The dilemmas of sexual definition: how to proceed with child born with severe genital malformations?

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Abstract

The birth of a child, usually a festive event, can become great pain when the baby presents genital malformations that prevent the immediate assignment of gender and social setting. Sometimes, male children with severe anatomical changes and the impossibility of surgical phallic construction are, phenotypically transformed into women, a procedure under questioning, particularly by civil society members. From a real case of a newborn with the diagnosis of cloacal exstrophy, the difficulties and ethical questions involved in decisions related to gender definition are discussed in this paper, from many experts' point of view, who are directly or indirectly involved in approaching these children.

Key words: Congenital abnormalities. Genitalia. Child. Gender identity.

In majority of cases, male children with significant anatomic changes in genital region, which make impossible surgical phallic reconstruction, are phenotypically transformed into women. Progressively, this stand has been under criticism, inclusively by civil associations of people with intersex. Along with arguments such as the need to define precociously the social and psychological gender, others arise such as: why is it necessary for gender definition to have defined external sexual organs?

A genetically male child (46,XY), but without a penis, referenced to tertiary care service, place professionals in face of a dilemma: what to do? Change him, anatomically, into a girl or preserve its male gonads?

The newborn of male gender, genetically defined (cariotype 46, XY), born at end of normal labor. He presented severe congenital malformation, with normal testicles, but absence of penis and other malformations in the renal and

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gastrointestinal systems and compatible with the *cloacal exstrophy* diagnosis, a very rare case. The needed clinical and surgical procedures were undertaken, but the additional problem was the definition of the child's gender. It was defined in a meeting of the responsible professionals with the family, attending a family's decision, that the child's gender would be female. It was necessary that his mother, an 16 years old adolescent, take all decision with assistance of her legal responsible, and then a medical report was sent to civil registry office in order to register the child as a girl.

Two features from this situation motivated the presentation of this article. First, the more complex is the situation, the more necessary is the participation of professionals with different training background, with diverse view, to choose along with the family the alternative to be sought for. Second, that one of ethics functions is to question always, to seek in the usual something unusual, to question the established. As the German playwright Brecht's text states: *Do not say ever, this is natural. Feel perplexed in face of the daily routine. Under the familiar, discover the unusual. Under the daily routine, discover the unexplainable, uncover the unexplainable. As all that is considered customary causes restlessness. In the rule, seek the abuse*. To look for the unusual, to get restless in front of the daily routine and not consider anything of the human being as determined by nature constitute the core of ethical reflection – that only is ethical if it is plural.

Pediatrician's point of view

A newborn at end of normal labor, with prenatal and labor without intercurrences, presented at birth congenital malformation compatible with cloacal exstrophy diagnosis: exstrophy of hemibladder, bilaterally exteriorized ureters, bilateral scrotum bag with palpable testicle at left, bifid rudimentary phallus more visible at left and enlargement of pubic sinfisis. His cariotype is 46 XY and his

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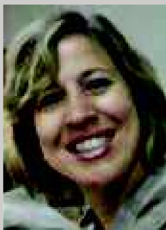

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basal testosterone dosing, 183 ng/dL (reference values for male newborns: 75 to 400 ng/dL). Omphalocele corrections were carried out, the closing of the vesical plate, an enteroanastomosis and a colostomy.

The classic cloacal exstrophy consists in the presence of omphalocele, imperforated anus, exstrophy of the two hemibladders, between which the terminal ileus prolapsed, and ambiguous genitals. It may associate, still, pubic diastasis, renal malformations, and spine. It is the most severe malformation of the inferior abdominal wall, with incidence of 1:200,000 to 1:400,000 births [1]. Due to presence of very rudimentary phallus, and the impossibility, until now, to carry out a phallic reconstruction, one discusses the possibilities to define the phenotype gender for the child: male but without penis, or female after gonadectomy and future construction of the vagina.

The treatment is lasting, comprising several surgical procedures [2]. The major stages are: colostomy/ileostomy, vesicostomy, and omphalocele correction (at birth); attempt to turn the child into fecal and urinary continent (preschool age), construction or increase of the vagina (adolescence). Urinary continence affects the majority of children. Fecal continence is more difficult, and often it is necessary a definitive colostomy/ileostomy.

The three most important case studies published worldwide comprise 112 children, being 54 males, of which 43 were castrated and transformed, phenotypically, into women. Despite the option of castration for most cases, recently this process has given rise to questioning, because, frequently, the patients maintain a masculine behavior [1-3].

Keeping the child as a male, fertility is preserved, not interfering with the natural biological and hormonal (testosterone) conditions, operating since

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intrauterine life. But, will this person consider himself as a man before society, not having a penis? The option for the female sex, with the carrying out of an early gonadectomy, construction of a vagina and female hormone replacement therapy during adolescence, poses new questions. This option eliminates the reproductive capacity of the individual. The behavior of this *new woman* would be imposed by the imprinting of testosterone present in the pre and post birth period or by social and familiar environmental conditions?

Literature reports that the majority of the male children that were transformed into women showed a masculine behavior during school years [2]. Another observation is that male children that do not present a penis with a suitable size/and or function are unsatisfied, and suicide has been also mentioned [2,3].

The surgeon's point of view

Cloacal exstrophy is a rare anomaly, first described by Littre in 1709 [1]. Just over half of the patients are genetically of the male sex, presenting testicles in the scrotum or cryptorchidism. The presence of a rudimentary hemipenis on each side is characteristic, generally unsuitable for a satisfactory phallic reconstruction. Newborn female babies with cloacal exstrophy usually present a vagina on each side.

The survival of infants with this malformation was uncommon in the past, when it was considered a morbid terminal disease, with low hope of survival and no possibilities of attaining a minimum quality of life, even after properly conducted anatomical reconstruction. In 1960, Rickham reported the first treatment with patient survival [4]. However, the post-operatory mortality was still high, results only improving,

considerably from 1980 onward[1,4]. Currently, the survival rate reported in international cases is for almost 100% of the cases [1].

In spite of the significant improvement for results reached in present day practice, there are still many challenges and controversies when it comes to these patients. Due to the complexity of the malformation, which affects multiple body structures, treatment is also complex, with multiple reconstructive surgeries that consequently, result in multiple hospitalizations. To reach the goal of a successful surgery it is paramount that the family has a true grip and understanding of the problem, and this demands from the health staff patience, insight and sensibility in order to orient and clarify distressing questions and doubts that may arise. This approach must be multidisciplinary, involving a qualified and specialized medical staff.

In any malformation case in which there are evidently ambiguous genitalia, careful assessment of the following aspects is mandatory: adequate definition of the gender, indication for genitourinary surgery and a clear explanation for the family. Each of these aspects must be considered as part of a process, not as isolated issue.

The adequate definition of the child's gender must be conducted as early as possible, as this identity diminishes parental anxiety and anguish. Cultural and social aspects play a relevant role in this context, particularly in a heterosexual society focused on the reproductive feature (essential for the individual's survival) and on the external appearance of genitalia.

Usually, an individual with cloacal exstrophy has a rudimentary hemipenis on each side. Due to the reduced dimensions and the wide distribution of the parts, in most cases the rebuilding of the phallus is extremely difficult or even impossible, considering current techniques. There have been recent reports of phallic reconstruction, uniting both hemipenises [5]. However, there are no functional evaluations available of the true value of this procedure. For this reason, the majority of surgeons dealing with this rare malformation make an option to perform an orchiectomy and lead these children to early adaptation into the female gender.

Historically, the transformation preference into the female gender was a consensus in medical literature. However, recent studies have emphasized evidence of androgenic hormones in the pre-birth differentiation of the brain. This fact seems to partially explain the inadequate transition and adaptation to the female sex of some genetically male patients. These retain a masculine imprint in their bodies, habits and social behavior, and fail to achieve a comfortable adaptation. Likewise, there are reports of patients who have undergone penile reconstruction, raised like boys, but extremely dissatisfied with the inadequacy of their penis from the onset of puberty.

Besides the difficulty (or impossibility) of adequate penile reconstruction, there are other challenges in the surgical treatment of patients with cloacal exstrophy, in relation to urinary and fecal incontinence after surgical repair, resulting from lack of good local sphincter musculature. The majority of these patients need surgical procedures for continent urinary derivation, from intermittent bladder catheters to permanent fecal stoma or fecal derivation using intestinal enema. Such procedures have brought comfort to patients, keeping them dry without daily use of diapers and improving quality of life. The reconstruction of the vagina in genetically male children is made whenever convenient, or during early adolescence.

For most cases in which the child is genetically male, the transformation to the female sex seems to be the best option. However, this remains a difficult decision, where the particular circumstances for each case should be assessed, along with the family and with its consent, after the necessary clarifications. In accordance to this, it is extremely important to convey to the family, in accessible language, all the important information so that they can understand the proposed therapy to be defined and subsequently implemented. It is essential to clarify that whatever the decision is, it might not produce the desired results, since there are no consensual solutions to the problem from a technical standpoint.

In fact, there are many controversies that still persist, and no solution has been encountered for this dilemma. The opinions differ and are many times conflicting, even in the most highly specialized centers for the treatment of this malformation. The prospect is that changes in therapy strategy will continue occurring as new surgical techniques are introduced which enable improved penile reconstruction, as well as broadening of knowledge on the ethiophysiopathology of the disease plus the input of bio psychosocial experience, derived from long-term patient follow-up.

Endocrinologist and psychologist's point of view

One of the most difficult situations to handle in the field of pediatric endocrinology is that of ambiguous genitalia (AG) not only because there are several medical diagnostic points-of-view, but mainly because of the emotional components involved.

It is undeniable that the first question asked after the festive event of childbirth is: *is it a boy or a girl?* And that is one of the reasons why the birth of a child with GA is an emergency situation. The family needs that answer. They need to insert that child in society and being a *citizen* implies in having a defined gender. We are thus facing the dilemma of deciding, together with the family, what would be best for that child in the future.

Considering all the aspects of the problem, the influence over the family decisions is important: we hold the

knowledge for some of the future possibilities for that child. The dilemma is embodied in the case of a newborn male, genetically defined, with normal testicles and malformation of the genital area with absence of phallus. In the light of current knowledge and surgical techniques, it is considered virtually impossible that penile reconstruction will allow adequate male sexual functions for this child in the future. And in the future, will this be possible? It is arguable then that the correct decision would be to let the child decide, when it is capable, what is best for him. But how can a child grow up to be a teenager without a name and a defined place amongst the other children?

In parallel, in recent years there is increasingly strong evidence that intrauterine exposure of the fetus to high concentrations of androgens such as testosterone, secreted by the fetal testes from the 9th-10th week of pregnancy, might leave *marks* on the nervous system that could be responsible for male behavior after birth [6]. Thus, how can we know what is the parcel of responsibility of those possible *marks* and of family attitudes in regards to this child?

When support is sought from scientific literature it is observed that the behavior of adults who had sexual definition under these circumstances is quite varied: some adapt perfectly to the sex they were assigned to, others rebel and demand re-definition [7,8]. Therefore, there is no uniformity in the findings. Observations made through these individuals' evaluations show that the degree of misinformation might be very large: 50% considered themselves misinformed, according to a study carried out in Johns Hopkins University, published in 2003[9].

In the face of so many uncertainties, how must we address the questions that arise when discussing ambiguous genitalia? What is it to be a man? What is it to be a woman? Up to what extent do parents have the right to determine their child's gender? Must the doctor interfere through surgery, or any other procedure, in order to define the child's gender? Must this be left for later on, when the patient him/herself can make his/her own choices? What other psychosocial problems could arise from the non-definition of gender?

These questions lead to other fundamental issues that might guide to possible answers: how is a child brought up? in which ways? How is the issue of gender presented to a child? We have important indications in Freud's study text *Project for a Scientific Psychology* [10]. In this work, Freud states that when the baby is born, it finds itself in a state of total helplessness. It needs an experienced other to meet its basic needs. This sets apart the human baby from the other animals. This fundamental dependence on the mother, who interprets the baby's needs, would set it apart from the natural or instinctive state, launching it to another area which Freud

called *drives*. He formulated the concept of drive as opposed to instinct Which means that everything that reaches the baby will be mediated by the interpretation of what the mother does, being implicit its significance, its desire. Thus, the mother, or whoever takes her place from the beginning, is involved in the formation of the baby.

Once established this bond, the child starts to direct its demands to the other, assuming that this one knows how to go about it. The *fundamental other* is therefore a privileged place where the child can find knowledge: for the child, it is the mother. In terms of sexual differentiation, we know it is not different. The child will have to, beyond observation of anatomy, signify or in the words of Zaidel, beyond the biological determinants, there is the subjective implication of sex, which would be the assumption. This assumption proposed by Lacan is quite different from what is called to "come out from the closet", released in the U.S. as the "psychological transformation of self", but what Lacan called 'sexuation'; which is on the one hand to subscribe regarding the significant, and on the other hand, it is also a matter which deals with the body. This means: the meaning is then the meeting of the body and the *significant.* It operates on two keys: first, it permits to signify the evident difference between the two sexes from observation; the absence or presence of primary and secondary sexual characteristics are determined by the prevalent image of the phallus, which allows naming the body as a sexuated body. Second, like all signifier, the phallus produces a meaning, from which being a man or a woman means something, even though they do not know what.

Therefore, it seems wrong that choice of gender can be defined later – maybe during adolescence - derived from the understanding that the subject would be then able to decide, in spite of everything he/she has previously experienced. What is known, instead, is that the decision to choose his/her sex is closely related to his/her story, to the relationship he/she established with the primary other, from which he/she was made[11]. In which case, if the doctor interferes or not, this will also be part of the subject's history, before which he/she should stand. Medical intervention will only be important if it can contribute so subject's suffering can be relieved, or if it can promote his/her social integration.

Finally, it is important to highlight that the child is born within a certain time, country, family, and society, with specific racial and economic conditions, that constitute situations he/she did not choose, because they were determined prior his/her birth. Those determinants are contingency situations that will be part of this subject's life and which he will have to face.

Lawyer's point of view

'Oh! My landscapes of yore… Old, old… Not alive any more…' Cecilia Meireles' poetry could apply to the legal system, which in its hieratic structure and hierarchy clings to immutability

– either because of the symbolic and pursued social security, or because of relatively slow changes in the past Instead, new spectra of ethical and moral choices entailed by growing scientific knowledge demonstrate growing divergence with conducts that are barred and forbidden by the legal system as being a part of life.

Legal standards and norms discipline current and common reality – *id quod plerumque accidit*: "What normally happens". For this reason, or in spite of it, the *normative vacuum* is frequent in the legal system. Moreover, in the legal system not only the value of the rule must be attended, but the exception to the rule as well. The importance of the exception in the legal field is promptly understood; being this the one that governs the conduct of men, and each man is, in itself, an exception. If law is an instrument of justice, neither the science nor technique is sufficient to know how to handle it.

In the study of the case under question, the legal rules do not dispose anything, nor do they order. In fact, this is, within the carneluttian perspective[12], an exception, whose cornerstone is the dignity of each child: to be attributed to her/him a plethora of guarantees because of unity, *uniqueness,* and individuality, in pursuit of his/her personal achievement in childhood, youth, adulthood and old age. Thus, the whole structure of principles and normative with which to work focuses on the view that all responses are of fallible and human nature. In former days, Henrique Vaz wrote that *the guiding principle of our itinerary was what we call the anthropological motives*[13]. Today, we can echo his words; the guiding principle of our itinerary is the child's health.

Today, we can echo his words; the guiding principle of our itinerary is the child's health. Handling one end of this issue, we are faced with the child's family and the issue that involves free and informed consent. All the proceedings adopted by the health care team must be based on the understanding, the support and the free and informed consent of the family. We should remember that in this particular case, the child's mother, single and only 16 years of age must take all decisions assisted by legal guardians, as mentioned in art. 4th, incise I, of the Brazilian Civil Code [those over 16 and under 18] [14]. Due to the uniqueness and specificity of the situation, legal authorization is necessary. Indeed, the judge's authorization is supportive and grants guarantees, be it in relation to the professional team involved, or in relation to the child's own family, because, after all, the judge says what is the law (the concept is neither new nor original: the assertive is derived from Anglo-Saxon law).

The definition of sex and the necessary and diverse surgeries, including those involving the mutilation of the child's rudimentary phallus show the need for extensive follow-up and ample discussion, to substantiate the sexual definition as to be *a male or a female.* In everyday life as well as within the legal universe, the definition of sex is always dual: the gender is either male or female.

On the backdrop of Christian-Hellenistic base for the entire Western civilization, we see that the perspective of the duality of sex lies in the collection of myths, legends and stories about creation, even in biblical accounts.

For now, distinctions are imposed between *sexual definition*, *sexual identity and sexual orientation*. The sexual definition is a situation relevant to gender: male or female. Therefore, from this first definition derive, among others, the right to a name, the equality of rights between men and women and constitutional prerogatives regarding women, and differentiation of treatment in relation to criminal laws.

Sexual identity is a person's view of himself – as a man or as a woman – regardless of the mirror image, of the person's gender or, even, the very situation that it is attributed by the legal system. Finally, sexual orientation is the affective and sexual attraction for the same sex – male or female homosexuality – or for the other sex – male or female heterosexuality. In fact, sexual orientation is guarded by a fair legal system that, under no circumstances, can condemn affective tendencies, and thus cannot interfere in the free and conscious desire of individual people. Sexual orientation is considered the cornerstone for the development of personality, and personal stances taken in order to face life.

The choice of a sexual definition can be entrusted to others: family, medical staff, judiciary functions. Despite the undeniable fallibility and uncertainties inherent to human life, that choice should be made as soon as possible. The alternative necessarily will consider or the possibility of growth of a male person with a rudimentary phallus, which in common language would be called *a man without a penis, or a small penis*, or the mutilation of the rudimentary penis resulting in an *apparent* definition for the female sex. In the case of sexual definition – when opting for surgical intervention in favor of a female sex – the same reasoning and justification could be applied, considering the differences – of a gender reassignment surgery.

The consequences of failing to choose would be disastrous for the dignity of the child itself – for a healthy psychological and social formation – there included the subjection to labeling and definitions by the same legal system, which with its rather formalistic vein, could also become a reflex source for future-life embarrassing situations. Evidently, even taking all the precautions for the social definition of the child, there is no damage exemption for the inexistence of conflict in the future: the human soul is, in itself, an inextricable labyrinth. There will be times when the soul's path is clear and straight, others, it is deviated, dark and tortuous, and, for what was lost, it must be stated: *I do not feel the space I enclose. Nor the lines I project: if I look at myself in the mirror, I err. I don't find myself in my own projection*[15].

Regarding the right to sexual definition, law 1,664/03 of the Federal Council of Medicine (CFM)[16] could be applied regarding the guidelines and policies to be adopted. by the health staff involved in the case. Indeed, the right to health concerns an early sexual definition, an adequate definition of gender and treatment in timely manner in order to assure the *apparent* gender, of high importance for their social inclusion. At first, sex definition implies child's legal identity, and necessarily, it will bear upon his/her future self-image.

In the winding path of legal rules, the milestones are: the dignity of the human being and the right to health respectively recognized in Art. 1, item III, and on Art. 196, both extracted from the 1988 Constitution [17]. After the choice for mutilating surgery has been decided upon, it is licit within the legal system, derived from the intention and the spirit that guides it – therapeutic intent and the will to heal and caring of the child.

The criminal-legal arguments for this type case are abundant: *social adequacy*, according to the original meaning by Hans Welzel [18]; *regular exercise of rights; unenforceability of diverse behavior*. Similarly, in the legal-civil realm, art.13 of the Brazilian Civil Code establishes that, unless by medical claim, it is defended the right of disposal of own body, when it implies in permanent decrease of physical integrity, or against the moral code[14].
If initially, there seems to be in the Civil Code legal permission for carrying out mutilating surgeries in children, there is, in the formulation of the text, two questions that must be answered:

1. Should the mutilating surgery be seen as a medical requirement? It is useful to remember that the perspective should always be the right to develop a full and dignified life;
2. The words *to oppose moral conduct* could actually assume the biased meanings it conveys, moralist and backward? Or, on the contrary, should it be committed to the mutations and changes of life, and refer to the meaning assigned to it, of respect for otherness?

Finally, to close the discussions under a legal standpoint, some ethical-legal questions which cannot be yet answered, need to be presented to the child's family, should they choose the mutilating surgery: should the child know the truth about his/her clinical condition? Or rather, should this be hidden? Truth, incomplete truth or non truth could affect the healthy course of his/her life? Would the child have the right not to know the full truth? These and other similar doubts constitute crucial problems that must be faced by the family in order to attain the psycho-social well-being of the child.

Feminist's point of view

There is no consensus in the feminist movement concerning the described case (child of male sex with cloacal exstrophy). We can say it is a debate still not addressed by the feminist movement, what probably means that

there will probably be divergent opinions on the subject.

Several feminist theorists are opposed to the presence of MTF transsexuals (male to female) in the feminist movement [19]. The reported case brings up the debate on genetic sex (chromatin), gonadal sex (hormonal or endocrine), morphological sex (anatomical), psychological sex (behavioral, emotional and cognitive), social sex, legal sex, sexual roles, sexual orientation and paraphilias. It also obliges us to seek the true understanding of words, especially those whose involvement with sexuality is explicit, for example, intersex, gays, lesbians, bisexuals, transformers, transvestites, transgender, gender, gender expression, and sexual orientation. Without such an insight, it is impossible to address the issue that the variability of sexuality demands the development of a discourse contrary to the gender theory consolidated in its sociological aspect.

The case presented is of a child with genetic and endocrine sex without male genitalia. Therefore, any surgical intervention for the re-designation of gender will be one of transgender iatrogenesis. There are indications that the artificial definition of sex reinforces the stigmatization of differences. In parallel, the extent of respecting what is different, especially regarding the diversity of identities, have not been well understood yet. Intersex are born with male and female organs, or with an anatomy that mixes male and female attributes (one ovary and one testicle, malformed or incomplete penis or testicles in the abdomen. The present case is not one of intersexuality, much less of transsexuality. However, the surgical procedure is and can be considered as a sex-change intervention. What remains unclear is whether such an intervention can be characterized as severe bodily injury, since the Brazilian law permits it, on an experimental basis, for proven cases of transsexuality [20], which obviously does not apply for this case.

It is not commendable to follow traditional practice: make a woman out of all the boys in a similar situation. It is of paramount importance that health professionals understand that sexuality involves a wide array of variability, and this implies in multiple sexual identities as being within the patterns of normality. Thus, it is ethical to seek for a possible consensus (social and ethical contract) so that they can be accepted socially. It is essential to know how to understand the viewpoint and wishes of the mother and father of the child, and overall, to establish the best conditions so that both can understand, endure, have doubts, and make decisions considering the diversity of sexual identities. It must not be overlooked that the right to be different is an idea that must be understood by health professionals so that they can transfer it appropriately to the parents of the child whose life story is initiating in the midst of many difficulties.

Health professionals need to take into account the processes of civil defense associations against medical power, such as the American Society of Intersex and Hermaphrodites with an Attitude (USA) which have accused American pediatricians of intersex child mutilation when these patients have not adapted to the sex chosen for them by doctors. The intersex advocacy movements claim that all surgeries should be carried out only in adults. They are against any surgical mutilation of children.

There is a painful report regarding a similar case. In 1973, the American sexologist John Money disclosed the recommendation that the boy David Bruce Reimer be raised as a girl, since he had his penis accidentally amputated during a surgery for phimosis. At the age of 12 months the child had his testicles excised, received a vagina, female hormones and therapy. For several years, Money reported satisfactory results. But the rebuttal came after 14 years: the patient gave up trying to live like a girl, had a penile reconstruction and a few years later, got married and adopted children. But he became depressed, his marriage ended and in 2004, at the age of 34, he committed suicide [21].

For over 30 years it has been shown that prenatal hormones play a fundamental role not only in the development of physical sexual characteristics, with the onset of genital organs, but also in the mental sex aspects. Studies carried out in 1938 with daughters of users of diethylstilbestrol during pregnancy were born with male-like genitals and since childhood acted like boys [22]. Androgens (male hormones) and estrogens (female hormones) both endogenous and exogenous can alter the development of the brain functions. Many of the features related to sex are determined hormonally during a set interval in the early stages of development and can be influenced by small variations in hormone balance. Evidence suggests that, once determined, the characteristics related to sex may be irreversible [23].

Criticism to binary genders is sustained mainly, in the understanding of gender as a mental or psychological sex which is *useful in distinguishing the sexual identity that each person assumes and is currently called 'option' or sexual 'preference', which is not simply an option, but a part of the set of characteristics with which a person comes to the world. The painful experiences of transsexuals, who insist on a sex change, show they do not choose freely and spontaneously, but that they have a strong inclination in that direction* (...)*We must recognize that gender should include diversity of identities assumed from sexuality, not only heterosexuality (male and female) but also gays and lesbians, transsexuals, intersex and asexuated, because there is also a large number of people who have no sexual orientation at all! If we deny this original sense of gender, we will have to invent another word, for when it comes to sexuality we can not fail to recognize these variability* [24].

The discourse that contradicts the theory of the binary gender is backed by the fact that Money's studies – which supposedly confirmed the success of the binary concept of gender and that were used to demonstrate that gender is a social construction, as well as to prove that education is more important than biology – proved to be one of the greatest frauds of medicine in the last century [24]. David Bruce Reimer, raised from the age of eight months as a girl, under the watchful guidance of Money, despite the intensive use of female hormones, grew up showing strong signs of masculinity, with discomfort and torture in the psychological aspect, for having his male identity imprisoned inside a female body and by having to follow the social conduct imposed on girls. It is paradoxical that the study that was the basis of supremacy of *creation* over biology is seen today as the paradigmatic example that biology cannot be overlooked, but it is compulsory that it be understood in its dialectic and procedural relationship with the physical and cultural environment. These are evidences that we must include to define and set limits to our professional practice.

Final comments

There is no optimal solution for such a complex problem, either from the strictly medical point of view (surgical and clinical) as from any other viewpoint. A complicating factor is that the decision regarding which sex should be assigned to that child, ideally should be made as early as possible, without taking his/her opinions into account. The consequences of this decision will remain, however, for life.

If, on the one hand, because of surgical, psychological and legal matters there is urgency for this definition; on the other hand, the currently rising value given to the autonomy and the right to be different pose a disturbing question: are these peculiarities anatomic aberrations to be corrected or differences to be accepted?

Interestingly, if the problem from the standpoint of health care is recent, created by technological innovation, which allowed keeping these children alive and with viable surgical alternative, the situation has been long known. We believe also that a reply to this dilemma was given almost five centuries ago. In one of his essays, Montaigne reports a very similar case*: I just saw a shepherd of nearly thirty years who has not the slightest sign of genitals; has three orifices through which urine escapes without stop; he is bearded, feels desire and seeks contact with women; […] what we call monsters are not in the eyes of God, who sees in the immensity of His work the infinity of shapes that in it He included; we must believe that the figure that horrifies us belongs and is connected in some way to the same gender. From His wisdom nothing derives that is not good and normal and under rule, but we do not perceive the harmony and relationship; […] we call against nature that which is against the conventions: but all that exists is in accordance with her, whatever it might be. May this universal and natural reasoning expel the error in us and the astonishment that this novelty conveys in us* [25].

To recognize and accept the differences are, and always will be, the pillars of an ethical attitude.

Resumen

Los dilemas de la definición sexual: ¿cómo proceder con niños nacidos con graves cambios genitales?

El nacimiento de un niño, por lo general un acto festivo, puede convertirse en un gran sufrimiento cuando el bebé presenta alteraciones genitales que impiden la asignación inmediata del género social y de educación. A veces, los niños varones con graves cambios en la anatomía y con la imposibilidad de la reconstrucción quirúrgica de un pene, son fenotípicamente transformados en mujer, conducta que viene siendo cuestionada, especialmente por los miembros de la sociedad civil. A partir de un caso concreto de recién nacido con el diagnóstico de extrofia cloacal, las dificultades y los problemas éticos que rodean la decisión de definir el género son discutidos, en este artículo, bajo el punto de vista de varios especialistas, directamente o indirectamente involucrados en el abordaje de estos niños.

Palabras-clave: Anomalías congénitas. Genitales. Nino. Identidad de género.

Resumo

O nascimento de uma criança, habitualmente um evento festivo, pode se transformar em grande sofrimento quando a mesma apresenta alterações genitais que inviabilizam a imediata atribuição do sexo social e de criação. Algumas vezes, crianças do sexo masculino com alterações anatômicas graves e a impossibilidade de construção cirúrgica de um pênis são, fenotipicamente, transformadas em mulheres, conduta que vem sendo questionada, especialmente, por membros da sociedade civil. A partir de um caso concreto em recém-nascido com o diagnóstico de extrofia de cloaca, as dificuldades e questionamentos éticos que envolvem as decisões para a definição do gênero são discutidos, neste artigo, sob o ponto de vista de vários especialistas, envolvidos direta ou indiretamente na abordagem dessas crianças.

Palavras-chave: Anormalidades congênitas. Genitália. Criança. Identidade de gênero.

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Authors' participation in the work

All professors, psychologist, and the pediatrician comprised the team responsible for child care during their internship in the Clinics Hospital. They were responsible also , along with a lawyer and a feminist, for the designing and preparation of manuscript. Everyone participated in discussions and literature review.