersexed children.[cclxxx]

2.3 Ethical Issues

Before the emergence of bioethics, during the 1930s and the 1940s, doctor did not do many assessments to determine what was the best sex assignment for an intersex child, they were more oriented towards the correction of what was perceived as a wrong external conformation.[cclxxxi] The surgery was done with the idea that it would have helped the individual to discover his or her true sex, leading to performing such surgeries on intersex individuals quite easily and without many concerns even in their adult life. Some surgeons stated that sometimes the operations were conducted basing on the patients' desires, Hugh Hampton Young underlined how he accepted to operate a patient that demanded a testicle implant.[cclxxxii] The surgeon proceeded to perform it and reported how in the first year after the procedure the patient was feeling like a «real man» and that he was living a satisfying sexual life. Sadly, it is also reported how this satisfaction did not last on the long period.[cclxxxiii] Apart from the shallowness by which surgeons decided to operate, the surgeries were quite experimental as there was no common knowledge on intersex individuals and the main excuse for such procedure was that patients demanded them.[cclxxxiv] The trend of operating intersex cases in infancy that arose in the 1950s seems to clash with the rise of core bioethical principles (informed consent, non-maleficence and autonomy) after the second World War. Management of intersex newborns seemed not to benefit from the enhancement of the patient care.[cclxxxv] After the elaboration of the Nuremberg Code in 1947 physicians had new standards to follow, in order to prevent any repetition of the atrocities deriving from the Nazi medical experiments and therefore prescribing voluntary consent as a minimum requirement for research. Another groundbreaking event was the Declaration of Geneva in 1948, in which there is a particular emphasis on the concept of respect of autonomy and dignity of the patients.[cclxxxvi] During this period some physicians started to question the legitimacy of corrective surgeries on newborns, but -as Elizabeth Reis argues on her paper «Did Bioethics Matter?»- the bioethical principles that were becoming of core importance for the treatment of adult patients seem to have had an extremely lighter impact on the ones of intersexed newborns. As an example, clinicians encouraged parents to agree to surgeries and promoted silence towards the children even when they would have grown up, sometimes non-disclosure to parents was practiced too as it was thought that it would have favored the bond between parents and children.[cclxxxvii] Once Money's procedures were standards of care, it was difficult for parents to withhold consent from a procedure that was considered as extremely reasonable and very likely to succeed. Nowadays, many

clinicians prefer to advocate against the surgery, but many others still endorse it and succumb in parents' desire to have a «normal child».[cclxxxviii]

Autonomy, Law and «the Habitus»

Autonomy is a word that derives from two Greek words: autos ("self") and nomos ("governance") and its first employment was of a political nature, as it was used to referring to some Hellenistic city-states that had an independent government.[cclxxxix] When extended to individuals, autonomy is more referred to being able to choose with an adequate understanding of the matter and without any external interference. An autonomous individual is able to act according to his own plans and desires.[ccxc] Specifically, an autonomous choice that leads to an informed consent must be done by someone who acts intentionally, with a deep understanding of the situation and without controlling influences.[ccxci] The term informed consent appeared decades after the Nuremberg trials and its recent connotation consists in the doctors' obligation to disclose the right amount of information to an understanding and consenting patient.[ccxcii] The right for an autonomous choice aims at preserving the individuals' right to bodily integrity and self-determination and it entails: the requirement for doctors to fully inform the patient and receive the clear consent to proceed.[ccxciii] It is obvious that the ability to weigh risks and benefit in necessary to give informed consent and some patients might not be able to do it as they are unconscious due to a medical condition or they might be too young, as with intersexed newborns.[ccxciv] Supposedly, close family members are the ones entitled to take a decision for the impaired person, supposing they have the sufficient knowledge of his or her wishes and interests and that they are interested into the patient's best interest.[ccxcv] In cases as severe as terminating the life of a child in a vegetative state; donating an organ to benefit a sibling of the impaired child or approving the involuntary sterilization of either a child or an incompetent adult, courts generally review the parents' consent to the treatment.[ccxcvi] Generally, legal institutions do not interfere with parental choices, unless there is a strong dissonance between what is medically advised and the chosen path, or in cases in which the courts determine that the parental choice might not be fully taken in the patients' best interest.[ccxcvii] In the aforementioned cases, the control over parents is exerted as there might be a violation of extremely important rights as the right to life of reproductive choice.[ccxcviii] On top of that, in some cases parents might have mixed feeling, deriving from the dissonance of their interest from the child's ones.[ccxcix] In organ donation cases, they have to decide if expose their other child to substantial risks of an operation to benefit their impaired son or daughter.[ccc] Even though the approval for a cosmetic surgery entails difficult issues, this kind of approval is not scrutinized by courts to assess if the child's rights are fully respected.[ccci] There is a strong dichotomy in the way sterilization and cosmetic genital surgery (that usually leads to infertility) are treated in the United States jurisdiction.[cccii] The former has been prohibited since the 1942 case Skinner v. Oklahoma, in

which the court sustained that the right to procreation in protected by the Constitution leading to the limitation of circumstances in which sterilization could be performed.[ccciii] Operations on intersexed newborns, on the other hand, have not the same limitations as the infertility deriving from cosmetic reassignment surgeries is a side effect and not the main purpose.[ccciv] Some organizations argue that the courts' approval should be sought in cases that cause invasive and irreversible procedure that do not comprehend sterilization.[cccv] The executive director of Advocates for Informed Choice stated that even with an upgraded notion of informed consent we would still face problems linked to parental decision.[cccvi] Parent could not be able to correctly assess the long-term interests of the newborn; the informed consent procedure might not take an account cultural biases; the choice might be dictated from shame deriving from raising an intersexed child.[cccvii] Parents even feel the stress of making what might be best for their child, sometimes leading to biased decisions, as demonstrated by the psychologist Suzanne Kessler, who conducted a study in a college and divided the students in two groups basing on their sex.[cccviii] She then asked to the females group whether they would have been satisfied if their parents agreed to a clitoromegaly correction surgery, while the males were asked whether they would have preferred to be reassigned as a female or live with a micropenis. 93% of the females said that they would have not wanted their parents to agree to the surgery, as they thought that a clitoromegaly would have not worsened their life quality as much as the inability to orgasm; in the male group more than half would have accepted the micropenis, but if it was made clear that their penile sensibility would have been impaired by the operation almost all male students rejected it.[cccix] It is fascinating to notice how the reasoning became way different when the students when asked if they would have consented to a cosmetic (and not life-saving) surgery for their intersexed child, discovering that almost 100% of students would have approved the surgery thinking it would have been less traumatizing for the child than feeling different from other people.[cccx] This reversal of the rationale used to take decisions can be explained by the child psychologist Linda Budd, who stated that parents usually have the tendency to do what they think will make the child's life easier, providing quick fixes and therefore failing to let them develop competent adults.[cccxi] She also evoked the metaphor of the «curling mom», referring to curling players that are cleaning the stone's path to lead it to its destination, representing a parent that wants to smooth the child's life at any cost.[cccxii] Of course, there are psychological incentives to be that type of parents, as the sense of accomplishment for making the child safe and adhering to what the philosopher Pierre Bourdieu defined as the «habitus».[cccxiii] This concept was explained as principles that organize and generate the practices that somehow shape the individuals' actions, in order to conform to the desirable outcomes even without consciously aiming to do so.[cccxiv] Meaning that said habitus can be defined both as a «structured structure» and a «structuring structure» and the dichotomy of men and women is a great example.[cccxv]

These differences can be considered responsible of structuring the social order and to place us in a certain role (as girls and boys or mothers and father) and the concept of being «outside the norm» proves how pervasive can this concept be for human beings, which can act both in a conscious and in an unconscious way.[cccxvi] Parents wish that their children adhere to what is perceived as the norm and the way the management of intersex conditions is shaped suggests that this implicit normative order is quite present in the medical field when we are talking of cosmetic surgeries.[cccxvii] Following the «habitus» reasoning, the birth of an intersex child prompts a clash with the conceptions that are taken for granted, leading to its correction.[cccxviii]

Non-disclosure Issues

Information disclosure is necessary if physicians want to obtain a proper informed consent and a clinician that fails to correctly inform a patient might be part of a controversy that might lead to the requirement of monetary compensation.[cccxix] Over time and because of the many litigations that occurred in the informed consent field, there has been an ongoing improvement in this procedure, especially regarding disclosure.[cccxx] Disclosing information is an activity in which both the professional and the patient take part and if the process is correctly done, subjects will have a sufficient understanding to decide what to do.[cccxxi] In Money's protocol it was advised to five children age-appropriate information about their condition, a guideline that reflects the tendency to act in full honesty regarding disclosure in medicine, nevertheless there are some clinicians that advocate for full non-disclosure of the diagnosis.[cccxxii] On the other hand, Money also informed parents with unclear terms like «genital unfinishedness» and also argue in favor of a relocation of the operated child if she or he underwent a reassignment surgery, therefore his position on this point seems quite unclear.[cccxxiii] It must be noted that Professor Geenberg, an internationally recognized expert on legal issues linked to intersex conditions, underlines that many clinicians identify some deception as necessary for the practice to be successful and that children benefit more by being told less than knowing the whole truth.[cccxxiv] She also notes that physicians tend to what is not usually disclosed is the possibility for children to not identify with the surgically assigned sex, because that do not want parent to doubt about their choices regarding such intervention.[cccxxv] Moreover, this kind of course of action requires to accept that there will be continuing partial deception regarding the biological characteristic of any intersex individual, as noted by Professor Dickens.[cccxxvi] Physicians, but moreover parents, tend to prefer the non-disclosure or partial disclosure path as they feel that the child could share the information at school and might be teased for his or her conditions, or that in general too much knowledge could be detrimental.[cccxxvii] This is justifiable for small children, but in some cases this kind of tendency is preserved during the individuals' adolescence or adulthood.[cccxxviii] It must be noted that the fear that too much information might be detrimental for the patients' psychological wellbeing

is not supported by almost no empirical data.[cccxxix] But moreover, intersexed individuals that discover their condition (and the secrecy behind it) at an advanced age might betrayed by both parents and clinicians and develop a sense of shame.[cccxxx] On the other hand, full disclosure to children does not mean that everything will be easy, since the irreversible process of gender reassignment is likely to be already done once the children are told about their situation.[cccxxxi] Many intersexed individuals, while recalling their childhood experiences, state that they lived in an atmosphere of shame and stigma linked to their bodies and that they felt humiliated because of the invasive medical procedures they had to undergo.[cccxxxii] More importantly they feel that this attitude of not discussing their condition exacerbated feelings of anxiety and abnormality they were experiencing, leading the children to close on themselves.[cccxxxiii] Non-disclosure also happens when children have to undergo further surgical procedures as recalled by Teresa Diaz, who is affected by partial androgen insensitivity syndrome: «I had some fear that they'd do surgery on my clitoris, but since they hadn't said anything, and they seemed to be very explicit about everything else, I started to breathe a little easier».[cccxxxiv] She proceeds to explain that her clitoris was a recent and pleasant discovery, but unfortunately her mother and the clinicians did not fully inform her and she later discovered that her clitoris had been removed, leaving a crusty and painful area.[cccxxxv] Later on, two years later and when Diaz was fourteen years old, she had to undergo another surgical procedure linked to the previous vaginoplasty that no one told her about.[cccxxxvi] She remembers that the only information she received were the ones obtained while talking to a psychologist the night before the operation.[cccxxxvii] What is concerning about the non-disclosure operated in intersex cases is that it goes against what has been prescribed in the last decades, since physician's therapeutic privilege and paternalism have been rejected by the clinical medicine, leading to the full information disclosure practice.[cccxxxviii] It can be argued that a newborn is absolutely not capable of understanding any information, but some information should be disclosed once the child start growing and being more self-aware, a practice perpetuated even in terminal conditions in most of the medical field.[cccxxxix]

Respect of Bodily Integrity

Bodily integrity, connected to autonomy and self-determination, has been coined by Feinberg that sustained that the respect of this right determines the possibility for a child to take important life choices for himself or herself, without someone intervening.[cccxl] The surgical treatment of intersex newborns differs from procedures in which children do not take part in the decision, such as orthodontic treatment or vaccinations, as the sex reassignment surgery will impair a functioning intimate tissue, leading to an infringement of the bodily integrity.[cccxli] As a matter of fact, the children's development is irreversibly limited by surgeries they had to undergo without giving valid consent and will not be able to easily determine their gender identity and moreover the operated child

might not be satisfied of gender chosen by the decisionmakers.[cccxlii] Furthermore, it is difficult to argue in favor of the reassignment surgery because of different reasons: in the past, due to what was defined as the «concealing model» parents were not totally informed about their child's condition, a parental unawareness that was considered functional to the avoid confusion that might have led to a scarce bond with the newborn; while in the cases in which caregivers are wholly informed about the child's conditions it remains unclear whether they are able to give a rational informed consent to this unnecessary cosmetic procedure, mainly because of the irreversible impact those will determine but also because the biases parents are subjected to (cultural, emotional, lack of medical knowledge).[cccxliii] More importantly, there are no sound proofs that genital interventions have worse outcomes if postponed to once the child can freely choose or at least be part of the decisional process.[cccxliv] The postponement would solve the bodily integrity infringement, as it avoids the possibility for a decisionmaker to limit the range of choices that a child would have if he or she were not operated on the base of cultural and social rules.[cccxlv]

2.4 Who Should Decide?

There are different factors that might disturb the parents' rationality, as the fact that a child with atypical genitals cannot be correctly labeled as male or female and therefore its naming is not possible; the newborn is generally taken away right after birth from parents to conduct further tests and the medical personnel might use ungendered pronouns, using «the baby» instead.[cccxlvi] In this sense, biology seems to determine the newborn's social and legal identity and without a precise gender assignment the child seems to be socially inexistent.[cccxlvii] Birth registration can also be distressing for parents, as they need to provide the child's name and the sex, which in the case of an intersex child has still to be assigned.[cccxlviii] In some European States (Portugal and Finland) sex categorization does not have a time limit, but most of the States prescript a maximum amount of time in which the registration must be done, ranging from a period of a week to three years.[cccxlix] More importantly, all European countries, apart from Germany, do not provide a third option in which intersexed individuals can be categorized.[cccl] All these dynamics put a lot of distress on parents, making it difficult to assess if it is morally and legally correct for parents to give valid consent for their intersexed child non-therapeutic operation.[cccli] Those surgeries are highly invasive as they determine irreversible outcomes and the recent publicly of intersexed individuals' interviews have shown how most people felt violated by it, without a sufficient justification.[ccclii] Who should make the decision, then? It is still a debated issue, as some professionals think parents should be the one choosing and some others think that the medical personnel should be responsible for gender determination, mainly because the choice should not be based on emotion but rather on science.[ccliii] Even within the medical

equips that work with intersex cases there might be disagreement upon this matter, leading to power struggles that might influence the process. Some surgeons think they are not suitable for choosing the newborn's gender and therefore they refuse to take part to the decision, while some urologist might think that there should be an agreement between what parents prefer and what the physician thinks is correct to do.[ccceliv] Some clinicians think that the inability to deeply understand medical, biological and chromosomal matters does not allow parents to give a full informed consent and proceed to explain how it is not viable to make them understand what intersex is about.[ccclv] Some scholars critiquing the current procedure but think that the newborns' surgical treatment should be allowed anyway, argue that parents do not necessarily guarantee the protection of the child's rights or best interest.[ccclvi] They suggest a strong role for an independent court or a hospital ethic committee when decision has to be taken, as those would be composed of not emotionally involved people that are adequately informed on the matter.[ccclvii] The ideal ethical committee, they suggest, is composed of various professionals together with intersexed adults.[ccclviii] All things considered, allowing parents to give the final consent to the surgical route seems to be controversial as they might not be capable of correctly evaluate the child's priorities on the long run.[ccclix] One solution might be waiting until the person is capable of giving legally valid consent, but it must be noted that there is no empirical evidence that delaying surgeries leads to optimal outcomes or that adolescent are able to make more rational decisions, as they might be influenced from others factor (as social pressure).[ccclx] On the other hand, forcing intersexed individuals to wait for adulthood might be psychologically exhausting.[ccclxi] One alternative, proposed in the book Intersexuality and the Law, advocates a model composed a two-step approach involving both a court and an ethics committee.[ccclxii] The ethics committee should be sufficiently heterogeneous and composed of different type of experts (i.e. endocrinologists, sociologists, psychologists, pediatricians) and adults living with an intersex condition.[ccclxiii] This committee would have four different purposes: provide guidance to parents; provide expertise for the court guidance; analysis of the different outcomes of different treatments; inform and educate parents, children and other physicians on the intersex matter.[ccclxiv] The ethical committee would then elaborate an advisory opinion and the court would proceed to approve the procedure, with the protection of the newborn or child as a priority.[ccclxv] To better guarantee his or her best interest, an advocate for the child would be required in the court proceeding.[ccclxvi] The procedure decided for the child should be clearly analyzed and discussed for a complete and accurate assessment of the prevalence of benefits over the risks.[ccclxvii] This procedure would guarantee that the ultimate decision maker is fully informed, there is a lower risk of irrational decision and every facet of the child situation is explored.[ccclxviii] Another alternative to the traditional paradigm could consist into waiting until the intersexed newborn becomes old enough to decide on his or her own, but it must be noted that there

are no extensive studies that prove that delaying surgeries lead to less psychological discomfort.[cccLxix] This option would determine the full respect of the individual's right to autonomy and privacy, but on the other end it does not ensure that the choice taken by the intersexed adolescence might be the best one.[cccLxx] Cosmetic surgery is advertised and promoted as the salvation from what is not the idealized norm and some specialized doctors even state that intersex women choose an elective genitoplasty with unreal feminine standards in mind.[cccLxxi]

2.5 Europe and Bodily Modifications

Historically, genital alterations have been practiced for thousands of years. Some findings suggest male circumcision might have been practiced since Stone age there is no doubts that it was done by Egyptians, Aztecs, American Indians and more.[cccLxxii] Female bodily alterations, on the other hand, do not have documented origins but they are generally dated as prior to the major religions as Islam or Christianity.[cccLxxiii] The underlying reasons for female mutilations are cultural, religious, gender-related, socio-economic and due to immigration, it has spread from Africa to European countries.[cccLxxiv] Those modifications were not carried only in the past and in 2007 the World Health Organisation estimated that estimate that 125 millions females have been subjected to genital mutilations, while 30% of all males have undergone circumcision.[cccLxxv] A statement done by WHO together with UNICEF and United Nations Population Fund (UNFPA) estimated that female genital mutilation is performed without any medical reason. There are different recognized forms of female mutilation: clirodectomy (partial or total removal of clitoris and/or its foreskin); excision (clitoris and labia removal); infibulation (narrowing of vaginal opening to avoid sexual pleasure); various other modifications of the vagina with no medical reason.[cccLxxvi] Male circumcision is supposedly datable before Islamic and Judaic traditions and it is practiced all over the world, but the number of circumcised male il slowly lowering.[cccLxxvii] This procedure is linked with the passage to «manhood» when linked to religious rituals, but it is also carried for medical and health related reasons as: phimosis resolution, prevention of urinary tract infections and sexual diseases and more. It usually performed at birth and it entails the partial loss of sensibility of the penis.[cccLxxviii] These two bodily modifications share with sex reassignment surgeries some traits: parents decide to intervene on non-consenting children and for non-therapeutic reasons.[cccLxxix] All the similarities aforementioned led the member of Intersex Society of North America to compare nonconsensual genital modification to female genital mutilation, referring to reassignment surgeries as «intersex genital mutilations» because of the override of important right as bodily integrity, informed consent and autonomy.[cccLxxx] But for some reasons, all those three practices have been treated differently and have determined different global reactions.[cccLxxxi] The European Parliament has condemned female genital mutilation

as it violates fundamental right and has invited States to outlaw it; the UN has adopted a resolution to eliminate such procedure globally.[cccclxxxii] Conversely, the legal framework regarding sex reassignment surgery on newborns and male circumcision is extremely different and there are not specifical legal limitation in the European states, apart from some Member States.[cccclxxxiii] More specifically, Malta outlawed non-life saving surgeries in 2015, with a legal disposition that prohibits sex reassignment procedure is the intervention can be performed when the patient can give consent. Portugal approved a law on unnecessary surgeries that postpones them until the intersexed individuals have chosen their gender identity, meaning that those surgeries are not totally banned.[cccclxxxiv] Germany had some of his courts stating that the individuals' rights were not respected, as the surgeons did not give the patient the right amount of information about the surgery.[cccclxxxv] Regarding the circumcision, the Italian law case of the Court of Padova saw the recognition of the violation of bodily integrity due to the circumcision, but the procedure has still been considered lawful as it serves to integrate the child in a culture or religion and due to the fact that it is accepted by the society.[cccclxxxvi] In Sweden specialized protocols have been created for intersex treatment, ruling that between the age of two and twelve no genital surgeries should be performed, but unfortunately gender reassignment surgery is done when the child is around the sixth month of age.[cccclxxxvii] States as Switzerland, Austria and Germany adopt the recommendation of Paediatric Endrocrine societies, both the American and the European one, and therefore they apply the so-called Chicago Consensus.[cccclxxxviii] The German Court also stated that the parents' fundamental right to approve procedures for underage children is limited by the infants' right to bodily integrity and self-determination, rights that are infringed once the circumcision is practiced.[cccclxxxix] In 2021, Germany proceeded to ban surgeries on intersex babies, unless that a family court approves it. The main fear of intersex rights group is that parents and doctors will ignore this law by avoiding the intersex diagnosis, moreover seen the fact that the legislation does not foresees any punishment.[cccxc] All things considered, it is easy to deduct how male circumcision is seen as a private matter that overrides the child's rights but in an acceptable way, as it is considered functional to the child's wellbeing and a religious matter and therefore it has gained a deep social acceptance.[cccxci] Parents do not face legal charges if they decide to make their child undergo circumcision, except in the cases in which one of the two adults refuses to give consent to the procedure, leading to a court case that aims at correctly assessing what constitutes the child's best interest.[cccxcii] Female genital circumcision prompts from a patriarchal mindset and ritualistic believes and is more debated, but it is condemned by any western state and parents in most of the European countries are punishable if they give consent to such procedure.[cccxciii] Intersex genital surgeries are considered a needed practice to conform the child to what is perceived as normal and healthy, as the

intersex individuals (apart from salt-wasting conditions) is generally healthy and does not need corrective operations.[cccxciv]

3. Real Cases Analysis

3.1 Findings on Operated Individuals

David Reimer (or John/Joan) Case

Even though David Reimer was not originally intersexed, his case was extremely influential both for the elaboration of Money's theories gender-socialization theories and for the debate around intersex treatment.[cccxcv] Firstly, because the initial outcomes made Money state on the original report that rearing patters had a huge influence on the child's psychosocial differentiation, determining a male or female identity basing of how the individual was nurtured.[cccxcvi] What made this case so famous was the entailed connection with other social challenges, most importantly the challenge revolving around the re-emerging of the theories of gender differences rooted in biology.[cccxcvii] This case, earlier known in the medical field as the John/Joan case, was the story of a set of identical male twins that developed phimosis.[cccxcviii] Such condition is characterized by the closing of the foreskin, making it difficult for the patient to urine and to have healthy hygiene.[cccxcix] It is generally solved with a surgical treatment involving classic circumcision practiced with a knife and a bell clamp, but sometimes surgeons decided to do the operation with a cautery as it closes any blood vessel thanks to the high temperature.[cd] In the twins' case, the cautery usage determined the destruction of one of the boys' penis, leading parents to search for different professionals' opinions which were not positive, as the penile reconstruction was not developed enough to offer a viable remedy.[cdi] After some time, they say a TV show featuring Dr. Money and they consequently went to the hospital in which he worked, the Johns Hopkins, to meet him.[cdii] The chosen path was to raise Bruce as a girl: the idea was to allow John to have a functioning vagina that would allow him to have pleasant sexual intercourse and what could have been considered as a normal life, thanks to the reassignment surgery.[cdiii] It was later told by the Reimers that they did not understand, during the meeting with Money, that he and his colleagues were practicing the reassignment operations only on intersexed individuals and not on newborns that did not present atypical genitalia at birth, making the Doctor's undoubtful statements on the success of the operation way less believable.[cdiv] Moreover, Money seemed to exert a lot of pressure on them via letters, telling the parents that they were procrastinating and that they could not wait any longer.[cdv] Ron and Janet Reimer, as the time was passing by, were more and more convinced about allowing the doctors to proceed with the surgical operation.[cdvi] She states in an interview: «I though, with his injury, it would be easier for Bruce to be raised as a girl – to be raised gently. He would not have to prove anything like a man had to»; while Ron said «You know how littles boys

are. Who can pee the furthest? Whip of the wiener and whiz against the fence. Bruce would not be able to do that, and the other kids would wonder why».[cdvii] What made the parents even more concerned were the humiliations that sex life would have given their child and if what Money promised them – the prospect of a happy and typical life – turned out to be true, they would not have to worry anymore.[cdviii] After the meeting and the Johns Hopkins and after the couple took its time to reflect, Bruce did not have his hair shortened anymore and all of his masculine clothes turned into girly gowns and his name changed to Brenda.[cdix] When the child was twenty-two months, surgeons proceeded to remove his testes and to remodel his scrotum to look like rudimentary vagina, as the scrotum was sewed to resemble two symmetrical labia.[cdx] The Reimers did their best to teach Brenda how to be a girl by reinforcing her feminine behavior and buying her girly toys such as dolls, but they remember their girl refusing most of those things.[cdxi] Brenda refused to wear dresses and expressed the desire to shave once she was teaching her father playfully teaching her brother how to do it. Brian, the other twin, remembers how she has never seen Brenda as girly because they used to play to the same games, she was continuously asking to borrow his toys and was not interested in what was thought a woman had to learn or in marriage.[cdxii] Brenda's mother complained about these difficulties to Dr. Money in some letters and he reassured her calling Brenda's attitudes as «tomboyishness».[cdxiii] Five years after the operation, in 1972, Money decided to make his «Twins case» public.[cdxiv] He spoke about it at the American Association for the Advancement of Science in Washington meeting, but moreover he cited the case in his book «Man & Woman, Boy & Girl».[cdxv] In the book he even mentioned the fact that Brenda's gender identity sometimes seemed to be oriented towards male behavior, but he considered this tendency as insignificant comparing to all the other ways Brenda was conforming to other girly stereotypes and affirmed that her attempts to urinate while standing and dismissed them as in his opinion many girls try do to that and in her case, it depended on copying her brother.[cdxvi] The case, from that point, started to be cited in many medical and scientifical books and studies and became extremely popular and Dr. Money kept mentioning it and adding details as he was invited to different events.[cdxvii] He even added photos of the two twins and close-ups of Bruce right after his penis was destroyed. It was considered like a flawless medical success. Years later, when Brenda was seven, Dr. Money became to think that it was the time to perform the conclusive surgeries on Brenda's body: the first to lower the urethra in a female position and the last one to create the vaginal canal. He considered it a critical passage as the girl's psychological identity would not have been correctly developed if they did not conclude the physical changes. Despite Money telling Brenda «We can make it [the genitals' appearance] look like it's supposed to look» the girl strongly refused to accept the idea of surgery and started to resist to the visits at the Johns Hopkins. Brenda's continuous refusal of the surgery regardless of the doctor's efforts made him frustrated, while on the

other hand the girl's mental health was deteriorating due to the pressure received to accept the further procedures. Even inside the household there was a growing tension as the parents' colluded with the doctor to convince Brenda to undergo surgery, leading to her to strongly oppose to them and to the extended family that were pressuring on her to act like a lady.[cdxviii] When the family suspended the contacts with Dr. Money, he kept continued to promote the case as extremely successful, but Brenda actually switched back to the male life and chose to be called David. He underwent mastectomy to remove the breasts deriving from estrogen therapies and underwent many surgeries in order to convert his genitalia from female-looking to male-looking. The result of the penile reconstruction was a sensationless tissue with the urethra at the base of the penis, but the reconstruction allowed him to a partially satisfying sexual life once he was married.[cdxix]

Ruby, Paige and Maggie

Ruby has two daughters: Paige and Maggie. Both of them were affected by salt-wasting congenital adrenal hyperplasia, leading to an adrenal crisis almost immediately after the delivery. Paige was born in 1961 and was firstly labeled as male. She had her first surgery at three months, the second surgery at two. The latter daughter was operated at three months as well and she underwent a clitorectomy as she needed to look more female. She subsequently suffered from numerous infections, leading to more surgeries that left her with no clitoris left and the massive presence of scarring. The two sisters were subjects of medical care for their whole childhood, as they had to undergo different studies in which they were made purposedly ill to study salt levels in their body and examinations in private parts at such an early age. Maggie developed a strong resentment both towards her mother and the physicians, as Ruby recalls: «Maggie is angry with me as an adult. She felt that she was raped, medically raped. »[cdxx]

Sara and Jim Finney

The moment after Sara and Jim's child was born they were told they had a girl, but they were not convinced as the genitalia seemed too masculine for a female. Right after the delivery they were interviewed and described how distressing the birth of an intersexed child had been for them, firstly because the endocrinologist told them not to name the baby immediately and secondly because they did not know what to tell other people. Another thing making them upset was the idea of referring to the child as «it». What was concerning to the parents was also the idea of waiting before naming the child and they were resented by the fact that everyone was referring to him or her only as «the baby» and therefore they proceeded to name the child as Sam James. The endocrinologist was not happy with them naming the baby, as the medical personnel suggested to wait for the test result to determine the gender assignment. The final diagnosis was mixed gonadal dysgenesis, with the newborn presenting a testicle on one side and a poorly developed gonad on the other. The Finneys had two

options: making their child undergo many surgeries to become a boy, with the 90% risk of developing a gonadal cancer or removing the gonads and giving the newborn female like phenotype, administrating estrogen and growth hormone. Both Sara and Jim were really hoping to have a boy and the final decision of raise Sam James as a girl made them feel as they lost a son. What oriented their choice were two main things: firstly, the medical information they received from the doctors and their pressure as the physicians thought the best thing to do was the female sex and secondly the attended social impact on the child's life. As Sara stated: « "I am going to have a short, feminine, small-sized boy". Kids are cruel. If he takes a shower in high school and they see a small penis, that's it. […] I thought, "What the hell did I give birth to?" » demonstrating how distressing can be these kind of choices for a parent and how difficult it is to make the so-called right decision. [cdxxi]

Susannah Temko, «A different kind of superpower: what it means to be intersex»

«To give you an idea of the intersex experience: what if, when you were an infant, your parents or your doctors looked at your labia, your penis, your testicles and thought «they're healthy, but they're not normal» […] what if they went so far as to sign you a different sex, based off these measurements and then they lied to you on what they had done. What if these surgeries sterilized you? What if they resulted in immense pain and scarring? What if you had to take medicines for the rest of your life to replace the healthy organs they took away? ». When Susannah Temko was sixteen, she was told she is intersex and she has XY chromosomes and presented of gonads instead of ovaries. When delivering her TED talk, she underlines that intersex are treated like they do not exist even though there are many historical records of their presence and that they are more on less the same amount of red-headed people. She points to the biases that affect both medicine and law. Regarding the medical field she underlines that most children affected by intersex conditions are routinely operated to make their healthy anatomy more similar to what is perceived as normal. Many people are not told they are intersex and the ones that are informed are oriented towards secrecy because of stigma and shame. While in the law realm, the existence of intersexed individuals challenged preexisting categorization and lack of protection of laws like gender recognition or the equality act. She also underlines that nowadays the challenge for intersex people is to be less invisible and publicly heard, feeling part of the society and not some sort of mythological creature. Being visible would mean to end the binary concept of normality and to gradually overcome the stigma around intersex people, meaning that many parents would not agree to sterilizing surgeries in order to «fix» their child.[cdxxii]

1.2 Findings on Non-Operated Individuals

«I am so pleased I never had surgery. The people I met, most of them, black and white, who have had surgery as babies, usually had confused parents whom the doctors incorrectly informed, and the

children were subject to surgery which has ended up being far more traumatic and confusing… We have been raised in a world that makes us feel like monsters. My advice to other intersex people is to love and accept. Only then you will make the right decision about surgery… surgery is not a magic pill that has no consequences. » Nthabiseng Moekwena, South African intersex activist.

Micropenis and sexual satisfaction

An article titled «Mutually Gratifying Heterosexual Relationship with Micropenis of Husband» treated the cases of three intersex individuals, of which two were two genetical females affected by congenital adrenal hyperplasia that had been raised as males and a genetic male affected by micropenis.[cdxxiii] The two female individuals were used as an example, by the authors, to prove that men with a clinically small phallus could have a satisfying sexual and romantic relationship. Both of the CAH affected individuals raised as men were able to establish heterosexual relationships and become fathers thanks to donor insemination underwent by their wives and this served to prove how also fertility is not necessarily required in order to create a family.[cdxxiv] What was groundbreaking about this article was that it was openly stated, by the authors, that intravaginal sexual intercourse was not necessary for a happy relationship and that people with micropenis were able to experience physical pleasure.[cdxxv] Two things must be noted about this study: it shows how intersexual individuals can function only in a heterosexual paradigm and that there are not observations about the treatment of female microphallus, as the authors were advocating only against the surgical treatment for the male one.[cdxxvi] Another study conducted on a sample of twenty males ranging from ten to forty-free years old tried to analyze if there were a link between male gender and the penis size. The authors noted that none of the patients felt «less male» basing of the size of the penis and that it did not stop them from having a sexual life.[cdxxvii] There are two main problems linked to this study: the sample comprehends ten years old children and the questions about sexual activity were only linked to masturbation and penile-vaginal intercourse. [cdxxviii]

Emily Quinn, «What I've learned from having balls»

« I was ten years old when I found out I could not have children. While other kids were on the playground or afterschool activities I was at the gynecologist office, having genital exams, cap scans, MRIs, blood run. I found out I was born without a uterus and inside my body I have testicles instead of ovaries. […] Imagine what it would feel to learn that about yourself at age ten». When Emily Quinn found out she was intersex she was given only a little information about their condition, apart from the fact that she needed to remover the testes in order to avoid cancer and that she had XY chromosomes. Doctors told her she had a rare disorder and it was very unlikely for her to meet people like her and that she had to keep all this secret. At age twelve, in a science class, she found out that her chromosomes were typically male and it clashed with her external appearance. The fact that no

one told her any relevant information about her condition determined two things: she was extremely angry at her mother for not telling her and she went to look it up on the internet, searching for some answers. All that she found consisted into forums that described individuals with atypical sex characteristics as hideous individuals, making her feel ashamed of her own body and making her feel as she was keeping a terrible secret. She recalls about having this recurring dream in her teenage years, in which she told everything about her «deepest, darkest shame» right after her boyfriend proposed to her, leading to him running away. When she tried to open herself at age seventeen, a friend of her started crying and stated that if she were in her same condition, she would have killed herself. It is not surprising hearing Emily Quinn state that she lived her condition in deep shame and that she felt worthless. When she turned eighteen, the gynecologist said she would have never been able to have a sexual intercourse if she did not undergo a corrective surgical operation. She decided to postpone di operation as she was close to starting college and did not feel ready for the testes' removal. It was once that she was in college that she met a doctor that she trusted, as this physician spoke openly about her condition and did not require her to undergo invasive genital examination that the young woman was used to. Quinn states that she now feels as violating and degrading the fact that many doctors examined her genital and that she perceived as normal getting undressed right after entering the doctors' offices. She sustains that for testes removal -which in these cases are situated in the abdomen- a genital examination is not needed and that physicians were analyzing her just for the sake of curiosity. She is extremely happy of not undergoing any removal surgery, underlining how painful it is to be surgically treated and how unsettling some of the side effects are. Quinn argues against the concept that intersexed individuals are perceived a deviant or abnormal, stating that 150 million people in the whole globe cannot just have «broken» bodies. All the experiences that she lived led her to become an activist of a leading organization in the United States and to develop the main character of Adventure Time, a well know TV show, publicly representing the intersex community for the first time and making many teenagers or adult less alone.[cdxxix]

Conclusion

Needless to say, intersex management is a complex and still debated issue that involves many emotions, interests and moreover uncertainty. Atypical genitals, over the last centuries, have been treated following different approaches but it does not seem that the ideal one has been found yet. Affected individuals had to bear, first and foremost, unwanted surgeries that in some cases left them with an undesired assigned sex and subsequently they had to live with the stigma associated with their condition. Two main things that, in my opinion, would be useful: collecting sound and long-term data regarding both operated and unoperated individuals and educate people on what intersex is.

Moreover, since that science has shown how sex is not just binary, but it is composed by different pieces that interact with one another in complex ways that are still not deeply explainable. Secrecy and stigma around intersex should not be existing, as those are simple medical conditions as many others that are not perceived with such embarrassment and moreover it makes parental choice more oriented towards «fixing» the wrong child that does not satisfies binary conception of sex. Culture surely plays a huge role in intersex management: parents that receive an intersex diagnosis usually live it with deep shame and feel responsible for the child condition and usually wonder what the child will do once he or she will have to socialize and the other children notice their different characteristics. If there were a deeper a broader understanding of how many differences are entailed even within the same sex, there would be way less shame and fear of slight differences. What could be crucial as well might be a legal reform, which might be also done on a European level, providing stricter guidelines for the intersex treatment and there should also be the inclusion of a third sex that detaches from the traditional ones. This latter modification would determine less pressure on parents that have to register an intersex child, because currently in most states it is required the newborn to be either female or male. What should be avoided at all costs are early surgeries on children that still have not chosen their identity and that cannot participate in the decision making, a perception proved by the many activists and interviews that are now making us more aware of what being intersex means.

SUMMARY.

1. Visione d'insieme

Intersessuale è un termine ombrello che si può riferire a diverse casistiche, alcune delle quali diagnosticabili prima della nascita o poco dopo il parto, mentre altre possono essere scoperte a ridosso della pubertà o quando l'individuo tenta di concepire. Questo avviene perché lo sviluppo atipico delle caratteristiche fisiche può interessare la parte esterna dei genitali e quindi essere palese alla nascita, oppure può manifestarsi con delle variazioni interne e quindi non immediatamente individuabili. Per comprendere al meglio le dinamiche attraverso le quali un individuo sviluppa delle caratteristiche fisiche ambigue, bisogna capire come avviene la differenziazione del sesso all'interno dell'utero. Ad essere responsabili di detta differenziazione sono i cromosomi, che nel caso di una femmina si presentano come uguali (XX) e sono differenziati (XY) nel caso in cui l'essere umano sarà maschio. L'embrione, prima che avvenga la vera e propria differenziazione del sesso, presenta sia delle caratteristiche maschili che femminili, per cui vi saranno sia i condotti di Wolff che i dotti di Muller. La presenza del cromosoma Y determina l'inizio dello sviluppo delle gonadi e quindi dei testicoli, procedimento molto complesso e composto di vari passaggi che devono verificarsi in un preciso ordine. Laddove i testicoli si formano correttamente, iniziano a produrre il testosterone e l'ormone

Antimulleriano. In particolare, il testosterone è necessario per la corretta formazione di pene, scroto e uretra; l'ormone Antimulleriano fa invece sì che le forme primitive di utero e tube di Falloppio scompaiano. Nei casi in cui il procedimento non si verifichi nella corretta modalità o ordine, la formazione del fenotipo maschile non avverrà e alla nascita il neonato potrebbe presentare genitali ambigui; scroto non unitario che ricorda una vagina; pene gravemente sottosviluppato. Negli individui di sesso femminile, l'assenza di ormoni Antimulleriani fa sì che vi sia un ulteriore sviluppo delle tube di Falloppio e dell'utero, mentre l'assenza di testosterone causa lo sviluppo delle caratteristiche esterne, come labbra e clitoride. Anche in questo caso, qualunque tipo di problema durante la differenziazione determina delle caratteristiche atipiche, che potrebbero essere esterne o interne. L'iperplasia surrenalica congenita è una delle variazioni ormonali che determina lo sviluppo di caratteristiche sessuali ambigue e consiste in un deficit di enzimi necessari alla regolazione degli ormoni, causando una variazione nella struttura dei geni. Il deficit di enzimi più comune è quello di 21-idrossilasi, seguito da quello di 3-beta-idrossisteroido e quello di 11-idrossilasi; tutte queste mancanze determinano una forte virilizzazione nei feti di sesso femminile e una bassa virilizzazione nei feti di sesso maschile. A prescindere dalle caratteristiche atipiche, i feti di entrambi sessi avranno un apparato riproduttivo interno funzionante. In alcuni rari casi, i neonati affetti potrebbero avere una crisi surrenalica che può metterli in pericolo di vita se non trattata tempestivamente. La sindrome di insensibilità agli androgeni è una disfunzione ormonale che colpisce solamente gli individui di sesso maschile, che nella maggior parte di casi la ereditano dalla madre. Questa patologia rende incapace il corpo di sintetizzare gli androgeni prodotti dai testicoli, facendo sì che, a seconda della gravità del singolo caso, il neonato presenti dei genitali totalmente femminili o ambigui. Quando il fenotipo si presenta come totalmente femminile, si può parlare di sindrome di insensibilità completa agli androgeni e la diagnosi viene fatta tendenzialmente durante la pubertà perché si sospetta la presenza di un'ernia inguinale (che in realtà sono i testicoli), oppure quando l'individuo non ha le mestruazioni e sembra essere affetto da amenorrea primaria. La sindrome di insensibilità parziale agli androgeni, al contrario, non causa un fenotipo indubbiamente femminile per via di una parziale risposta agli androgeni prodotti dallo scroto. I genitali possono quindi variare tra un pene ipospadico con scroto e testicoli e dei genitali quasi indistinguibili da quelli femminili, in cui però la vagina non avrà profondità e vi saranno dei testicoli ritenuti. Anche il deficit 5-alfa-reduttasi colpisce solo la popolazione maschile e fa sì che il corpo non sia in grado di convertire il testosterone in diidrotestosterone, causando il mancato sviluppo dell'intero apparato riproduttivo maschile tranne per i testicoli, che invece sono funzionanti. Normalmente, coloro i quali sono affetti da questo deficit presentano un micropene che ricorda un clitoride e i testicoli, seppur funzionanti, sono ritenuti. Laddove non venga fatta una gonadectomia, durante la pubertà avviene una maggiore virilizzazione

dell'individuo che determina un ingrandimento del pene; produzione di sperma; abbassamento del tono di voce e un aumento della massa muscolare. Nei casi più gravi il deficit di 5-alfa-reduttasi fa sì che i neonati presentino una vagina a fondo cieco, che non permetterà la penetrazione o le mestruazioni, ma che però farà sì che l'individuo verrà cresciuto come una femmina. In questi casi viene consigliata la rimozione dei testicoli prima della pubertà, procedura che alcuni dottori consigliano assieme a una cura ormonale, al fine di evitare un distaccamento tra il sesso che si impone al paziente e la sua identità sessuale. Nel caso in cui il paziente sembra essere orientato verso un atteggiamento maschile le gonadi non verranno rimosse, ma bisognerà scendere a patti col fatto che i criteri culturalmente imposti della grandezza del pene non verranno soddisfatti e che sarà necessaria una falloplastica per incrementarne la grandezza, laddove fosse percepito come necessario. La disgenesi gonadica può colpire sia gli individui 46,XX che 46,XY e si caratterizza con la presenza di gonadi non funzionanti nel caso in cui si presenti nella sua forma completa, in casi meno gravi vi è invece una gonade funzionante (testicolo o ovaio) e una sottosviluppata. Nella sua forma più grave vi è totale assenza di ovaie o testicoli, sostituiti da ovotesticoli (una gonade che presenta sia del tessuto ovarico, che testicolare) oppure da gonadi sottosviluppate e non funzionanti. Non vi è produzione di ormoni e quindi l'individuo 46,XY non presenterà un fenotipo maschile, mentre gli individui di sesso femminile avranno un clitoride ipertrofico e non avranno le mestruazioni. La sindrome di Klinefelter è una variazione cromosomica degli individui 46,XY e che al contrario di quelle precedentemente citate non causa delle caratteristiche atipiche dei genitali, ma che viene comunque inclusa all'interno dello spettro dell'intersessualità da molti studiosi. I sintomi legati a questa sindrome sono vari: testicoli di misura ridotta; ginecomastia; bassa quantità di peli; infertilità e disfunzioni nella sfera sessuale. Una terapia a base di testosterone può essere somministrata per indurre una maggiore virilizzazione e la prevenzione di osteoporosi, oppure viene prescritta vita natural durante nei soggetti che presentano un grave ipogonadismo. I soggetti che presentano questa patologia dovranno essere seguiti sul lungo periodo in quanto è molto probabile che insorgano altre patologie come diabete, disturbi cardiovascolari o osteoporosi. La sindrome di Turner, come la sindrome di Klinefelter non causa variazioni nell'apparenza dei genitali, è stata scoperta nel 1938 da un endocrinologo americano. Essa colpisce solo individui 46,XX e avviene laddove uno dei due cromosomi non funziona correttamente o non funziona affatto. A parte le manifestazioni cliniche che derivano da questa patologia (statura ridotta; petto largo; anomalie tratto urinario ecc), vi è un'insorgenza di patologie cardiache nel 41% delle donne affette. Le pazienti sembrano presentare problemi comportamentali ed emozionali, la cui gravità sembra essere collegata all'origine del cromosoma X problematico: alcuni studi mostrano che laddove esso sia stato ereditato dalla parte materna, vi siano maggiori difficoltà emotive e psicologiche. Attorno ai dodici anni viene somministrata una terapia a base di

estrogeni per indurre la pubertà e per prevenire l'osteoporosi. La mancanza di linee guida precise per la classificazione di alcune patologie che determinano l'intersessualità e la mancanza di una concezione univoca di come maschio e femmina debbano apparire alla nascita determinano un'incertezza nei dati che riguardano il fenomeno dell'ambiguità dei genitali. Ad esempio, studiosi diversi a volte indicano numeri tra loro differenti, Chase indica che i casi di genitali ambigui lampanti sono 1 su 2000; Blackless parla di 1 neonato ogni 50, di cui 1-2 su 1000 vengono sottoposti alla riassegnazione chirurgica del sesso. Un dato molto preoccupante riguarda invece il trattamento di bambini intersessuali in Sud Africa e Cina. Molte ostetriche di alcune parti rurali in Sud Africa hanno infatti dichiarato di aver ucciso bambini intersessuali perché vengono percepiti come una maledizione per l'intera comunità, ma stabilire quanto spesso questo avvenga non è semplice in quanto non vi sono dati precisi che trattino la questione.

2. Trattamento dell'Intersessualità e Dilemmi Etici

Lo sviluppo della medicina attorno al diciannovesimo e al ventesimo secolo ha fatto sì che gli individui intersessuali non venissero più considerati come invisibili e sono state registrate delle informazioni riguardanti la loro esistenza, in cui viene denotato come nonostante non venissero operati sembra conducessero una vita soddisfacente e felice. L'interesse nell'intersessualità è cresciuto progressivamente, soprattutto perché caratteristiche fisiche ambigue mettevano in dubbio l'ordine sociale basato sull'assioma binario, che costituiva la norma. Cominciano ad essere elaborati dei modelli che possano spiegare le cause di quello che al tempo veniva chiamato «ermafroditismo», come quello del francese Geoffroy Saint-Hilaire o quello di James Young Simpson. L'anatomista francese sosteneva che per essere definito veramente maschio o femmina, un individuo doveva avere tutti i sei segmenti degli organi sessuali interamente maschili o femminili. Questi erano stati individuati precedentemente dallo studioso e se un individuo avesse presentato dei segmenti di entrambi i sessi, questo sarebbe stato intersessuale. La categorizzazione di Young, invece, era basata sulla dicotomia «ermafrodite spurio» e «ermafrodite puro», in cui quest'ultimo era quell'individuo che presentasse le caratteristiche di entrambi i sessi. Questa nomenclatura è sopravvissuta fino al 2006, anno in cui è stato proposto un totale rinnovamento. Fino alla seconda metà del diciannovesimo secolo non vi è stata certezza su quali caratteristiche fossero un indice certo per l'assegnazione del sesso. Nel 1876 Klebs propose un modello che si basava sull'analisi delle gonadi, classificando come «pseudoermafrodita» quegli individui che avevano testicoli o ovaie, ma che presentavano un'anatomia esterna ambigua. Il problema di questa teorizzazione consiste principalmente nella diagnosi incerta: le gonadi potevano essere analizzate solo tramite palpazione quando i pazienti erano vivi e con l'autopsia una volta deceduti, ma anche in questo caso vi era comunque un alto grado di

incertezza a causa di ambiguità o malformazioni delle gonadi stesse. Questa tipologia di valutazione risultava molto utile al fine di preservare la netta distinzione tra maschio e femmina e quindi non mettere in dubbio i ruoli di genere e la classica distinzione binaria. Attorno all'inizio del ventesimo secolo, grazie allo sviluppo scientifico, l'attenzione si spostò sulla differenziazione tra i due sessi sul piano biologico. La prospettiva con cui i medici si approcciavano a questo tipo di casi stava passando dal sesso basato solamente sulle gonadi al tentativo di stabilire quale realmente fosse il «sesso migliore» che più avrebbe soddisfatto un individuo. Il chirurgo William Blair Bell comprese che gonadi e genitali non erano l'unico indicatore per la determinazione del sesso e che bisognava prestare una notevole attenzione anche ai caratteri sessuali secondari. Come tutti gli altri modelli, anche questo mirava ad annichilire l'ambiguità fisica, con la differenza che vi era un forte interesse verso l'endocrinologia. Infatti, si erano cominciati a isolare alcuni tipi di ormoni secreti dalle gonadi, considerati responsabili per la differenziazione del sesso all'interno dell'utero. Si iniziò a pensare che gli estrogeni fossero prodotti esclusivamente dalle gonadi femminili e che il testosterone, al contrario, venisse secreto solo da organismi maschili. Dieci anni dopo, nella seconda decade del Novecento, si scoprì che essi erano presenti sia in individui di sesso femminile che maschile. Tutte queste scoperte dimostrano che il trattamento dell'intersessualità, soprattutto in quel periodo storico, avveniva con un grosso margine di dubbio rispetto alla correttezza del trattamento e dei futuri risultati. Ciononostante, le operazioni chirurgiche di riassegnazione del sesso iniziarono a essere utilizzate più frequentemente. Il Presidente del Gruppo di Supporto per le persone affette da sindrome di insensibilità agli androgeni afferma che dal 1950, circa il 25% dei neonati con genitali ambigui sono stati sottoposti alla riassegnazione chirurgica del sesso e la conseguente terapia ormonale. Non ci sono studi che valutino i risultati dell'operazione sul lungo periodo, mentre quelli esistenti presentano descrizione vaghe e limitate delle funzioni sessuali. La chirurgia di riassegnazione del sesso viene valutata, alla nascita di un bambino intersessuale, da un gruppo di diversi esperti che può essere permanente all'interno di un ospedale o formato ad-hoc. Generalmente all'interno dell'équipe è presente un endocrinologo pediatrico, un chirurgo o un urologo pediatrico, un ginecologo, un genetista e spesso uno psicologo o un assistente sociale. Il ruolo di questo gruppo di professionisti è estremamente determinante, in quanto ognuno di essi dovrà valutare attentamente le caratteristiche del singolo caso e una volta terminato dovrà esservi un confronto con i genitori del bambino intersessuale, a cui le nozioni mediche dovranno essere spiegate in modo semplice e comprensibile. La presenza dello psicologo serve proprio alla procedura di informazione dei genitori, al fine di aiutarli ad elaborare i diversi sentimenti in cui incorreranno in questa situazione ed eventuali paure. Tradizionalmente, a guidare la riassegnazione del sesso, era la grandezza del pene e in molti casi in cui vi era un individuo 46,XY con un micropene molto accentuato, era molto più probabile che si

optasse per una riassegnazione di sesso femminile. Nel 1980 diversi criteri per l'«accettabilità» del pene vennero elaborati, stabilendo che si sarebbe potuto parlare di micropene laddove l'organo non avesse superato 1.5 o 2.5 cm, a seconda del dottore che analizzava il caso. Da un lato il fatto che ci fosse un criterio scritto evitava delle valutazioni totalmente arbitrarie, ma il problema con questo genere di valutazione risiede nel fatto che la grandezza del pene di un neonato non predice necessariamente quanto sarà sviluppato in età adulta. Ad oggi, si preferisce gestire l'intersessualità in modo più olistico e quindi si cerca di creare un'armonia tra diversi indicatori come cromosomi, ormoni e geni. Anche se non vi è ancora certezza su cosa determini esattamente l'identità di genere, vi è un convenire globale che questi fattori hanno una forte influenza. Quindi, nel periodo neonatale, si prendono in considerazione: sesso interiore (biologico e genetico); caratteristiche sessuali esterne; capacità di riproduzione e potenziale abilità di avere rapporti sessuali; come la società percepirà il sesso dell'individuo. Lo scopo dell'operazione, oltre a tentare di scongiurare infezioni del tratto urinario a causa della conformazione atipica, è principalmente quello di favorire una futura riproduzione in casi in cui è possibile e di conservare i nervi che permettono di provare piacere durante un rapporto sessuale. Le procedure chirurgiche a cui sono sottoposti i neonati intersessuali hanno dei risvolti negativi e permanenti, ad esempio molti adulti affermano che l'operazione gli ha comportato una sensibile diminuzione del piacere, dolore cronico e visibili cicatrici. L'apparenza dei genitali -che nonostante le numerose operazioni rimane a dir poco atipica- e la riduzione del piacere, causano in molti il timore di essere rifiutati e un conseguente scarso desiderio sessuale. In molti casi le persone intersessuali decidono di evitare di essere coinvolti in relazioni o in rapporti prettamente sessuali proprio per questo genere di problemi. L'operazione, attorno agli anni Trenta e Quaranta, veniva percepita come qualcosa che avrebbe aiutato l'individuo a scoprire il suo vero sesso e perciò queste procedure erano fatte senza preoccuparsi troppo delle implicazioni sul lungo periodo. Attorno agli anni Cinquanta, come conseguenza del Codice di Norimberga e la Dichiarazione di Ginevra, avviene la teorizzazione dei principi fondanti della bioetica come consenso informato, rispetto dell'autonomia e della dignità del paziente. Questi principi però sembrano non aver impattato sul trattamento dei neonati intersessuali al tempo e sembrano continuare a non farlo in modo determinante oggi. Rimane difficile comprendere, nel caso delle operazioni sui neonati intersessuali, quanto i genitori siano in grado di prendere delle decisioni che facciano l'interesse del paziente sul lungo periodo e quanti essi siano in grado di valutare correttamente la situazione ed i risvolti sul lungo periodo. A dimostrazione del fatto che la decisione razionale non sia scontata vi è lo studio della psicologa Suzanne Kessler, la quale ha chiesto a degli studenti se fossero disposti a correggere chirurgicamente atipicità come micropene e clitoridomegalia. Quasi tutti gli studenti, sia del gruppo dei maschi che delle femmine, hanno votato contro le operazioni chirurgiche, in quanto non erano

disposti a sacrificare la sensibilità dei tessuti per un'apparenza più «normale» e che nessuna delle due caratteristiche fisiche avrebbe, secondo gli studenti, creato un impedimento nel vivere la propria vita sessuale serenamente. La logica applicata in questo caso si ribalta totalmente quando viene chiesto agli studenti di valutare un'eventuale operazione per un neonato intersessuale: quasi il 100% dichiara di essere a favore della chirurgia, perché risulta essenziale per rendere la vita del bambino più facile ed evita il trauma derivante dal sentirsi diverso da ciò che viene considerato come «la norma». La questione della corretta informazione del paziente e dei familiari laddove si tratti di un minore, rimane un argomento molto dibattuto nel trattamento dei bambini intersessuali. Molti dottori argomentano a favore di fornire informazioni parziali o non fornirne affatto, per evitare che l'individuo intersessuale in giovane età possa condividere dei dettagli (a scuola, ad esempio) che potrebbero causarne la marginalizzazione o la stigmatizzazione. Anche i genitori condividono questo tipo di approccio, che è giustificabile nel caso in cui si parli di bambini piccoli, ma che in molti casi viene mantenuto anche in età adolescenziale e oltre. Le persone intersessuali adulte, nelle interviste, enfatizzano sul fatto che proprio questo clima di segretezza e di omissione di informazioni ha contribuito a creare un senso di vergogna e dolore. L'integrità fisica è un altro diritto degli individui che viene intaccato con l'imposizione di operazioni chirurgiche cosmetiche per la riassegnazione del sesso. Questo diritto consiste nel prendere delle decisioni molto rilevanti per la propria persona, senza che vi sia un'influenza esterna. Nei casi in cui la chirurgia viene effettuata, lo sviluppo dell'individuo verrà influenzato irreversibilmente e verranno danneggiati tessuti molto delicati, senza la certezza che il sesso scelto sarà soddisfacente per l'essere umano in questione. Tutto questo comporta un infrangimento del diritto all'integrità fisica, come del resto avviene per la mutilazione femminile e la circoncisione. Quest'ultima pratica, essendo socialmente accettata e legata a delle implicazioni religiose non viene considerata una pratica barbarica come le mutilazioni femminili, che invece vengono combattute aspramente in Occidente. È interessante notare che riassegnazione del sesso e mutilazione femminile, benché entrambe coinvolgano l'amputazione non consensuale di tessuti sani, vengano concepite in modi totalmente opposti. Alcuni attivisti della Intersex Society of North America hanno rinominato, proprio in forza di queste similitudini, le operazioni sui neonati intersessuali come «mutilazioni genitali intersessuali».

3. Analisi di Casi Reali

Il caso di David Reimer, benché egli non fosse un individuo intersessuale, è stato estremamente influente. Divenne estremamente famoso sia perché il John Money lo utilizzò frequentemente per avvalorare la tesi in cui veniva sostenuto che indurre, con l'educazione, un individuo a identificarsi in un certo sesso fosse sufficiente a surclassare ogni caratteristica biologica; sia perché l'epilogo è

stato così negativo che è stato fortemente spettacolarizzato. Vittima di una circoncisione mal effettuata, Bruce Reimer venne allevato come se fosse sempre stato una bambina, con l'idea che sarebbe stato più semplice costruire una vagina funzionante (essenziale per condurre una vita sana) che tentare una ricostruzione del pene, totalmente distrutto. I genitori di Bruce, ormai divenuto Brenda, tentano in ogni modo di rafforzare il comportamento femminile e di scoraggiare quello maschile. Brenda mostrava i tipici atteggiamenti che culturalmente vengono ricondotti al genere maschile, determinando forti tensioni sia in famiglia che durante gli incontri col Dr. Money. Una volta terminati gli incontri con il Dottore, Brenda decide di tornare alla sua identità maschile, prendendo il nome di David. I Reimer, come affermano in alcune interviste, credevano che l'operazione sarebbe stata la strada più semplice e che avrebbe fatto sentire Bruce meno diverso dagli altri. I genitori di bambini intersessuali si trovano invece a dover gestire situazioni che, poco dopo la nascita del bambino o della bambina presentano un maggiore grado di incertezza: ai Finney, appena terminato il parto, è stato comunicato di aver avuto una bambina nonostante l'apparenza esteriore dei genitali sembrasse suggerire il contrario. Poco dopo, una volta compresa la situazione da parte dell'équipe medica, è stato consigliato loro di non dare un nome alla bambina o al bambino finché il sesso non fosse stato certo e di parlarne utilizzando un nome neutro: «the baby». Sara e Jim Finney parlano di questa situazione come terribilmente stressante sia perché trovavano terribilmente impersonale utilizzare il nome neutro e perché non avevano idea di come rapportarsi con parenti e conoscenti che continuavano a chiedere se avessero avuto un bambino o una bambina. Nelle interviste di chi ha subito svariate operazioni per rientrare correttamente nella categoria maschio o femmina viene condannata in ogni modo la scelta di operare individui intersessuali rimuovendo tessuti perfettamente funzionanti e sani, senza attendere che la persona interessata abbia un'età sufficiente per valutare razionalmente. Questo è il caso di Susannah Temko, attivista per i diritti degli intersessuali che sostiene che questa categoria di persone è spesso percepita come invisibile ed è proprio questo ad alimentare la stigmatizzazione delle persone intersessuali. Questa segretezza e stigmatizzazione inerente al mondo dell'intersessualità viene riscontrata anche dall'attivista Emili Quinn, che nel suo TED Talk solleva problemi relativi al fatto che spesso le persone intersessuali vengono tenute all'oscuro della loro condizione e che spesso le visite a cui vengono sottoposti sono inutilmente invasive. Durante tutta la sua vita, prima di diventare un'attivista, Quinn ha vissuto la sua condizione con estrema vergogna e considerava il suo essere intersessuale come un oscuro segreto che non avrebbe mai dovuto rivelare, nemmeno alle sue più care amiche.

Conclusione

Il dibattito relativo al mondo dell'intersessualità è ancora in fase di sviluppo e comprende molti aspetti, ciò che è indubbio è che i modelli finora imposti e messi in pratica sembrano non soddisfare gli individui che vi vengono sottoposti. Ciò che risulta particolarmente problematico è il sottoporre dei neonati ad operazioni che hanno solo fini cosmetici e che non mirano a risolvere un qualche tipo di patologia pericolosa per la salute dell'individuo, a parte alcuni rari casi in cui bisogna intervenire su una crisi adrenale oppure laddove bisogna correggere delle malformazioni che possono determinare infezioni. Inoltre, molte persone che hanno subito l'imposizione di un determinato sesso non si sono, in età adulta, rispecchiati in esso e quindi hanno dovuto accettare l'idea di aver subito un'operazione sostanzialmente deleteria e che in nessun modo ha avuto un impatto positivo sulla propria vita. Potrebbe essere utile collezionare dei dati sufficientemente consistenti che vadano ad analizzare la questione sul lungo periodo, sia su individui non operati che operati; inoltre bisognerebbe porre maggiore attenzione sul fatto che la scienza suggerisce che il sesso non può essere concepito solamente all'interno di un paradigma binario e che è composto da una serie di sfaccettature, che per il momento non possono essere comprese a fondo. Un'altra questione che andrebbe risolta è la segretezza e lo stigma che circonda l'argomento intersessualità, una dinamica subdola che spesso induce i genitori a non comunicare con i propri figli intersessuali riguardo alla loro condizione clinica, ma che contribuisce anche alla creazione di una concezione in cui l'intervento chirurgico di riassegnazione del sesso è visto come un modo per «aggiustare» delle persone che altrimenti sarebbero «sbagliate». Una riforma legale che vada a trattare apertamente questa tipologia di tema potrebbe essere estremamente utile, soprattutto se fatta sul piano Europeo e successivamente adottata dagli Stati Membri in modo uniforme, in cui potrebbero essere prescritte delle linee guida per il trattamento clinico dell'intersessualità che si distacchi dalle modalità tradizionali e con cui potrebbero essere aboliti (o quanto meno sensibilmente dilatati) i limiti di tempo normalmente in vigore per registrate un neonato come maschio o femmina in quanto anche questa problematica crea uno stress non indifferente sui neogenitori.

[i] Creighton, Sarah. «Surgery for Intersex». *Journal of The Royal Society of Medicine,* vol. 94, no. 94, May 2001, pp. 218-220
[ii] Jones, Tiffany. «Intersex Studies: A Systematic Review of International Health Literature». *SAGE Open,* April-June 2018. DOI: 10.1177/2158244017745577
[iii] Hindmarsh, Peter, and Kathy Geertsma. *Congenital Adrenal Hyperplasia. A Comprehensive Guide.* Academic Press, 2017
[iv]Harper, Catherine. *Intersex.* Taylor and Francis, 2020
[v] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[vi] Harper, Catherine. *Op. cit.*
[vii] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[viii] *Ibid.*

[ix] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Transgenderism and Intersexuality in Childhood and Adolescence: Making Choices.* SAGE publications, 2003
[x] *Ibid.*
[xi] *Ibid.*
[xii] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[xiii] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Op. cit.*
[xiv] *Ibid.*
[xv] Greenberg, Julie. *Intersexuality and the Law.* NYU Press, 2012
[xvi] *Ibid.*
[xvii] *Ibid.*
[xviii] *Ibid.*
[xix] *Ibid.*
[xx] *Ibid.*
[xxi] *Ibid.*
[xxii] *Ibid.*
[xxiii] *Ibid.*
[xxiv] Treccani. «Ermafrodito». https://www.treccani.it/vocabolario/ermafrodito/ . Vocabolario online.
[xxv] Harper, Catherine. *Op. cit.*
[xxvi] Greenberg, Julie. *Op. cit.*
[xxvii] Hughes, A. et al. «Consensus Statement on Management of Intersex Disorders». *Archives of Diseases in Chilhood,* vol. 91(7), July 2006, pp. 554-563
[xxviii] *Ibid.*
[xxix] *Ibid.*
[xxx] Harper, Catherine. *Op. cit.*
[xxxi] *Ibid.*
[xxxii] *Ibid.*
[xxxiii] Kotula, Dean. *The Pallus Palace: Female to Male Transsexuals.* Alyson Pubns, 2002
[xxxiv] *Ibid.*
[xxxv] *Ibid.*
[xxxvi] New, Maria et al. «Congenital Adrenal Hyperplasia». *Endotext*, March 2017, https://www.ncbi.nlm.nih.gov/books/NBK278953/
[xxxvii] Harper, Catherine. *Op. cit.*
[xxxviii] *Ibid.*
[xxxix] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[xl] *Ibid.*
[xli] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Op. cit.*
[xlii] Witchel Feldman, Selma.« Congenital Adrenal Hyperplasia». *Journal of Pediatric & Adolescent Gynecology.* April 2017. DOI: https://doi.org/10.1016/j.jpag.2017.04.001
[xliii] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[xliv] Harper, Catherine. *Op. cit.*
[xlv] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[xlvi] Witchel Feldman, Selma. *Op. cit.*
[xlvii] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[xlviii] *Ibid.*
[xlix] Harper, Catherine. *Op. cit.*
[l] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[li] Harper, Catherine. *Op. cit.*
[lii] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[liii] Harper, Catherine. *Op. cit,*
[liv] Harper, Catherine. *Intersex.* Taylor and Francis, 2020
[lv] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[lvi] Hindmarsh, Peter, and Kathy Geertsma. *Congenital Adrenal Hyperplasia. A Comprehensive Guide.* Academic Press, 2017
[lvii] *Ibid.*
[lviii] *Ibid.*
[lix] *Ibid.*
[lx] Harper, Catherine. *Op. cit.*
[lxi] Hindmarsh, Peter, and Kathy Geertsma. *Op. cit.*
[lxii] Harper, Catherine. *Op. cit.*
[lxiii] Hindmarsh, Peter, and Kathy Geertsma. *Congenital Adrenal Hyperplasia. A Comprehensive Guide.* Academic Press, 2017
[lxiv] *Ibid.*
[lxv] *Ibid.*
[lxvi] *Ivi,* chapter 5
[lxvii]*Ibid.*
[lxviii] *Ibid.*
[lxix] *Ibid.*
[lxx] *Ibid.*
[lxxi] *Ibid.*

[lxxii] *Ibid.*
[lxxiii] *Ibid.*
[lxxiv] *Ibid.*
[lxxv] *Ibid.*
[lxxvi] *Ibid.*
[lxxvii] *Ibid.*
[lxxviii] *Ibid.*
[lxxix] *Ibid.*
[lxxx] Fulare, Sushrut et al. «Androgen Insensitivity Syndrome: A Rare Genetic Disorder». *International Journal of Surgery Case Reports.* Vol. 71, February 2020, pp. 371-373
[lxxxi] Harper, Catherine. *Op. cit.*
[lxxxii] *Ibid.*
[lxxxiii] Fulare, Sushrut et al. *Op. cit.*
[lxxxiv] Mongan, Nigel et al. «Androgen Insensitivity Syndrome». *Best Practice & Research Clinical Endocrinology & Metabolism.* Vol. 29, April 2015, pp. 569-580
[lxxxv] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Op. cit.*
[lxxxvi] Fulare, Sushrut et al. *Op. cit.*
[lxxxvii] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Op. cit.*
[lxxxviii]Fulare, Sushrut et al. *Op. cit.*
[lxxxix] Harper, Catherine. *Op. cit.*
[xc] *Ibid.*
[xci] *Ivi,* chapter 10.
[xcii] *Ibid.*
[xciii] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Op. cit.*
[xciv] Harper, Catherine. *Op. cit.*
[xcv] *Ibid.*
[xcvi] *Ibid.*
[xcvii] *Ibid.*
[xcviii] *Ibid.*
[xcix] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Op. cit.*
[c] Harper, Catherine. *Op. cit.*
[ci] *Ivi,* chapter 11.
[cii] *Ibid.*
[ciii] *Ibid.*
[civ] *Ibid.*
[cv] *Ibid.*
[cvi] *Ivi,* chapter 12.
[cvii] *Ibid.*
[cviii] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Op. cit.*
[cix] Bonomi, M. et al. «Klinefelter Syndrome (KS): Genetics, Clinical Phenotype and Hypogonadism». *Journal of Endocrinological Investigation.* Vol. 40, September 2016, p. 124
[cx] *Ibid.*
[cxi] *Ibid.*
[cxii] *Ivi,* p. 123
[cxiii] *Ibid.*
[cxiv] Harper, Catherine. *Op. cit.*
[cxv] *Ibid.*
[cxvi] Bonomi, M. et al. *Op. Cit.*
[cxvii] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Op. cit.*
[cxviii] *Ibid.*
[cxix] *Ibid.*
[cxx] Harper, Catherine. *Op. cit.*
[cxxi] *Ibid.*
[cxxii] Kikkeri Shankar, Nidhi, and Shivaraj Nagalli. «Turner Syndrome». *StatPearls Publishing.* January 2021, DOI: https://pubmed.ncbi.nlm.nih.gov/32119508/
[cxxiii] Cui, Xiaoxiao et al. «A Basic Understanding on Turner Syndrome: Incidence, Complication, Diagnosis and Treatment» *Intractable & rare diseases research.* Vol. 7, no. 4, November 2018, pp. 223-228. DOI: 10.5582/irdr.2017.01056
[cxxiv] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Op. cit.*
[cxxv] Cui, Xiaoxiao et al. *Op. cit.*
[cxxvi] Cohen-Kettenis, Peggy and Friedmann Pfafflin. *Op. cit.*
[cxxvii] *Ivi,* p. 38
[cxxviii] Harper, Catherine. *Op. cit.*
[cxxix] *Ibid.*
[cxxx] *Ibid.*
[cxxxi] Behrens, Kevin. «A Principle Ethical Approach to Intersex Paediatric Surgeries» *BMC Medical Ethics*. Vol. 21, no. 108, October 2020, p. 1, DOI: 10.1186/s12910-020-00550-x.

[cxxxii] *Ivi,* p. 2
[cxxxiii] New, Maria et al. «Congenital Adrenal Hyperplasia». *Endotext*, March 2017, p. 1, https://www.ncbi.nlm.nih.gov/books/NBK278953/
[cxxxiv] Harper, Catherine. *Op. cit.*
[cxxxv] New, Maria et al. *Op. cit.*
[cxxxvi] *Ibid.*
[cxxxvii] *Ivi,* p. 2
[cxxxviii] *Ibid.*
[cxxxix] Harper, Catherine. *Op. cit.*
[cxl] Fulare, Sushrut et al. *Op. cit.*
[cxlicxli] Harper, Catherine. *Op. cit.*
[cxlii] *Ibid.*
[cxliii] *Ibid.*
[cxliv] Bonomi, M. et al. *Op. cit.,* p. 123
[cxlv] *Ivi,* p. 125
[cxlvi] Harper, Catherine. *Op. cit.*
[cxlvii] «About the MAGIC Foundation» https://www.magicfoundation.org/About/ . Accessed on September 2021
[cxlviii] Harper, Catherine. *Op. cit.*
[cxlix] Cui, Xiaoxiao et al. *Op. cit.*
[cl] Kikkeri Shankar, Nidhi, and Shivaraj Nagalli. «Turner Syndrome». *StatPearls Publishing.* January 2021, DOI: https://pubmed.ncbi.nlm.nih.gov/32119508/
[cli] Karkazis, Katrina. *Fixing Sex. Intersex, Medical Authority, and Lived Experience.* Duke University Press, 2008, p. 34
[clii] *Ibid.*
[cliii] *Ivi,* p. 35
[cliv] *Ibid.*
[clv] Feder, Ellen. *Making Sense of Intersex. Changing Ethical Perspectives in Biomedicine.* Indiana University Press, 2014.
[clvi] *Ibid.*
[clvii] *Ibid.*
[clviii] *Ibid.*
[clix] Karkazis, Katrina. *Fixing Sex. Intersex, Medical Authority, and Lived Experience.* Duke University Press, 2008, p. 35
[clx] *Ibid.*
[clxi] *Ibid.*
[clxii] *Ibid.*
[clxiii] *Ivi,* p. 36
[clxiv] *Ibid.*
[clxv] *Ibid.*
[clxvi] *Ibid.*
[clxvii] *Ibid.*
[clxviii] *Ibid.*
[clxix] *Ivi,* p. 37
[clxx] *Ibid.*
[clxxi] *Ibid.*
[clxxii] *Ibid.*
[clxxiii] *Ibid.*
[clxxiv] *Ivi,* p. 38
[clxxv] *Ibid.*
[clxxvi] *Ivi,* p. 39
[clxxvii] *Ibid.*
[clxxviii] *Ibid.*
[clxxix] *Ibid.*.
[clxxx] *Ivi,* p. 40
[clxxxi] *Ibid.*
[clxxxii] *Ivi,* p. 41
[clxxxiii] *Ivi,* p. 42
[clxxxiv] *Ibid.*
[clxxxv] *Ivi,* p. 43
[clxxxvi] *Ibid.*
[clxxxvii] *Ivi,* p. 44
[clxxxviii] *Ibid.*
[clxxxix] *Ibid.*
[cxc] *Ibid.*
[cxci] *Ivi,* p. 45
[cxcii] *Ibid.*
[cxciii] *Ivi,* p. 47
[cxciv] *Ivi,* p. 48
[cxcv] *Ivi,* p. 49

[cxcvi] *Ibid.*
[cxcvii] *Ivi,* p. 50
[cxcviii] *Ivi,* p. 51
[cxcix] *Ibid.*
[cc] *Ivi,* p. 52
[cci] *Ibid.*
[ccii] *Ibid.*
[cciii] *Ibid.*
[cciv] *Ivi,* p. 55
[ccv] *Ivi,* p. 56
[ccvi] *Ibid.*
[ccvii] *Ibid.*
[ccviii] *Ivi,* p. 65
[ccix] *Ibid.*
[ccx] *Ibid.*
[ccxi] *Ivi,* p. 68
[ccxii] *Ibid.*
[ccxiii] *Ivi,* p. 69
[ccxiv] *Ibid.*
[ccxv] Karkazis, Katrina. *Op. cit.* Part 3, chapter 8
[ccxvi]*Ibid*.
[ccxvii] *Ivi,* p. 77
[ccxviii] *Ibid.*
[ccxix] *Ibid.*
[ccxx] *Ivi,* p. 78
[ccxxi] *Ibid.*
[ccxxii] *Ivi,* p. 83
[ccxxiii] *Ibid.*
[ccxxiv] *Ibid.*
[ccxxv] *Ivi,* p. 84
[ccxxvi] *Ibid.*
[ccxxvii] *Ibid.*
[ccxxviii] Karkazis, Katrina. *Op. cit.* Part 3, chapter 8
[ccxxix] *Ibid*.
[ccxxx] *Ibid*.
[ccxxxi] *Ibid*.
[ccxxxii] *Ibid*.
[ccxxxiii]*Ibid*.
[ccxxxiv] Reis, Elizabeth. «Did Bioethics Matter? A History of Autonomy, Consent, and Intersex Genital Surgery» *Medical Law review.* Vol. 27, no. 4, pp. 658-674, April 2019. DOI: 10.1093/medlaw/fwz007
[ccxxxv] *Ibid.*
[ccxxxvi] Anarte, Enrique. «Germany bans surgeries on intersex babies, but loopholes feared». *Thomson Reuter Foundation News,* 26 March 2021, https://news.trust.org/item/20210326152311-qeren/
[ccxxxvii] Harper, Catherine. *Op. cit,*
[ccxxxviii] Creighton, Sarah. «Surgery for Intersex». *Journal of The Royal Society of Medicine,* vol. 94, no. 94, May 2001, pp. 218-220
[ccxxxix] Karkazis, Katrina. *Op. cit.*
[ccxl] *Ivi,* p. 97
[ccxli] Brain, Caroline. «Holistic Management of DSD». *Best Practice & Research Clinical Endocrinology & Metabolism.* Vol. 24, no. 2, April 2020, p. 340. DOI: 10.1016/j.beem.2010.01.006.
[ccxlii] *Ibid.*
[ccxliii] *Ibid.*
[ccxliv] *Ivi,* p. 341
[ccxlv] *Ivi,* p. 340
[ccxlvi] *Ibid.*
[ccxlvii] *Ivi,* p. 341
[ccxlviii] *Ivi,* p. 342
[ccxlix] Karkazis, Katrina. *Op. cit.*
[ccl] *Ibid.*
[ccli] *Ibid.*
[cclii] *Ivi,* p. 101
[ccliii] *Ivi,* p. 102
[ccliv] Karkazis, Katrina. *Fixing Sex. Intersex, Medical Authority, and Lived Experience.* Duke University Press, 2008.
[cclv] Mouriquand, Pierre et al. «Surgery in Disorders of Sex Development (DSD) With a Gender Issue: If (Why), When, and How?». *Journal of Pediatric Urology*. Vol 12, no. 3, pp. 139-149. DOI: 10.1016/j.jpurol.2016.04.001
[cclvi] Hughes, A. et al. «Consensus Statement on Management of Intersex Disorders». *Archives of Diseases in Chilhood,* vol. 91(7), July 2006, pp. 554-563

[cclvii] Karkazis, Katrina. *Fixing Sex. Intersex, Medical Authority, and Lived Experience.* Duke University Press, 2008.
[cclviii] Hughes, A. et al. «Consensus Statement on Management of Intersex Disorders». *Archives of Diseases in Chilhood,* vol. 91(7), July 2006, pp. 554-563
[cclix] *Ibid.*
[cclx] Creighton, Sarah. *Op. cit.*
[cclxi] Mouriquand, Pierre et al. *Op. cit.*
[cclxii] Creighton, Sarah. *Op. cit.,* p. 219
[cclxiii] *Ibid.*
[cclxiv] *Ibid*.
[cclxv] Mouriquand, Pierre et al. *Op. cit.*
[cclxvi] *Ibid*.
[cclxvii] *Ibid*.
[cclxviii] Creighton, Sarah. *Op. cit.*
[cclxix] Hughes, A. et al. *Op. cit.*
[cclxx] Mouriquand, Pierre et al. *Op. cit,*
[cclxxi] *Ibid*.
[cclxxii] *Ibid*.
[cclxxiii] *Ibid*.
[cclxxiv] Hughes, A. et al. *Op. cit.*
[cclxxv] Mouriquand, Pierre et al. *Op. cit.*
[cclxxvi] Hughes, A. et al. *Op. cit.*
[cclxxvii] Mouriquand, Pierre et al. *Op. cit.*
[cclxxviii] Hughes, A. et al. *Op. cit.*
[cclxxix] Greenberg, Julie. *Op. cit.*
[cclxxx] *Ibid*.
[cclxxxi] Reis, Elizabeth. «Did Bioethics Matter? A History of Autonomy, Consent, and Intersex Genital Surgery» *Medical Law review.* Vol. 27, no. 4, p. 660, April 2019. DOI: 10.1093/medlaw/fwz007
[cclxxxii] *Ibid*.
[cclxxxiii] *Ivi,* p. 661
[cclxxxiv] *Ibid*.
[cclxxxv] *Ivi,* p. 659
[cclxxxvi] *Ibid*.
[cclxxxvii] *Ivi,* p. 668
[cclxxxviii] *Ivi,* p. 670
[cclxxxix] Beauchamp, Tom and James F. Childress*. Principles of Biomedical Ethics.* Oxford University Press, 1994, p. 120-121
[ccxc] *Ibid*.
[ccxci] *Ibid*.
[ccxcii] *Ibid*.
[ccxciii] Greenberg, Julie. *Op. cit.*
[ccxciv] *Ibid*.
[ccxcv] Beauchamp, Tom and James F. Childress*. Op. cit.*
[ccxcvi] Greenberg, Julie. *Op. cit.* Chapter 2
[ccxcvii] *Ibid*.
[ccxcviii] *Ibid*.
[ccxcix] *Ibid*.
[ccc] *Ibid*.
[cccci] *Ibid*.
[cccii] *Ibid*.
[ccciii] *Ibid*.
[ccciv] *Ibid*.
[cccv] *Ibid*.
[cccvi] *Ibid*.
[cccvii] *Ibid*.
[cccviii] Feder, Ellen. *Op. cit.* Chapter 2
[cccix] *Ibid*.
[cccx] *Ibid*.
[cccxi] *Ibid*.
[cccxii] *Ibid*.
[cccxiii] *Ibid*.
[cccxiv] *Ibid*.
[cccxv] *Ibid*.
[cccxvi] *Ibid*.
[cccxvii] *Ibid*.
[cccxviii] *Ibid*.
[cccxix] Beauchamp, Tom and James F. Childress. *Op. cit.* p. 146
[cccxx] *Ibid*.

[cccxxi] *Ibid*.
[cccxxii] Karkazis, Katrina. *Op. cit.*
[cccxxiii] Reis, Elizabeth. *Op. cit.*
[cccxxiv] Behrens, Kevin. «A Principle Ethical Approach to Intersex Paediatric Surgeries» *BMC Medical Ethics*. Vol. 21, no. 108, p. 7 October 2020, DOI: 10.1186/s12910-020-00550-x.
[cccxxv] *Ibid*.
[cccxxvi] *Ibid*.
[cccxxvii] Karkazis, Katrina. *Op. cit.,* p. 188
[cccxxviii] *Ibid*.
[cccxxix] *Ibid*.
[cccxxx] *Ivi,* p. 189
[cccxxxi] *Ibid*.
[cccxxxii]*Ibid*.
[cccxxxiii] *Ibid*.
[cccxxxiv] *Ivi,* p. 221
[cccxxxv] *Ibid*.
[cccxxxvi] *Ibid*.
[cccxxxvii] *Ibid*.
[cccxxxviii] *Ibid*.
[cccxxxix] Behrens, Kevin. *Op. Cit.*
[cccxl] Kehrer, Ino. «Cuts Into Children's Future: a Comparative Analysis Between FGM, Male Circumcision and Intersex Genital Surgeries.» *PHRG Peace Human Rights Governance.* Vol. 3, November 2019, p. 350, DOI: 10.14658/pupj-phrg-2019-3-3
[cccxli] *Ivi,* p. 351
[cccxlii] *Ibid*.
[cccxliii] *Ivi,* p. 344
[cccxliv] *Ivi,* p. 351
[cccxlv] *Ivi,* p. 352
[cccxlvi] Karkazis, Katrina. *Op. cit.*, p. 96
[cccxlvii]*Ibid*.

[cccxlix] Randjelovic, Kristian. *Intersex Research Study. Albania, Bosnia and Herzegovina, The Former Yugoslav Republic of Macedonia and Serbia.* United Nations Development Program, 2017.
[cccl] *Ibid*.
[cccli] Bennett, Theodore. *Cuts and Criminality.* Taylor and Francis, 2016, chapter 5
[ccclii] *Ibid*.
[ccccliii] Karkazis, Katrina. *Op. cit.*, p. 127
[ccccliv] *Ivi,* p. 128
[ccclv] *Ibid*.
[ccclvi] Greenberg, Julie. *Op. cit.,* chapter 2
[ccclvii] *Ibid*.
[ccclviii] *Ibid*.
[ccclix] *Ibid*.
[ccclx] *Ibid*.
[ccclxi] *Ibid*.
[ccclxii] *Ibid*.
[ccclxiii] *Ibid*.
[ccclxiv] *Ibid*.
[ccclxv] *Ibid*.
[ccclxvi] *Ibid*.
[ccclxvii] *Ibid*.
[ccclxviii] *Ibid*.
[ccclxix] *Ibid*.
[ccclxx] *Ibid*.
[ccclxxi] *Ibid*.
[ccclxxii] Bennett, Theodore. *Op. cit.,* chapter 3
[ccclxxiii] *Ibid*.
[ccclxxiv] Kehrer, Ino. *Op. cit.* p. 336
[ccclxxv] Bennett, Theodore. *Op. cit,* chapter 3
[ccclxxvi] Kehrer, Ino. *Op. cit.* p. 336
[ccclxxvii] *Ibid*.
[ccclxxviii] *Ivi,* p. 337
[ccclxxix] *Ivi,* p. 338
[ccclxxx] Rubin, David. *Intersex Matters.* State University of New York Press, 2017.
[ccclxxxi] Kehrer, Ino. *Op. cit.* p. 339
[ccclxxxii] *Ibid*.
[ccclxxxiii] *Ibid*.

[cccclxxxiv] *Ivi,* p. 340
[cccclxxxv] *Ivi,* p. 341
[cccclxxxvi] *Ivi,* p. 342
[cccclxxxvii] Randjelovic, Kristian. *Intersex Research Study. Albania, Bosnia and Herzegovina, The Former Yugoslav Republic of Macedonia and Serbia.* United Nations Development Program, 2017
[cccclxxxviii] Randjelovic, Kristian. *Intersex Research Study. Albania, Bosnia and Herzegovina, The Former Yugoslav Republic of Macedonia and Serbia.* United Nations Development Program, 2017
[cccclxxxix] Kehrer, Ino. *Op. cit.* p. 342
[cccxc] Anarte, Enrique. «Germany Bans Surgeries on Intersex Babies, but Loopholes Feared». *The Thomson Reuters Foundation News*, 26 march 2021.
[cccxci] Kehrer, Ino. *Op. cit.* p. 343
[cccxcii] *Ibid*.
[cccxciii] *Ibid*.
[cccxciv] *Ibid*.
[cccxcv] Karkazis, Katrina. *Op. cit.* p. 68
[cccxcvi] *Ibid*.
[cccxcvii] *Ibid*.
[cccxcviii] Kotula, Dean. *Op. cit.*
[cccxcix] *Ibid*.
[cd] *Ibid*.
[cdi] Karkazis, Katrina. *Op. cit.,* p. 69
[cdii] *Ibid*.
[cdiii] Karkazis, Katrina. *Op. cit.* p. 72
[cdiv] Colapinto, John. *As Nature Made Him.* HarperCollins, 2013, chapter 3
[cdv] *Ibid*.
[cdvi] *Ibid*.
[cdvii] *Ibid*.
[cdviii] *Ibid*.
[cdix] *Ibid*.
[cdx] *Ibid*.
[cdxi] *Ibid*.
[cdxii] *Ibid*.
[cdxiii] *Ibid*.
[cdxiv] *Ivi,* chapter 4
[cdxv] *Ibid*.
[cdxvi] *Ibid*.
[cdxvii] *Ibid*.
[cdxviii] *Ibid*.
[cdxix] Harper, Catherine. *Intersex.* Taylor and Francis, 2020
[cdxx] Feder, Ellen. *Op. cit.* chapter 2
[cdxxi] Karkazis, Katrina. *Op. cit.* p. 91
[cdxxii] Temko, Susannah. «A different kind of superpower: what it means to be intersex» *Youtube*, uploaded by TEDx Talks, 11 June 2019, https://www.youtube.com/watch?v=Vaq4Ij0qmog
[cdxxiii] Karkazis, Katrina. *Op. cit.* p. 103
[cdxxiv] *Ivi,* p. 104
[cdxxv] *Ibid*.
[cdxxvi] *Ibid*.
[cdxxvii] *Ibid*.
[cdxxviii] *Ibid*.
[cdxxix] Quinn,Emily. «What I've learned from having balls», *Youtube,* uploaded by TEDx Talks, 25 October 2019, https://www.youtube.com/watch?v=28Ip-STEPKU