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Intersexuality and the "Chicago Consensus": the vicissitudes of nomenclature and their regulatory implications*

Intersexualidade e o "Consenso de Chicago" as vicissitudes da nomenclatura e suas implicações regulatórias

Intersexualité et le "Consensus de Chicago": les vicissitudes de la nomenclature et leurs implications régulatrices

Paula Sandrine Machado

ABSTRACT

The aim of this article is to analyze the composition and meaning of the "Chicago Consensus," published in two medical journals in August 2006. The "Consensus" recommends the use of the nomenclature "Disorders of Sex Development" (DSD) instead of the former classification of the "Intersexual States." Also, it suggests conducts related to diagnostic and intervention in these situations. The analysis points to the appearance of new terminologies, in which a medical specialty (genetics) is emphasized, and to the effort towards a classification progressively based on more "technical" terms and with very complex and specific codes. The "Consensus" reaffirms, thus, the fundamental role played by genetics and molecular biology in the discussion and production of knowledge inside the biologic and medical field of the "sexual determination and differentiation," as well as in research and interventions related to intersexuality. In this context, the emergence of the "sexcode" - a sex "revealed" in the microscopic level of the body - is highlighted.

Keywords: Intersexuality; "Chicago Consensus;" Medical classifications; Anthropology of science; Sex-code.

RESUMO

O objetivo deste artigo é analisar a composição e a significação do chamado "Consenso de Chicago", publicado em dois periódicos médicos em agosto de 2006. O "Consenso" recomenda o uso da nomenclatura "Disorders of Sex Development" (DSD) em detrimento da antiga classificação dos "Estados Intersexuais". Sugere, ainda, condutas em termos de diagnóstico e intervenção nessas situações. As análises apontam para o surgimento de novas terminologias, nas quais uma especialidade médica (a genética) ganha destaque, e para o esforço no sentido de uma classificação calcada em termos cada vez mais "técnicos" e com códigos muito complexos e específicos. O "Consenso" reafirma, assim, o papel fundamental ocupado pela genética e pela biologia molecular na discussão e na produção de conhecimento no interior do campo médico e biológico da "determinação e diferenciação sexual", bem como nas pesquisas e intervenções relacionadas com a intersexualidade. Nesse contexto, ressalta-se a emergência do "sexo-código", um sexo "revelado" no nível microscópico do corpo.

Palavras-chave: Intersexualidade; "Consenso de Chicago"; Classificações médicas; Antropologia da ciência; Sexo-código.

RÉSUMÉ

Cet article propose une analyse de la composition et de la signification du "Consensus de Chicago", publié dans deux journaux médicaux en août 2006. Le "Consensus" recommande l'usage de la nomenclature "Disorders of Sex Development" (DSD) au détriment de l'ancienne classification des "États Intersexuels". De plus, il suggère des conduites relatives au diagnostic et à l'intervention dans ces situations. Les analyses mettent en évidence d'une part le surgissement de nouvelles terminologies au sein desquelles une spécialité médicale (la génétique) gagne de l'importance, d'autre part, la tendance à l'élaboration d'une classification basée sur des termes de plus en plus "techniques" et composée de codes très complexes et spécifiques. Le "Consensus" réaffirme, ainsi, le rôle fondamental de la génétique et de la biologie moléculaire en ce qui concerne les débats et la production du savoir à l'intérieur du domaine médical et biologique de la "détermination et différenciation sexuelle", ainsi que dans les recherches et les interventions liées à l'intersexualité. Dans ce contexte, il faut noter l'émergence du "sexe-code", un sexe "révélé" au niveau microscopique du corps.

Mots-clés: Intersexualité, "Consensus de Chicago" ; Classifications médicales ; Anthropologie de la science ; Sexe-code.

In my doctoral dissertation (Machado, 2008), I analyzed the elements at stake in decisions involving “sex assignment” in intersex children and the sociomedical and quotidian "management"[1] of intersexuality. It was about understanding, on the one hand, the perspectives, practices and discourses of health professionals and, on the other hand, those of families and intersex youngsters. In the context of this study, one of the highlighted issues regards the different positions and appropriations with respect to the use of terminology concerning intersexuality, considering that even this denomination (intersex) is not self-evident, that is, it is as historically and socially dated as any other and refers to a particular sociopolitical context and its specific scientific production.

The West has dealt in various ways with bodies regarded as "androgynous" or "hermaphrodite" (Fausto-Sterling, 2000). Over time, changes in the forms of nomination, classification and apprehension of categories that refer to "variations of sex differentiation” were proposed and negotiated, from the older concept of "hermaphroditism", through the "intersexuality" of the twentieth century and reaching the current definition of "Disorders of Sex Development" (DSD). These usages have implications for how different social actors - doctors, lawyers, political activists, religious people, intersex persons and their families, among others - understand and act in such situations. That is, the changes do not only refer to a way of naming individuals, but also to the way of defining the "condition" that supposedly affects them and the strategies used to "correct" their bodies. Moreover, transformations and debates about nomenclature offer clues as to which social actors are regarded as possessing sufficient legitimacy to address the issue and how the different kinds of knowledge that are put into action interrelate. In other words, which kinds of knowledge are valued more and which are valued less, and which are accorded more weight and relevance when it comes to making decisions in these cases?

As shown by Anne Fausto-Sterling (2000), "hermaphroditism" was not always regulated by the medical sphere. According to her, until the early nineteenth century, decisions involving the status of intersex people were tasks of lawyers and judges. Michel Foucault (2001) shows how the issue was dealt with in legal - and especially criminal – terms until that period. In a course taught at the Collège de France, from January to March 1975, the author raised the issue of "Abnormality", pointing out how the definition of the "dangerous", "abnormal" individual of the nineteenth century referred to three figures. They were: the monster, the incorrigible and the onanist.

According to Foucault (2001), hermaphrodites were a kind of monster that was privileged in the Classical Era. He demonstrates how, over time, there have been changes in the way of dealing with this "monstrosity". The author notes that, until the sixteenth century, the mere fact of being hermaphrodite justified a death sentence. In the seventeenth century, there was a modification of this imperative and such a penalty ceased to be applied. However, the individual would commit a serious criminal infraction if, after choosing the "dominant" sex (which was mandatory), he / she used the "attached sex". The nineteenth century notion of monstrosity, then, was that there were not "mixed genders" but "nature's imperfections", which could develop into certain criminal conducts. From something inscribed in nature, the notion moved, according to Foucault (2001), to something that was gradually assuming a more moral character.

In the medical sphere, the term "intersexuality" as referring to "a wide range of sexual ambiguities, including what had previously been known as hermaphroditism" was probably used for the first time in 1917 (Dreger, 2000, p. 31).[2] In the 1990s, the name was appropriated also by intersex political activists engaged in the struggle to put an end to the early surgeries intended to "correct" so-called "ambiguous" genitals.[3] However, it must be noted that doctors and political movements do not define "intersexuality" in the same way. Intersex activist groups usually offer other definitions of the term, by which they seek to challenge the pathologizing of intersexuality, and increase the range of what can be included in the term beyond the medical definitions.[4]

The pertinence of the nomenclature "intersex" and the categories of "hermaphroditism" and "pseudohermaphroditism" comprised in this nomenclature were "officially" questioned in the medical field with the publication, in August 2006, of the so called "Chicago Consensus" in which the term "Disorders of Sex Development (DSD)[5] is proposed to replace the old nomenclature "Intersex" or "Intersex States". A group of fifty "experts" on the subject (doctors from different countries and also two political activists) met in 2005, in Chicago, with the intent of discussing various topics related to the medical "management" of intersexuality. From that meeting, the document was prepared. According to the consensus,

> Terms such as "intersex," "pseudohermaphroditism," "hermaphroditism," "sex reversal," and gender-based diagnostic labels are particularly controversial. These terms are perceived as potentially pejorative by patients and can be confusing to practitioners and parents alike (Lee *et al*., 2006. p. e488).

It is possible to suggest some hypotheses about the context in which the need to develop this "consensus" to change the nomenclature arose. On the one hand, one can point to a "formal" motivation, common to the development of any consensus in the medical field: a scientific update in relation to a specific area of knowledge and intervention, in order to dictate general and common protocols for medical practice. On the other hand, we can consider the formulation of the "Consensus": 1) as indicating the need to create terms which are supposedly more "technical", to be shared by an "initiated" and therefore more "restricted" audience; and / or 2) as a reaction to the visibility of the intersex political movement, especially in the United States, and to the issues that this movement is presenting to the medical interventions on intersex bodies since the 1990s.

It is worth noting that this concern about redefining medical categories, updating them, and, at the same time, distancing them from common sense, is something that also occurs in other areas of medicine. Jane Russo and Ana Teresa Venâncio (2006) point this out in their analysis of the revision of psychiatric classification that occurred in 1980 with the publication of the third version of the Diagnostic and Statistic Manual of Mental Disorders (DSM III) by the American Psychiatric Association. In this article, the authors describe, in addition to the academic clashes, the economic and political ones involved in the emergence of the new nomenclature. They emphasize, as well, the "multiplication" of diagnostic categories, increasingly detailed and presumably more "descriptive".

Considering that the choice of words is not random, my interest in this article is to examine the categories of classification used to identify the phenomenon - in this case, related to the definition and management of bodies that do not fit in the dichotomous standard male / female – as operatory for thinking about the issue and also about how these categories are involved in the conducts to be adopted in relation to intersexuality. Therefore, it is important to emphasize that the nomenclature issue can be considered from two perspectives: one horizontal (that is, temporal) and one vertical (considering the different social spheres involved in the present moment of the discussion), which help to place practices carried out on the bodies of intersex children in a broader social context.

The aim of this study is to analyze the current reformulation of medical classification. This analysis is centered on the composition and meaning of the "Chicago Consensus", published in August 2006 in two journals of wide circulation among physicians: Pediatrics - Official Journal of the American Academy of Pediatrics, and the Archives of Disease in Childhood. As already noted, the "Chicago Consensus" recommends the use of the term "Disorders of Sex Development" (DSD) over the older terms "intersex", "hermaphroditism" and "pseudohermaphroditism". It also offers guidelines in terms of diagnosis and intervention in these cases (Lee *et al*., 2006). Therefore, this study will specifically analyze the text of the "Consensus". Moreover, I will try to point out some implications concerning the use of terms that aim at describing certain bodily characteristics.

It should also be noted that the analysis of this document is inscribed among the issues addressed during my doctoral research. It is, therefore, supported by ethnographic data collected during the research, for which participant observation was performed in two hospitals of reference: one located in Rio Grande do Sul, Brazil, and another in Paris, France. In addition to the participant observation, semi-structured interviews were conducted with professionals in these hospitals (who formed the multidisciplinary team responsible for the diagnosis and subsequent follow-up of cases), with family members of intersex children / youngsters and with intersex youngsters. Although these data are not the focus of this article, they background the analyses offered herein and may be referenced throughout the text.

Though I chose to focus only on the aspect of the composition of the document itself, I regard the nomenclature as a privileged locus of analysis about a specific discussion that interweaves the categories of science, intervention, political movement and the everyday experience of doctor-patient relationships. Furthermore, I argue that we must embark on a theoretical and methodological consideration of the definitions, as well as of the transformations they involve and by which they are simultaneously involved. If, on the one hand, this exercise is about questioning the usage of theoretical categories, including those used by the researcher, on the other hand, it is also necessary to analyze the displacement caused by knowledge, in the sense proposed by Marilyn Strathern (1995).

Strathern, analyzing some consequences of the new reproductive technologies for kinship, points out that knowledge has an effect of displacement. By talking about "displacement" and not about "change", the author seeks to show how knowledge can lead to rearrangements in the comprehension and treatment of facts. If before, for example, the notion of family was directly linked to procreation and construction of social identity, with the new reproductive technologies it is possible to think of procreation (the union of gametes) as detached from reproduction (which implies social ties). According to Strathern, that means having more relatives and, paradoxically, fewer relationships. Knowledge and the act of making it explicit, thus, cause rearrangements in social relations, bringing along, she argues, more uncertainty for scientists, doctors and others who use them.

One of the effects of this displacement is "making the implicit explicit" (*Idem*, p. 347), which means that any given knowledge is continually juxtaposing itself to others, leading to new arrangements. What is at stake, Strathern observes, are not only new procedures that would help to get closer to ‟nature", but different forms of knowledge. As the author points out, when the implicit becomes explicit, conceptions change, along with the ways of understanding and ‟looking". "Displacement becomes radical" (*Idem*, p. 347).

Fleck ([1935] 2005), in 1935, emphasized the fact that scientific ideas circulate, and that there is no total rupture between two consecutive ideas (as Kuhn's notion of paradigms would later suggest, for example). [6] On the other hand, Fleck (*Idem*, p. 53), similarly to Strathern, points to repositionings, or even "mutations" in styles of thinking, which imply that the emergence of new concepts destabilizes the old ones and indicates other elements to be taken into account, in addition to other ways of constituting "natures" and "scientific facts". In his work, in which he covers the history of syphilis and the "discovery" of the Wassermann reaction (diagnostic test for syphilis), Fleck shows that there is a construction of these "scientific facts", which takes place based on a collective work of individuals. In this sense, there is a historicity of the "discovery", which can not be perceived as an isolated event but as a production that occurs in the context of a "collective and a style of thought." The production of scientific knowledge, in Fleck's view, is a social and cultural phenomenon (Löwy, 2005). At the same time, he does not see the social aspect as something that constrains science, but that makes it possible and legitimates it. (Latour, 2005).

On one hand, thus, Fleck's work ([1935] 2005) leads us to regard the elaboration of the "Consensus" as a sociocultural process. This implies, therefore, the existence of social transformations that would culminate in the production of both another "social" and another "nature".[7] On the other hand, the analysis of Strathern (1995) helps us to assess the issue of medical definitions and classifications as effects of displacements generated by scientific knowledge - in this case, more specifically, biogenetic knowledge, as we will further explore. The idea that there is a rearrangement of domains also refers to practical unfoldings generated by new knowledge: what is it that changes? Which social and cultural re-orderings are engendered? Are they really engendered? In the case of intersexuality, if this displacement is really possible, when and where can we perceive it and / or provoke it, incite it?

The choice of the "Chicago Consensus" for addressing these issues is justified for two main reasons: first, it is the most current reformulation, drafted by a group of "experts" that define it, precisely, as a "consensus"; second, it is a privileged document, in which it is possible to identify some guidelines for the "management"[8] and "diagnosis" of people born with sexually "non-standard" bodies, pointing to something that, during the fieldwork in Brazil (but especially in France) was proving increasingly clear: the important role played by genetics and knowledge in molecular biology on decision-making, discussions and scientific productions regarding intersexuality.

The analysis of the "Chicago Consensus" brings to our attention at least two topics that will be examined in more detail in this article: 1) the emergence of new terminologies, in which a medical specialty (genetics) gains prominence, 2) the effort toward a classification based on increasingly "technical" terms and with very complex and specific codes.

The Chicago Consensus and the substance of the invisible

The official title of the article that became known as "Chicago Consensus" is "Consensus statement on management of intersex disorders". In its very introduction, we can find the general objective of the text and of the meeting between the "experts" who contributed to its final form: "to review the management of intersex disorders from a broad perspective, review data on longer-term outcome and formulate proposals for future studies" (Lee *et al*., 2006, p. e488). In this sense, there is a recognition that the phenomenon in question is embedded in a complex plot, which includes advances in scientific development (which are converted into progress in techniques of diagnosis and intervention), general social aspects, as well as changes in the place assigned to the patient in the process of decision-making - patient advocacy. According to the "consensus", all these elements have led to the need to review the nomenclature.

Thus, in spite of explicitly considering a number of factors involved in the "management" of intersex infants, one can see a particular purpose of the "Consensus" which seems to overlap the others: the revision of the nomenclature. As described in the document, a new nomenclature is essential in order to include the advances of molecular genetics with regard to "sex development". It is interesting to note that the old nomenclature, "Intersexual States", already comprised, in practice, the knowledge of genetics; however this was not the basis of the classification. The new proposal suggests that "terms should be descriptive and reflect the genetic etiology when available and accommodate the spectrum of phenotypic variation" (*Idem*, pp. e488-e489). This suggests that highly "descriptive terms" would avoid possible misunderstandings, bringing the new nomenclature closer to something more "truthful", on the order of the "reality" of bodies. Thus, genetic etiology constitutes a naturalized version of sex, which would mark the differentiation between men and women on a deep level, a position formerly occupied mainly by the gonads.[9]

When it comes both to children born "intersex" and with a "DSD", it is about "cases" involving the decision to "rebuild" one sex or the other by means of surgical / clinical procedures, primarily in the postnatal period (although prenatal interventions may already be glimpsed in the field of medical possibilities). Specifically regarding "intersexual states", according to the medical literature, they could be divided into four main groups: female pseudohermaphroditism (presence of ovary, sexual chromosome 46XX,[10] internal genitalia considered "feminine", but external genitalia taken as "ambiguous"); male pseudohermaphroditism (presence of testicles, karyotype 46XY, external genitalia considered "feminine" or "ambiguous"); gonadal dysgenesis (presence of dysgenetic gonads[11]), true hermaphroditism (presence of ovarian tissue and testicles in the same gonad or separately) (Freitas, Passos, Cunha Filho, 2002). Anne Fausto-Sterling (2000, p. 52) developed a table in which she describes the most common "types" of intersexuality, which would be comprised by the main groups mentioned. These "types" would be as follows, according to the author: Congenital Adrenal Hyperplasia (under the category of female pseudohermaphroditism), Androgen Insensitivity Syndrome (a type of male pseudohermaphroditism), Gonadal Dysgenesis, Hypospadias (body characteristic that may be associated to some cases diagnosed as *incompletely developed genitals*), Turner Syndrome (type of gonadal dysgenesis) and Klinefelter Syndrome (also included, according to Fausto-Sterling, in the category of gonadal dysgenesis).

This classification between "hermaphrodites" and "pseudo-hermaphrodites" is supported by the dominant conception in the period that Alice Dreger (2000) called "The Age of Gonads", which supposedly began in the late nineteenth century and whose taxonomy - the division between "true hermaphrodites" and "pseudohermaphrodites" - maintained its more general structure virtually unchanged to this day. The foundation of this classification was that the "truth" about sex was determined by the "nature of the gonads". Thus, possessing testicles or ovaries was, for a long time, the unmistakable marker of difference between "true" men and women, as well as the yardstick to distinguish the "true" from the "pseudo" hermaphrodite. Subsequent to the "Age of Gonads", this criterion is reread. The issue, which was previously to possess or not ovaries or testicles, turns to the body's response to hormonal stimuli and to the surgical "constructions" of the genitals. Thus, a period is inaugurated in which an entire endocrinological and surgical arsenal is being increasingly used to "determine" and "build" the "true sex".[12]

Dreger (2000) notes that this division based on the gonads was untenable in medical practice until the early twentieth century,[13] although theoretically (for diagnosis and concerning physiological aspects) it was already very important for the physicians. The author reveals that, in the process of definition of the sex to be "assigned" to a "hermaphrodite" or "pseudohermaphrodite", other "features" were extremely relevant. These features referred to social and moral aspects related to the cultural expectations of gender. With the advances in genetics and surgical techniques, more elements were grouped for decision-making, which was becoming increasingly complex. The more scientific production in the biomedical area advanced in the search for unequivocal elements to discover where, after all, "real" sex was located, the more "ambiguities" appeared (Kraus, 2000). That's because more possible "levels" of location of sex in the body were being gradually revealed - anatomical, genetic, hormonal, gonadal levels – which were not necessarily mutually consistent and also could be combined in different ways (Machado, 2005).

It is worth noting that the sociocultural content of the considered biological aspects was always very present, and, after the "Age of Gonads”, especially as of the "Money Era" in the 1950s, it gained a new translation by means of the concept of *function*. *Function,* according to the medical definitions, comprises two aspects: the sexual one (regarding the possibility of engaging in sexual intercourse involving penetration) and the reproductive one (related to the conservation of the procreative capacity).[14] Thus, a decision that should take into account the best chance of performing such *functions* is the paradigm supported very strongly by the middle of the twentieth century.

The idea of "functionality" guiding choices with regard to the "management" of intersexuality has not disappeared in the "Chicago Consensus", but the new nomenclature offers a new framing for these *functions*. It is not just a new standardization, but also a new look, a different register of "nature" and, consequently, new regulatory processes. The most recent codification also reveals the emergence of a different biology, a different body, as well as another materiality that forms them. Table 1, reproduced from the "Consensus", outlines the review of the nomenclature.

Table 1

Previous	**Proposed**
Intersex	**DSD**
Male pseudohermaphrodite, undervirilization of an XY male, and undermasculinization of an XY	46,XY DSD

Female pseudohermaphrodite, overvirilization of an XX female, and masculinization of an XX female	46,XX DSD
True hermaphrodite	Ovotesticular DSD
XX male or XX sex reversal	46,XX testicular DSD
XY sex reversal	46,XY complete gonadal dysgenesis

Source: *Lee et al*. (2006, p. e489).

Soon after, still in the article about the "Consensus", an example of classification by "Disorders of Sex Development" is provided, which also deserves special attention (Table 2).

Table 2

Sex Chromosome DSD	**46,XY DSD**	**46,XX DSD**
45,X (Turner syndrome and variants)	*Disorders of gonadal (testicular) development*: (1) complete gonadal dysgenesis (Swyer syndrome); (2) partial gonadal dysgenesis; (3) gonadal regression; and (4) ovotesticular DSD	*Disorders of gonadal (ovarian) development*: (1) ovotesticular DSD; (2) testicular DSD (eg, SRY$^+$, duplicate SOX9); and (3) gonadal dysgenesis
47,XXY (Klinefelter syndrome and variants)	*Disorders in androgen synthesis or action*: (1) androgen biosynthesis defect (eg, 17-hydroxysteroid dehydrogenase deficiency, 5αRD2[nota 15] deficiency, StAR mutations); (2) defect in androgen action (eg, CAIS, PAIS[nota 16]); (3) luteinizing hormone receptor defects (eg, Leydig cell hypoplasia, aplasia); and (4) disorders of anti-Müllerian hormone and anti-Müllerian hormone	*Androgen excess*: (1) fetal (eg, 21-hydroxylase deficiency, 11-hydroxylase deficiency); (2) fetoplacental (aromatase deficiency, POR [P450 oxidoreductase]); and (3) maternal (luteoma, exogenous, etc).

	receptor (persistent Müllerian duct syndrome)	
45,X/46,XY (MGD,[nota17] ovotesticular DSD)		Other (eg, cloacal exstrophy, vaginal atresia, MURCS [Müllerian, renal, cervicothoracic somite abnormalities], other syndromes)
46,XX/46,XY (chimeric, ovotesticular DSD)		

Source: Lee *et al*. (2006, p. e489).

Below Table 2 there is a note that deserves to be highlighted as well. It reads:

> Although consideration of karyotype is useful for classification, unnecessary reference to karyotype should be avoided; ideally, a system based on descriptive terms (e.g., androgen insensitivity syndrome) should be used wherever possible (Lee *et al*. 2006, p. e489).

This quotation provides at least two indications: first, that the karyotype, and no longer the gonads, supports the structure of the classification, leaving it to the field of genetics, embryology and molecular biology. Second, it establishes that there are elements, such as the reference to the karyotype, which, while important from a conceptual and theoretical point of view, should be avoided in the context of the doctor-patient relationship, probably to avoid the supposed "confusion" that this information can create for patients and their families.

Looking at the two tables above, we see that some of the older classifications were grouped together. For example, the category "Man XX" or "Sex Reversal XX" is included in the category "46,XX DSD", as a disorder of testicular sexual development connected to a positive SRY and / or to a duplication of SOX9, considering that SRY and SOX9 are names given to two of the multiple genes described as involved in "DSDs". In its turn, the former category "True Hermaphroditism", in contrast, is diluted into three new classes: "DSD linked to the sexual chromosome", "46,XX DSD" and "46,XY DSD”.

Specifically regarding this last point, it is important to note that, according to Alice Dreger (2000), since the beginning of the "Age of Gonads," the "true hermaphrodite" was doomed to extinction in social terms. As the author demonstrates, the social existence of a "true hermaphrodite" was regarded, by definition, as impossible, for it was necessary to belong to one of the two sexes that were considered feasible. In this sense, Dreger questions the merely "scientific" justification as the only reason to adopt the gonads as a mark of sex distinction with regard to the period considered in her study. For her, this was an attempt to preserve the "clear" distinction between "men" and "women", regardless of the ambiguity that could be identified in their physical appearance or in the behaviors adopted by them. Thus, Dreger (2000, p. 153) believes it is not a mere "coincidence" that, at the same time in which she identifies the "disappearance" of the category "hermaphrodite", other historians suggest the birth of the category "homosexual". In the author's view, such changes were indeed about the need to locate these individuals - "the hermaphrodite" and "the homosexual" - in specific and autonomous classifications. Thus, definitions about the "real sex" or the "true" or "pseudo" hermaphroditism, rather than representing purely academic interests, always possessed important political and social implications (*Idem*).

Returning to the analysis of the tables and the "Consensus" as a whole, it is possible to observe that rearrangements occur both in the nomenclature and in relation to some aspects of the sociomedical management of intersexuality, as old classification and action parameters become insufficient from a technical and social standpoint. With regard to the transformations in the scientific field, a new taxonomy becomes necessary as, among other elements, the emphasis that is given to the different components involved in "sex determination and differentiation" changes. As previously noted, what sustains the new classification is notably the "genetic etiology" of sex, not just the way the supposed "disorder" is expressed in the phenotype, whether internal (which includes the gonads) or external.

Accordingly, the "Chicago Consensus" and its proposed use of the term "DSD" express something that, since the end of the 1990s, has been taking shape as the contemporary framing in the diagnosis and "management" of intersexuality: the central role played by genetics and molecular biology in the discussion and production of knowledge within the medical and biological field of "sex development (determination and differentiation)". Therefore, despite the "Consensus" stating that "psychosexual development is influenced by multiple factors such as exposure to androgens, sex chromosome genes, and brain structure, as well as social circumstance and family dynamics" (Lee *et al*., 2006, p. e489) -, in terms of "sex development", especially in the prenatal period, genetics and the web of knowledge that constitute it (generated by embryology and molecular biology, for example) seem to have acquired a certain preeminence in the process of defining sex. The genetic and molecular "invisible", in this perspective, gains concreteness - that is, substance - and executes, under the sign of another materiality, another body, the body of the genetic truth.

The subdivisions of the "Consensus" or what else is at stake?

The "Chicago Consensus" is composed of a series of subdivisions intended to address the "management" of intersexuality from a broader perspective. Thus, the article (Lee *et al.,* 2006) is divided in four major blocks: "Nomenclature and definitions", "Investigation and management of DSD", "Outcome in DSD" and "Future studies", in addition to two appendices: "Role of support groups" and "Legal issues". It is worth noting that half of the "Consensus" is dedicated only to the first two blocks, those focusing the nomenclature and the clinical-surgical-psychotherapeutic "management" of "DSDs".

I have already discussed the key elements developed in the "Consensus" in relation to the terminological aspects. As concerns the "management" of DSD, the document highlights:

> Optimal clinical management of individuals with DSD should comprise the following: (1) gender assignment must be avoided before expert evaluation in newborns; (2) evaluation and long-term management must be performed at a center with an experienced multidisciplinary team; (3) all individuals should receive a gender assignment; (4) open communication with patients and families is essential, and participation in decision-making is encouraged; and (5) patient and family concerns should be respected and addressed in strict confidence (*Idem*, p. e490).

Even if the options for the management of intersexuality presented by the "Consensus" remain basically unchanged - hormonal intervention and / or surgical intervention and "psychosocial" support, especially for the family, but also for the intersex people themselves - it is possible to identify a few changes. Among them, the recommendation stands out that the surgeries to reduce the clitoris in children with Congenital Adrenal Hyperplasia should only be considered in "degrees of virilization" *Prader* III to V. According to the medical literature, *Prader* is a measure of the degree of virilization of the genitals that may vary from I to V. Thus, under the new "Consensus", there would be no indication to operate in cases of *Prader* I and II. Indeed, as one of the Brazilian physicians explained to me, the change is concerned primarily with the contraindication of surgery in relation to virilizations classified as *Prader* II, since *Prader* I would be considered a normal virilization, indicative of only a "slight increase" in the size of the clitoris.

There is repeated emphasis on the importance of a multidisciplinary team from the moment of diagnosis, which, in ideal situations, would include at least: specialists in endocrinology, surgery and / or urology, psychology / psychiatry, gynecology, genetics, neonatology and, if possible, social work, nursing and medical ethics (*Idem*, p. e490). The novelty is the prescription of an enlargement of the group, with the incorporation of family participation and the potential indication of "support groups".

Nevertheless, the Consensus's new inclusiveness and the characterization of the new participants as fundamental in the process of decision making and monitoring requires close scrutiny. These social actors are positioned in quite circumscribed places. As described in the article, the family should be included in a process of communication and exchange of information, based on which they can decide about medical interventions. However, there is no specific guidance dealing with their participation in the decision making process regarding the child's sex assignment, for example. Thus, in practice, patients and family members would still not participate in all stages. At any rate, the movement toward "recognition" and "acceptance" of the place of patient advocacy (*Idem*, p. e488) may already point to some specific socio-cultural contexts of doctor-patient interaction.

We must also make an observation about the role assigned in the "Consensus" to the intersex political movement. Although activists were included in the meeting that resulted in the mentioned publication, with the participation of members of ISNA (Intersex Society of North America), the movement was recognized in the document under the banner of "support groups". Ultimately, this suggests that the text of the "Consensus" shies away from according full legitimacy to intersex activism, especially in reference to its political character and the ethical discussion that various groups raise in relation to the medical practice dedicated to the management of intersexuality.

The report by a German representative of the intersex movement, who was part of the group with the medical "experts", says that the subgroup responsible for discussing the issue of surgery - subgroup 4, Surgical Management of Intersex - did not include any activist (Thomas, 2006). According to Barbara Thomas, the larger group was divided into six, each one having been responsible for discussing specific issues in relation to the DSDs. According to Thomas, the political movement was represented only in the subgroups 3 (Investigation and Medical Management of Intersex in the Infant, Child and Adolescent) and 5 (Psychosocial Management of Patients with Intersexuality and Related Conditions), not in subgroups 1 (Recent Molecular Genetic Impact of Human Sexual Development), 2 (Brain Programming by Genes and Hormones - evidence-based) and 6 (Outcome Data: Evidence-based).

The proposed revision of nomenclature allows us to realize that the question of terminology is still open in the medical sphere and is the subject of many clashes and reflections.[18] Among other reasons, this is because not only the terms, but also the decisions regarding the intervention and the sex assignment in intersex children, raise some controversies in the medical sphere, as well as within the intersex political movement. Thus, the "Chicago

Consensus", by including some important activists (especially from North-American groups) in the team of experts who prepared the document, makes visible a series of tensions and conflicts in the context of the militancy itself: is intersexuality in the order of biology? Is it a category of identity? Is it a malformation? What are the ethical and political consequences of starting to use a term like "DSDs"?

Regarding this aspect, we need to ask why a group like ISNA, which, in its origin, raised as one of their main emblems the depathologization of intersexuality, began to advocate and to use the term DSD. On the ISNA website itself, we can find the explanation that this attitude "has opened many more doors", especially with respect to the possibility of dialogue with the doctors. Among other reasons, this may be a pragmatic strategy to make oneself "heard" within the medical sphere.[19] It may also reflect the fact that the term "intersex" did not establish itself as an effective identity category, capable of bringing together many adherents to the movement, contrary to what occurred in the context of the LGBTT communities (Koyama, 2006).

Still with regard to the discussions of the participation of activists in the elaboration of the "Consensus", we must also consider that the inclusion - although under the name of "support groups" – of representatives of a segment of the North-American intersex activism in the formulation of a medical document (a "consensus", to be exact) is not a standard procedure in the medical sphere. Such an option recalls, in this sense, the history of the AIDS epidemic in Brazil. Richard Parker, Jane Galvão and Marcelo Bessa (1999) note, to this effect, the intense action and articulation of social movements with various sectors of society and AIDS government programs in Brazil, and argue that this is a case in which political activism had a significant impact on the formulation of public policies.

Finally, there is another aspect stressed in one of the subsections of the "Consensus" - "Diagnostic evaluation" - that should be emphasized. It concerns the lack of protocols regarding the medical "management" of "DSDs". According to the "Consensus", there is no "single evaluation protocol" that can be applied to all circumstances, due to the wide "spectrum of findings and diagnoses" involved (Lee *et al.*, 2006, p. e491).

It may be suggested that this position undermines, to some extent, established ways of acting and thinking in the medical sphere, which, according to Kenneth Camargo Jr. (2003, p. 79), has largely centered its "theory" on the "theory of disease." According to the author, the latter is about producing diseases as diagnostic categories whose protocols for evaluation and action may be established in a stable and homogeneous fashion. It turns out that intersexuality and the very knowledge regarding "sex determination and differentiation" (or "sex development") raise challenges to medicine, and any attempt to establish a standard protocol becomes insufficient.

The technique, the codes and the space of morality

After highlighting and analyzing some aspects present in the article that became known as the "Chicago Consensus," in the third part of this article I will develop the previously mentioned idea that, in that document, there is an effort by a group of experts to establish a classification modeled on increasingly "technical" terms and with very complex and specific codes. Thus, terms such as "intersex", "pseudohermaphroditism," "hermaphroditism" and "sex reversal", regarded as "gender-based diagnostic labels" (Lee *et al*., 2006, p. e488), give rise to other "labels" mainly represented by letters and numbers (as evidenced by the acronym 46,XX DSD, for example), which are supposed to be less "controversial" than the first ones.

One may ask the question: what is so controversial about the old terms? Or, better: in relation to what do they generate so much controversy? If these terms can cause "confusion", as noted in the "Consensus", what, so to speak, should not be "confused" when it comes to sex differentiation? Finally, it is also worth asking: who has the power to talk about the "true sex" and the "reality of the body" in each of its more microscopic sections? And which tools (technical, conceptual, linguistic, among others) must we master for this purpose?

The proposed change of nomenclature and the very formulation and meaning of the "Chicago Consensus" offer interesting clues toward these issues. The central hypothesis that I intend to develop is that the use of increasingly "coded" terms answers, on the one hand, to the effort of trying to cover up the more relational aspects involved in the "diagnosis" of a person's sex, like the daily negotiations among health professionals, families and intersex people. It is as if, by means of this new proposal, it was possible to make invisible the processes and social relations involved in decision making regarding sex assignment in intersex children. The letters and numbers become naturalized variants of knowledge informed by sociocultural values and representations.

On the other hand, by moving away from expressions shared by common sense (such as hermaphroditism) or political activism (such as intersex) and approaching more "technical" codes, the new terms seek to make invisible the use of moral and / or identity-based categories of classification, associating the latter with a necessarily "pejorative" character. Thus, the old "true hermaphrodite" is not the same, from the social and cultural point of view, as the "Ovotesticular DSD" individual, even though these categories are related in the text of the "Consensus".

It is extremely important to point out, therefore, that the displacements generated by biogenetic knowledge go far beyond its scientific legitimacy. In the specific case of the sociomedical management of intersexuality, one of these effects is to make less evident the social elements involved in the process of decision-making, reaffirming the concreteness of sex - one out of two, and only two - by reconstructing its biological history inside the body. As pointed out by Rabinow (1999) with reference to the new technologies related to genetics, there is a kind of dissolution of the social, which leads, among other consequences, to the construction of another notion of nature, perhaps less "romantic" and with less fixed outlines. For Rabinow, some cultural categories - such as gender and sex - can rearrange themselves with others, being overlapped or even redefined by them. At this point I would like to introduce what seems to me to be another effect of the displacement promoted by the biogenetic knowledge: the emergence of what I shall call "sex-code.”

The sex-code is the one which is under the linguistic and cognitive domain of the new genetics and of molecular biology. Thus, it does not present itself by means of a language that can be shared by all, but only by a restricted group of “initiates.” In their daily lives, people do not ask whether they have a positive or negative SRY, whether they have or not a duplication in SOX9, whether they present or not a mutation in WT1 or perhaps in DMRT1. The sex-code is another truth about the subject, which is revealed by the body in each molecule, in each gene sequence. People are, paradoxically, increasingly inseparable (we can not escape the sex-code) and at the same time, increasingly distant from their sex-code.

Therefore, another biology is established. According to Jean-Paul Gaudillière (2000, p. 54), unlike the initial reductionisms, what we have today is a "science of complex systems”. Moreover, he says that we are not dealing any longer with the same assumptions as those of the embryology of the nineteenth century. There is, thus, a new conception of body, of "sex", and another understanding of the process of “sex determination and differentiation." The sex-code shows the body in its microscopic domain, at the same time in which it overlaps with its macroscopic domain.

Between the abstract and conceptual ideas supported by molecular biology and the "new embryology”, and clinical practice and quotidian interventions, however, there is a considerable distance. In this regard, Camargo Jr. (2003) already pointed out the possible paradoxes and contradictions that exist between medical theory and clinical practice. So, even though I myself use the word "intersex" / "intersexuality" and the "Chicago Consensus" proposes the term "DSD", during my doctoral fieldwork, other terms were also used by social actors, in specific contexts and conditions, both in the Brazilian and in the French hospital.

Although the medical literature mentioned "intersexual states", even the doctors whom I accompanied at the Brazilian hospital, for example, seldom used the term "intersex" amongst themselves and, as far as I could gather, never used that term during consultations with family members and / or with intersex children / youngsters. While, in a general sense, the term *ambiguous genitalia* was seen by them as inadequate (because it would not describe all "intersexual states" and also because it refers to the idea of "ambiguity"), the term *intersex* was also regarded as problematic. Nevertheless, I realized that in the course of their daily practice the medical staff used the term *ambiguous genitalia* amongst themselves when referring to certain conditions considered "intersexuality". However, this use was strictly contraindicated in the presence of families and intersex people, in which case they preferred using the expression *incompletely developed genitalia* (Machado, 2006).

The way the different classifications are put into action by doctors deserves a more detailed discussion. I restrict myself, here, to note that, in their daily lives, the doctors I followed mixed the use of some nomenclatures (such as *ambiguous genitalia* and *incompletely developed genitalia*) and classification systems (as I observed in the French hospital in relation to the pre- and post-"Chicago Consensus" systems), depending on the context of the enunciation – that is, whether it was done in a situation of academic discussion, whether it was restricted to the peers in the hospital's routine, whether it was addressed to patients and their families, among other possibilities. Furthermore, it should be noted that the use of the terms does not abruptly change in response to an external determination, since they reflect internalized perceptions and values.

Closing remarks

With regard to the medicine of the nineteenth and early twentieth century, the concern about the origin of "sexual difference" and the discovery of sex hormones as a promise of unveiling the "key" or unequivocal point to understand this differentiation deserve to be highlighted (Oudshoorn, 1994; Wijngaard, 1997; Rohden, 2008). So-called "hermaphrodites" played a key role in these definitions (Dreger, 2000). If medical knowledge requires a political and authoritative system over bodies in general, then intersex bodies constituted a privileged locus of action of these regulations, for they challenged the stability of the gender dichotomy as a norm. According to Elsa Dorlin:

> Medical power has historically been used as a palliative of the tensions and contradictions of the theory, to put an end to the exceptional cases, to the borderline cases, which were likely to undermine the explanatory models

> of bisexuation. In this sense, the issue of hermaphroditism, of the cases of sexual ambiguity that made assignation to one sex difficult, was the occasion for a long crisis both in the history of medical thought and of the theories of sexual difference or sexed differentiation (Dorlin, 2005, p. 123).

As I have demonstrated, the classifications and taxonomies used, which also act as regulatory practices, are integrating this political and authoritative system. As noted by Judith Butler (2002), the nomination creates distinctions, establishes boundaries, and follows a set of norms, which are extensively reiterated. Thus, the classificatory categories directed at the body, especially regarding "sex determination and differentiation", and the regulation of sexuality that they operate, possess implications for the way the sociomedical management of intersexuality occurs, and also how the bodily and ethical status of intersex people is seen. From a critical perspective, and considering the perspective of sexual rights as human rights, it is worth reflecting, among other things, upon the political and ethical implications, on a broader level of analysis, of terminologies as difference operators, and the concrete consequences that they may inflict on intersex bodies, such as clinical-psychotherapeutic-surgical interventions.

As pointed out above, changes in and clashes over nomenclature indicate that, on the one hand, the social actors involved in the process change, but, on the other, the way in which the knowledge of these actors interrelates, either becoming allied, either distancing themselves from each other, is transformed. Based on the analyses of the "Chicago Consensus", it becomes clear that naming, or the "act of naming" is established within a field of disputes (Bourdieu, 1996).

The reflections presented here also point to certain reconfigurations caused by scientific knowledge in the sphere of intersexuality. In the context of new reproductive technologies, Marilyn Strathern (1995) points out, for example, the emergence of new elements, caused by the production of knowledge and technologies, which tighten the boundaries of old definitions and generate displacements that disrupt the supposed stability of the domains of "nature" and "culture". At the same time, it is worth raising some questions for reflection based on the analyses carried out here: as concerning the interventions, what changes, in effect, with the "Chicago Consensus"? If, as I have argued in the paper, the biogenetic knowledge generates displacements, and, in this process, new concepts of body and sex emerge - the "sex-code" – why does the logic of the decisions seem to remain unchanged? What, in this sense, goes beyond the medical definitions?

The debates over nomenclature or the "right terms" to be used also show that there are disruptions and tensions not only between health professionals or fields of knowledge, but also in the context of the relationship between these professionals, the intersex people and their families. Still, the adherence of ISNA to the DSD nomenclature (and the subsequent dissolution of the group to found the *Accord Alliance*) seems to mark something important from the standpoint of intersex activism, in particular, and the activism for human rights, in general. As pointed out by Mauro Cabral (2008), this adherence to "medicalized" terms is inscribed in the process of transforming the body of the "political" subject into a body that needs medical care. It is the medicalization of the political that, ultimately, ends up mediating access to the rights.

I close this text by reinforcing the importance of taking a close theoretical and methodological look at this issue of definitions in "consensuses" and nomenclatures that describe bodily states - and statuses. As I demonstrated throughout this article, these definitions intertwine different issues and allow us to place the decisions that happen in hospitals in a wider social context of knowledge production. Thus, the terminology emerges as a knot located between technical, human and ethical-political considerations. This observation extends, as well, to my own research and my choices of terminology as a researcher. This way, it also projects itself on the ethical, political and theoretical-methodological implications of these choices.

Notes

1 I thank Professor Richard Miskolci (UFSCAR) for his suggestion about the use of this term, proposed at the time of the presentation of the work in the 31st Meeting of Anpocs. The word "management", here, refers to the idea of administration and governance. This notion is also linked to what Foucault (1988) describes as the power to manage life, or "biopower". In the way I use the term, "managing" is, at the same time, directing, regulating and monitoring in a systematic and constant way by means of specific tools and strategies. In this sense, doctors, as well as and family and intersex people "manage" intersexuality. By referring to a management considered "sociomedical", I seek to draw attention to the fact that there are sociocultural aspects, such as the gender, which are interwoven with technical and scientific arguments.

2 As the author explains, the term appeared in the article of the biomedical researcher Richard Goldschmidt (1917), entitled "Intersexuality and the endocrine aspect of sex.”

3 The first group of intersex activism was the Intersex Society of North America (ISNA), founded by Charyl Chase in the 1990s, in the United States (visit the website <http://www.isna.org>).

4 It is worth noting that ISNA started also to promote the use of the term DSD (without, however, abandoning the term "intersex").

ISNA has recently closed its doors, giving rise to a new organization, called *Accord Alliance*, officially inaugurated in March 2008 and adopting the new nomenclature DSD. Available in the website <http://www.isna.org>. [Access in May 2008].

5 An expression that has been translated into Portuguese as "*Anomalias do Desenvolvimento Sexual*" (ADS) ("Anomalies of Sex Development") (Damiani, Guerra-Júnior, 2007). There is also a proposal for "*Distúrbios do Desenvolvimento Sexual*" (DDS) ("Disorders/Disturbances of Sex Development"), as a Brazilian doctor has explained to me - the only Latin-American doctor that has participated in the meeting for the preparation of the "Consensus".

6 In the afterword to the French edition of Ludwik Fleck's work, Bruno Latour (2005) suggests that one of the injustices directed to that thinker is that his concept of "collective of thinking" was regarded as a mere "forerunner" of Kuhn's notion of "paradigm". According to Latour, for Fleck it was not just about studying the social context of sciences, but to pursue all the relationships, conflicts and alliances involved in the production of knowledge and in the history of thought. Latour considers him an instigating and visionary pioneer.

7 This aspect refers to the concept of "co-production" according to Sheila Jasanoff (2006), who points out the inseparability between the realm of "nature" and the production of "scientific facts", as well as the social and political order.

8 "Management" is a word used in the medical sphere, especially in the scientific literature. It refers to how a certain "condition" will be handled, conducted, dealt with.

9 About the role of gonads in the medicine of the late nineteenth and early twentieth century, with regard to the differentiation between men and women, see Alice Dreger (2000).

10 The acronym 46XX (or 46XY) is a biomedical convention, in which 46 concerns the total number of chromosomes of an individual and XX or XY refers to a pair of that set. They are called "sex chromosomes."

11 Gonads with "alterations".

12 It doesn't seem, however, that the "Age of Gonads" has been superseded. The idea of rearrangements on what concerns the definitions and medical interventions may be more appropriate in this case.

13 According to the author, it was only around 1915, with the advent of new medical technologies such as the laparotomies and biopsies, that it was in fact possible to identify testicles in living

women, ovaries in living men and ovotestes in living "true hermaphrodites" (Dreger, 2000).

14 On the importance of the idea of "function" in the empirical context in which my doctorate research was done, see Machado (2005).

15 It means 5 alpha-reductase.

16 Complete Androgen Insensitivity Syndrome (CAIS) or Partial Androgen Insensitivity Syndrome (PAIS).

17 Mixed Gonadal Dysgenesis.

18 For a medical analysis of the proposed revision of the nomenclature, see, for instance, Durval Damiani and Gil Guerra-Júnior (2007).

19 Visit the website <http://www.isna.org/node/1066>.

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