


Normalizing intersex children through genital surgery: the medical perspective and the experience reported by intersex adults

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Abstract

This paper explores the conceptions of specialized physicians regarding intersex child surgery, and contrasts them with the experiences of intersex adults. The gap between the views of health personnel—who affirm that they are “doing their best”—and those of intersex persons—who report the adverse consequences of surgery—highlights the need to stop unnecessary *normalization* surgeries in children. The findings of this study suggest that bridging the gap between the medical perspective and the experience of intersex people requires opening direct channels of communication among all those involved in the clinical process, incorporating intersex individuals into bioethics committees, encouraging contact with the parents of intersex children, implementing regulations that unambiguously delay or prohibit unnecessary interventions, promoting a debate on relevant ethical principles and human rights to protect the interests of all intersex people, and disseminating the contents of such a debate.

Keywords

Intersexuality, disorders of sexual development, sexual rights, social stigma, Mexico

Introduction

Intersex people are born with sexual characteristics that do not conform to binary norms associated with male and female biology. Their chromosomal patterns, endocrine systems, and gonads and/or genitals present variations reflected in anatomical differences that are not always physically visible (CONAPRED, 2017; ACNUDH, 2018; Brújula Intersexual, 2020). Intersexuality encompasses the Turner, androgen-insensitivity and Klinefelter syndromes, among others. While some undoubtedly require medical attention, it is essential to understand the consequences of interventions that have scarred the lives of intersex individuals. Delaying decisions until having complete knowledge of the situation and allowing for the possibility of living satisfactorily as an intersex person would have spared many individuals unnecessary suffering.

According to estimates, between 0.5% and 1.7% of the world's population is born with intersex variance (Carpenter, 2016). Global studies have reported this characteristic in 2% of live births (Hunt et al., 2018) and in 1 of every 1500–2000 infants (Chase, 1998; Gourley, 2014). Mexico lacks an intersex register; however, extrapolating the prevalence rate of intersexuality in USA (Hunt et al., 2018) to the Mexican population, calculated at 119,530,753 for 2015 (INEGI, 2016), approximately 2,390,615.06 individuals in Mexico would present an intersex characteristic.

Because of their physiological differences, intersex individuals find themselves readily thrust into the *medical environment*. Their bodies are medicalized because they are considered either ill (Topp, 2012) or incomplete (Sierra, 2009). The tendency to transform intersex people was strengthened in the 20th century, when the concept of alterations, disruptions or disorders of sexual differentiation (DSD) was accepted in the medical sphere as a way of classifying all individuals with conditions that lay outside biological

binarism (Alcántara, 2013; Lundberg et al., 2018). The term DSD went from being a biological reference to a “social diagnosis” (Brown et al., 2011). From the medical field, it spread to the social domain and led to intersex people being labeled as patients, as subjects suffering from an illness, thus medicalizing their entire lives (Jenkins and Short 2017). Intersex people reject the term DSD on the premise that it *pathologizes* them.

A number of countries have amended their laws to guarantee sexual rights and promote respect for the physical integrity and autonomy of the human body, including for those who are transgender and intersex (Rowlands and Amy, 2018). Resistance has also manifested itself in the form of public policies that acknowledge a third sex and, on this basis, regulate clinical treatments and surgery in Australia, Bangladesh, Canada, India, Kenya, Malta, Nepal, New Zealand, Pakistan, and the states of New York and California in the United States (ElMundo, 2007). These official initiatives have only partially curbed the social tendency to accept exclusively binary bodies, confusing sex with gender, orientation and identity (Roén and Pasterski, 2013); nonetheless, they constitute a fundamental step forward.

The discussions described above have prompted a reconsideration of intersexuality: its meanings, managements, and surgical treatments have changed (Griffiths, 2018; Holmes, 2002); also the politics and requirements for guarantee the citizenship of intersex individuals (Grabham, 2007); efforts are being made to eradicate stigmatization based on the idea that people must belong solely to one sex (Brújula Intersexual, 2020; Carpenter, 2016); and the pressure exerted on frightened parents to choose one sex for their infants is being questioned (Rowlands and Amy, 2018).

Several associations (ISNA, 2006; Brújula Intersexual, 2020; UNFE, undated) have brought to light cases of surgical *normalization* in infants. Mexican health authorities have failed to follow-up on the cases of intersex individuals who have undergone surgery and received treatment in public hospitals (Alcántara 2009a, 2009b, 2012; Brújula Intersexual, 2020; Chase, 1998). In Mexico, a number of government agencies and civil society organizations convened to discuss treatments for intersex individuals as well as their access to health services. Among the participants were the National Council for the Prevention and Eradication of Discrimination (CONAPRED), the Federal Bioethics Commission of the Ministry of Health, Brújula Intersexual A.C., and a group of academic consultants including the first three authors of this paper. The meeting culminated with the formulation and approval of a landmark document: the *Protocol for Non-Discriminatory Access to Healthcare Services for Gay, Lesbian, Bisexual, Transsexual, Transvestite, Transgender and Intersex Persons and Guides for Specific Care* (Secretaría de Salud, 2017; Secretaría de Gobernación, 2017). One objective of this initiative was to prevent unnecessary interventions for intersex individuals at public hospitals (DOF, 2017). Albeit a significant breakthrough, this document has yet to be disseminated disseminated actively to medical personnel in hospitals.

The aim of this article is to explore the conceptions of specialized medical personnel in the public health system that justify the *medical normalization* process performed on intersex infants in Mexico. To this end, we present the testimonies of health personnel and compare them with the opinions and experiences of intersex individuals themselves. *Medical normalization* is defined as the use of surgical techniques and/or medications to

change the internal and/or external genitals or gonads of infants such that they are categorized as either male or female according to social heteronormative standards. This medical posture and its implications do not necessarily match the wishes, orientation and self-identity of intersex individuals.

Material and methods

Between January and June 2017, we conducted a qualitative study in three Mexican cities: Guadalajara, Mexico City and Puebla. We adopted a qualitative design as it allowed for describing processes, exploring the experiences of all those involved and analyzing the meanings, concepts and values that guide specific practices implemented among small groups in conditions of stigmatization and secrecy. Using a qualitative design also allowed us to generate empirical data with strong internal validity (Morse 2003; Walsh and Downe, 2006). We worked with 15 participants who had undergone *medical normalization* processes; all were Spanish speakers and none belonged to ethnic minorities (Table 1).

Information was gathered by means of documentary research and semi-structured interviews (Chenail, 2011; Flick, 2000). We employed *snowball sampling* (Neuman, 2014; Tuckett, 2004) to recruit intersex people and medical staff in specialized hospitals. Exploration concluded upon reaching theoretical saturation (Fusch and Ness, 2015; Mason, 2010).

Table 1. Profile of informants and number of interviews.

Informants	Number	Data collection
Medical staff specialized in genetics, urology, endocrinology, pediatrics, and adult intersexual care in public hospitals*	7	1 face-to-face interview using notes to record the information gathered 6 audio-recorded face-to-face interviews
Intersex people 25–45 years old Diagnoses: Klinefelter's Syndrome (47 XXY) Congenital adrenal hyperplasia Androgen-insensitivity syndrome True hermaphroditism (ovotesticular disorder of sex development)	6	1 home interview conducted by telephone 1 face-to-face interview using notes to record the information gathered 4 audio-recorded face-to-face interviews
1 member of the medical staff specialized in certification processes and technical standards	1	1 telephone interview
Mother of an intersex child	1	1 audio-recorded face-to-face interview
Total	15	

*Including hospitals for patients without insurance as well as hospitals for workers

The first three authors of this paper prepared and conducted the interviews. They also designed the study protocol, theoretical framework and methodology. All were specialized in social topics and sensitive to issues of diversity, human rights and intersexuality. One member of the research/fieldwork team belonged to the intersex community. No intersex interviewees took part in designing the study or analyzing the data. Our project was submitted to *CONAPRED* for ethical approval. All participants provided prior informed consent (Figueroa, 2001) and received a clear explanation of the study objectives. They were apprised of their right to confidentiality and autonomy, and were advised that they could interrupt the interview at any time. The consent statements of all informants were recorded and their names and workplaces kept anonymous.

The interviews were transcribed and analyzed using Atlas TI software. Applying inductive reasoning (Bertaux, 1989; Chenail 2012; Saldaña, 2009), all members of the research/fieldwork team read and discussed the testimonies, codifying and clustering the contents according to families of codes and categories (Table 2). Two researchers from the National Institute of Public Health in Mexico were invited to review the medical aspects, methodology and discussion of our study.

Results

Processes and meanings surrounding the normalization of intersex bodies

The beginning of the normalization process: the diagnosis. From the perspective of the medical personnel interviewed, all newborns with an indication of DSD should be referred to a tertiary-care hospital, where an *interdisciplinary team* of endocrinologists, geneticists, pathologists, plastic surgeons, urologists and other medical professionals, as necessary, would initiate an intense interaction with the parents of the child. As one physician explained:

“To begin with, when a baby is born, if his/her genitals show any developmental problems towards [the definition of his] male or female genitalia, a Sexual Development Disorder is immediately recognized. At that moment, the doctor who identifies the problem should send him to a tertiary-care hospital.” (*Interview 1: medical personnel*)

Once at a specialized hospital, faced with a variation in sexual characteristics, an *interdisciplinary medical team* examines the “case,” deliberates and decides what actions should be taken on the basis of clinical and morphological criteria, endocrine system tests and a karyotype, or chromosomal picture. The latter is regarded by specialists as the most conclusive evidence for determining the true sex of a newborn. Based on these results, the team *assigns a sex* to the child and proposes a *solution*. In recounting their medical experience, the participating physicians affirmed that the assignment of a male or female sex to newborns reassured the parents. These doctors believed that it was practically their ethical obligation to establish such a diagnosis. Additionally, the physicians argued that the participation of several specialists guaranteed averting errors. In the words of two practitioners:

Table 2. Analysis: Inductive construction of codes, families of codes and categories.

Codes	Families of codes	Categories
<ul style="list-style-type: none"> • Steps to follow when an intersex newborn is identified through the public health subsystem • Ways of organizing the work of medical teams • Communication with the parents of intersex children 	<ul style="list-style-type: none"> • Proposed treatments • Interactions among social actors 	<p>The <i>normalization</i> process</p>
<ul style="list-style-type: none"> • Ethics committees • Supervision of patients • Opinions concerning sexual variance • Social actors involved in deciding whether to perform surgery or use other treatments • Education at home: What actions are required to facilitate the integration of a surgically intervened intersex child in society? • Explanations provided to parents by medical staff regarding surgery • The role of parents from a medical perspective • Differentiation between medical personnel and parents • The role of school • The conception of progress underlying surgical techniques and medical science 	<ul style="list-style-type: none"> • Medical imaginary: Transferring a biological change to the social sphere • Constructing sexual orientation, sexual identity and gender expression • The “secret” and paternal authority 	<p>Conceptualizations surrounding the <i>normalization</i> of intersexual bodies</p>

(continued)

Table 2. (continued)

Codes	Families of codes	Categories
<ul style="list-style-type: none"> • References to laws and guides for the treatment of intersex newborns • The right to health • Clear explanation to parents regarding informed consent • The relationship between physicians and adult intersex people 	<ul style="list-style-type: none"> • Legal frameworks for the protection of infants • The function of informed consent in the <i>normalization</i> process • Health system organization • Ethical tension 	Structures that justify <i>normalization</i>

“I can’t tell a dad, ‘you’re not going to say what it was [communicate the sex of your child to family and friends],’ but I can’t hide the sex of the baby from his parents, either... In my opinion, that is very irresponsible, because first comes [the obligation] to do no harm, and if I have all the evidence required to assign a gender, why should I deny it?” (*Interview 2: medical personnel*)

“Making a mistake is difficult because there are ‘many eyes’ overseeing the process.” (*Interview 1: medical personnel*)

The *interdisciplinary teams* attending to intersex infants are guided by up-to-date information on DSD management. They are well informed, maintain constant communication with peers, and work at the most prestigious public and private hospitals in Mexico. However, their sources of information omit professionals from other disciplines such as psychologists, sociologists, social workers and ethicists. These teams also lack knowledge from the field of sexual diversity. Whether the medical teams work in private or public hospitals, only one guide for treating hypospadias ([Instituto Mexicano del Seguro Social, undated](#)) is available to them; it should be noted, however, that staff at public hospitals are subject to legal and ethical restrictions, and are supervised by ethics committees to a greater extent than those working in private hospitals. The previously mentioned *Protocol for Non-Discriminatory Access to Healthcare Services* ([Secretaría De Salud, 2017](#); [Secretaría de Gobernación, 2017](#)) is theoretically applicable at federal-level tertiary-care hospitals; however, it is discretionary, and the standard has yet to complete the process required to become an Official Norm, as established by the guidelines for the issuance of rules in the medical field. The preceding information was provided via telephone by a member of the medical staff (*interview 8: medical personnel*)

Medical solutions. After *assigning the sex* of the child, medical personnel usually recommend hormonal treatments and/or surgery. In other words, they propose a solution to

normalize the *disorder* they have diagnosed: assignment to only one of the *sexes*, even though the individual is not in a position to provide consent or express the need to do so. This situation is described in the following statement from an intersex adult:

“When the result was given to me, it wasn’t done by the woman doctor who was going to explain it to me..., but by the chemist. When she saw the results, she said something like, ‘Oh, OK, have you thought about whether you’re going to feminize or masculinize yourself?’ I asked, ‘who says I want to do either one?’ And she said, ‘Well, the truth is that you’re not very masculine. and as a woman, you could be very attractive.’ At the time, I didn’t know what to say... I was very offended. I was surprised that she had that frame of mind. I think many doctors have exactly that kind of thinking.” (*Interview 9: intersex adult diagnosed with Klinefelter, intersex identity*)

The solution proposed by medical personnel to *cure* what is considered a sexual disorder rests on a concept that physicians express simply as changing sex. This course of action aims to adjust individuals to sexual binarism, a process that medical staff justify on the basis that it is facilitated by technological advancement. However, changing sex carries a different meaning for intersex people, as illustrated by the following interviewee:

“A woman doctor started examining me and said, ‘There’s a choice to be made here: do you want to be a man or a woman?’ So, you think, how can she ask me a question like that, of such magnitude, in front of other people? I still have a very vivid memory of this scene. I was in shock, didn’t know what to answer at the time, not because I didn’t know, but because of the power of the words. I mean, ‘what are you asking me?!’ These were difficult things, very difficult.” (*Interview 13: intersex adult diagnosed with androgen-insensitivity syndrome, intersex identity*)

The emergency. The *normalization* proposal from medical personnel is usually imbued with a sense of *urgency*: establishing a diagnosis and rapidly initiating treatment is considered vital. One member of the medical staff declared the following:

“DSDs must be *identified as soon as possible*, that is, at birth. All first-contact physicians must be familiar with these types of disorders and should send patients, *as soon as they can*, to the tertiary-care level, where there are specialized and multidisciplinary clinics... This is an *emergency*.” (*Interview 1: medical personnel*) (The italics in the quote were added by the authors.)

Labeling intersexuality as an *emergency* precipitates surgery under the assumption that haste will contribute to adjusting all the biological and social dimensions of intersex individuals rapidly. This idea presumes that a newborn person is analogous to an asexual, *malleable* and *empty vessel* with low pain sensitivity, whose identity and preferences can be externally molded. It denotes the intention to eliminate any obstacle that might hinder cooperation between doctors and family members; the latter agree to this by signing an informed consent form. To reach a decision, parents must rely on the advice of the principal physician. Persuasion on the part of medical personnel is often expressed very

forcefully, causing distress to the parents of intersex children. Physicians rarely either encourage parents to seek the support of a psychologist or counselor, or mention the possibility of exploring an alternative course of action. The following statement from the mother of an intersex infant clearly depicts this situation:

“[At the hospital,] the pediatrician didn’t tell me anything. He never told me anything. Then, after about three weeks or a month, I told the nurse, ‘that’s weird.’ I saw his genitals and then I realized [that there was something wrong], on my own, at a moment of great anguish, in front of the little boy who wasn’t eating, wasn’t breathing; he was on oxygen. I said, ‘What about this?’... Later, the doctor explained, ‘he has hermaphroditism with hypospadias.’ I didn’t understand anything. I felt so vulnerable, distressed. Then the doctor, superb... explained a most aberrant method: ‘they have to open up everything, divide it and build a conduit. With about 15 operations,’ he told me, ‘hermaphroditism is cured.’ He started telling me to go and see his medical team... but no one explained anything to me. He scolded me for searching on the Web. I said, ‘I’m going to get a second opinion.’ ‘Look,’ he said, ‘your son is in a [critical] moment and I can only guarantee his next 24 hours of life. You put one more doctor in this room, and all my team and I leave.’ Of course, I froze”. (*Interview 15: single mother of a child diagnosed with hermaphroditism*)

Removing, reconstructing and, then, discipline. The medical perspective assumes that, once all clinical interventions have concluded, gender identity can be constructed by means of a disciplinary educational process based on stereotyped gender roles. Parents conform to this approach and collude by keeping the secret. One intersex participant related the following:

“I was raised as a girl. My parents... never said anything, and now, as an adult, well, doctors told them not to speak about it because... if they did, the child might become a little fixated on it.” (*Interview 10: intersex adult diagnosed with congenital adrenal hyperplasia, intersex identity*)

From the medical point of view, *normalization* is also based on the idea that the biological functions of the genitals govern all psychosocial characteristics of individuals. In the words of one physician:

“The external genitals have a function, determined physiologically. We aim to maintain the adequate function of these external genitals... not only for reproduction, but also for sexuality, as much as possible.” (*Interview 1: medical personnel*)

A network of meanings has been developed where, once the gonads are removed or the genitals reconstructed-according to genetic and endocrinological studies-, *educational discipline* functions as a continuation of the medical process. It serves as an instrument to harmonize not only the physiological bodies of intersex infants, but also their feelings, tastes, preferences, and social interactions. As one physician put it:

“If that child is raised as a boy, even though not genetically a boy, the child will feel like a boy, because he will have already formed an identity at that age... A baby arrives *new*... This child

goes through reconstructive surgeries... a genital reconstruction takes place... The surgeries are carried out before the age of 2 and there can be several surgeries. The child is being made *normal*, rebuilt..." (Interview 3: medical personnel) (The italics within the quote were added by the authors.)

This perspective is derived from John Money's theory. Although it has been discredited and finds no support in the current medical literature, this view was shared by all the physicians interviewed. The idea that reconstructing a body and then adapting it to the dominant gender roles through *educational discipline* guarantees the prevalence of science over the *aberrations of nature* constitutes a preconceived notion that ignores the desires of the human beings subjected to these techniques.

Normal is what the "majority wants". The conceptions of physiological normality and *educational discipline* described above are also rooted in the belief that individuals should conform to what the majority wants, hopes or feels must be done. This is a statistical and epidemiological metaphor where the Gaussian curve is used as a parameter for comparison. Minorities are viewed as falling outside the sphere of normality. The following statement from a physician specifically addresses the relationship between normality and majority.

"The definition of the term *normal* is also very broad, encompassing numerous points of view. However, it is basically a Gaussian function point where the most frequently occurring events are located in the middle and the rarest/strangest are found at the ends [of the spectrum]... For example, if you ask people from our society if they want children, most will say yes...; those who say no are in the minority." (Interview 1: medical personnel)

The medical profession *can and must* attend to all problematic bodily functions. However, even though physicians are guided by, defend and, in fact, believe that they represent science, their dichotomous approach to physiology is not based on scientific evidence. This was clearly expressed by the following member of the medical staff:

"I have no idea how one can conclude that our species is divided solely into masculine and feminine. What probably weighs most heavily in this type of *problem* is that they [individuals not falling neatly into one of these two categories] will have reproductive *problems*." (Interview 1: medical personnel) (The italics within the quote were added by the authors.)

Normalization also carries a sense of responsibility: medical personnel feel that they can spare a child from the suffering caused by the *discrepancy*. Accordingly, they also view facilitating *appropriate socialization* of the intersex child as part of their mission. One physician stated the following:

"Sometimes their [referring to intersex children] genitals are observed when they go camping... If someone notices that the child is different, he/she is stigmatized. What parents least want is for [their child] to suffer... Parents don't want children to suffer. I think that we

also need to consider safety and a human being's self-image..." (Interview 3: medical personnel)

Medical power and the apparent decision of parents. As noted above, the decision to determine the sex of a child and offer an array of treatments for what is considered a *sexual disorder* is often—but not always—based on the results of chromosomal and hormonal studies. In some instances, information pertaining to the child's genetic code is ignored, and medical personnel opt to induce the parents to implement gender role learning and keep the *secret* within the family. A member of the medical staff recounted the following:

"[In the case of] the last child we operated on, the mother was the only one who knew. She was turned into a girl, and she doesn't know that she is a man, genetically speaking. She is now 14 or 15 years old, but we haven't told her... I can't tell her out of respect for her mother, who wants to wait for the right moment to tell her. When she is older and undergoes a karyotype and discovers that she has male genes, her mother will have to tell her. I made her vagina... Her chromosomes are those of a man, but her body is that of a woman." (Interview 4: medical personnel)

This practice violated the rights of the child. The doctor concealed the diagnosis and lied in complicity with the mother. What was the reasoning of the doctor in not disclosing the real diagnosis and instead choosing to lie? Not only did he lie; he contradicted the medical group that had concluded that the results of the karyotype represent the most compelling scientific evidence in this area. In complex cases, physicians view this issue as an ethical dilemma and feel that they are doing their duty. Specialized physicians and their technical skills are only a *means* for achieving *normalization*; it is parents who shoulder the final responsibility. Technology finally drives the decision to build male or female genitalia, and the parents generally accept this medical *solution*; the expertise of the doctor is not questioned. Parents have blind faith in the specialist, and the decision is only nominally in their hands. The circle is closed: under medical "supervision," parents make the decision to assign a sex to the child and manipulate the body utilizing the most modern medical techniques. Parents and physicians act in good faith; they believe in using modern technology and education to enhance the future quality of life of the child. They do not think in terms of potential harm, focusing exclusively on future benefits.

Structures that justify normalization

Informed consent. At public hospitals, all interventions, including intersex surgeries, are reviewed by ethics committees. In cases concerning minors, it is essential that the parents receive an explanation of the procedures. However, the fact that parents are aware of the procedures does not mean that they understand what they involve or grasp their full consequences. Nonetheless, parents generally sign the consent form. They have the last word, but make the decision—in a moment of great confusion and fear—based on information and advice derived exclusively from medical sources. The signed informed consent form protects medical personnel from possible liability for potential

complications; however, no one can really know what consequences these *normalization* procedures will have in the life of the intersex adult. Nevertheless, all decision makers agree to surgery or medication. Below is a relevant statement offered by a physician:

“Doctors and parents actively participate in the *normalization* process, and all take part in the decision. A couple cannot be forced into a procedure or treatment if they do not agree to it. We are not the ones who decide. We lay out the best option for the patient, and parents are given explanations based on studies and told what is best from the functional and physiological point of view. Each disease is different and has different elements.” (*Interview 1: medical personnel*)

In cases of children with ambiguous genitalia, a board comprised of members of the medical staff gathers to reach an agreement on what procedures to recommend to the parents. It is important to note that no intersex adults participate in these meetings, as their opinions are not considered scientifically valid. In cases of births of intersex children, the *interdisciplinary teams* believe that their scientific knowledge is incompatible with any views and experiences that might be offered by intersex adults. One informant from the medical staff stated the following:

“If I introduce the *interdisciplinary* group to a person who speaks a different language or has had bitter experiences because they were misdiagnosed or treated incorrectly, it would be very inconvenient, because if a father shows up, worried sick, and a suggestion is made to carry out a clitoroplasty on his daughter...and then a woman shows up who was treated incorrectly because her ‘sensitivity was taken away,’ this would slow everything down and wouldn’t correspond to the case [contribute to solving the *pathology* that the doctors are treating].” (*Interview 2: medical personnel*)

Health service organization and the concept of right to health. The way in which health services are organized in Mexico prevents specialized health personnel from knowing about the consequences that interventions during childhood can have on individuals once they reach adulthood. The Mexican public healthcare system is fragmented, with separate services for industrial workers, government employees and persons engaged in other activities. Children of bureaucrats and industrial workers are entitled to healthcare services only until they reach the age of maturity, and thus the *interdisciplinary teams* cannot continue to follow cases once the children become adults. Doctors are therefore unaware of the consequences of their early intervention on the lives of their patients. Furthermore, medical professionals are ignorant of the consequences of their treatments because adults whose genitals have been manipulated neither return to the hospital where they were treated, nor seek out the physician(s) who performed the procedure. In the words of one physician specialized in the treatment of intersex adults:

“They [intersex people] get tired [of the entire situation]. Generally, when we see them here it is for another reason or for a complication. They are patients who have been seen and treated many times. They’re not coming for a follow-up. They don’t want to know anything. They’ve

had surgeries, disorders of their sexuality. They don't have a sex life. They're not interested because there's pain, they don't feel much pleasure, and also because of the surgeries, which are not harmless: they cause adhesions or scar-like tissue, they have abnormal wound healing and [result in] many complications... They don't end up the same." (*Interview 5: medical personnel*)

One intersex interviewee recounted the following:

"...And the surgical process –going to the doctor, the psychologist– was difficult... to be constantly visiting the doctor, seeing the group of specialists, undressing in front of them, was very hard, traumatic." (*Interview 13: intersex adult diagnosed with androgen insensitivity syndrome, intersex identity*)

Medical personnel in public institutions believe that matching the body of an infant to one of the binary sex options is what is appropriate [the most appropriate course of action]. As the following physician related:

"They [the parents] care a lot if the baby is a man/male/'macho'. Particularly fathers and the type of people that we provide care for in the public sector, they care a lot about this. How am I going to tell them that their son's genitals are not well defined? Sometimes we deal with expectations such as 'I wanted to have a boy, or a girl'." (*Interview 2: medical personnel*)

But this does not necessarily have the same significance for intersex people. One informant described the situation as follows:

"Living as an intersex person is funny because when you walk down the street, depending on how you dress, you immediately reflect one gender or another. During most of my life, it wasn't much of a problem, it was something fun, funny. However, there were moments when it was offensive, because as an educated person, you know that this notion is generated by society, and it's offensive to see how people perceive one another when they want to put you in a box and they don't know how." (*Interview 11: intersex adult with diagnosis reported as forgotten, identity: usually a woman*)

Physicians justify surgery on the grounds that they are defending the right of the child to have access to treatments and live as normal a life as possible. They believe that failing to perform such procedures constitutes mistreatment of intersex infants. This is clear from the following narrative:

"That's why the prenatal study is important... so that this type of abuse doesn't happen: doctors believe that not providing treatment to children is abuse, and extrapolate this reasoning to intersex children. They cite cases where intersex children were seen by doctors, but nobody –not even the parents– detected their condition for lack of adequate care and information. I think this is a problem of social mistreatment and human rights because they are the product of a bad diagnosis." (*Interview 3: medical personnel*)

This vision differs from that of intersex individuals, who often feel that they have suffered abuse at the hands of the medical establishment. The following statement expresses the frustration of one intersex informant:

“I don’t know exactly how many surgeries were performed on me during my childhood. The last one was when I was between 4 and 5 years old... When I was 16 or 17... I found the papers that had been given to my mother... I asked my mom and she told me that I was ‘born wrong,’ that I had been born a hermaphrodite... I didn’t feel good or bad about the information I received, it wasn’t hard to assimilate, since I already sensed that something was not right for as long as I’d had awareness of myself. Two months before this happened, I told my mother that I liked women. My mom didn’t take it badly, but she told me that that wasn’t right because I was a woman at the time. Afterwards, I met a transsexual man at a lesbian girl gathering and he told me about hormone replacement therapy with testosterone, and what it meant to be transsexual. This led me to ask myself why I wasn’t happy as a woman, and it opened up the possibility of becoming a man... What has been difficult to accept are the surgeries that were performed on me without my consent when I was a child; I would have liked to have been asked how I felt.” (*Interview 14: intersex adult diagnosed with true hermaphroditism, identity: man*)

Lack of information and communication can lead to mistaken explanations of the diagnosis, with unintended consequences for the families of intersex people. One intersex informant related the following experience:

“I went to a doctor and he told us that it [DSD] is transmitted by the mother. But what affected me most was the emotional vibe, because my parents started blaming each other: my dad would say ‘they’re your family’s genes’ and my mom, ‘no, they’re yours,’ and the fact that the doctor reached that conclusion was, like, very stressful, it wasn’t pleasant.” (*Interview 10: intersex adult diagnosed with congenital adrenal hyperplasia, intersex identity*)

From the medical perspective, *normalization* resolves identity problems, but this is different from what intersex people experience and think. In the words of one intersex interviewee:

“I was given an appointment there –I think it was with the head of gynecology at the state level– and she told me that there weren’t many cases like mine, and that the government could pay for my treatment, at no cost to me. I asked her if this would affect my sexual pleasure and she responded that it would affect nothing at all. The procedure was explained to me... but [I was told that] if they cut you, you don’t feel anymore. Then I read... about a *bird* [woman] who had killed herself because she didn’t feel identified with being a woman but felt more identified as a man. Aside from the time it [the process] would take, I didn’t want to sacrifice my sexual pleasure, but doctors told me that if I didn’t [agree to the operation], I would continue to have sexual identity problems...that, in the long term, it was the best decision. But I have no identity problems; the problem lies in how you face this.” (*Interview 10: intersex adult diagnosed with congenital adrenal hyperplasia, intersex identity*)

Conclusions

The *normalization* process is carried out in tertiary-care hospitals by *interdisciplinary teams* generally composed of endocrinologists, geneticists, pathologists, urologists, plastic surgeons, and pediatricians. These teams do not include psychologists, social workers, ethics specialists or intersex people. When a case of intersexuality is detected in an infant, the parents are immediately contacted by and receive information from the respective *interdisciplinary team*, and are not exposed to other perspectives.

The members of *interdisciplinary teams* believe that intersex children have the right to enjoy a normal life and that it is a form of abuse not to diagnose and intervene in these cases. The physicians in these groups enjoy the necessary technical expertise to harmonize the body with the demands of the dominant culture, and they think it is their duty to choose one sex for intersex babies. From their perspective, they are protecting the human rights of these children. Medical teams do not benefit from exposure to the different opinions of experts in other disciplines, and they themselves *are* the ethics committee—thus, they carry out *normalizing* interventions and surgeries solely on the basis of parental consent. Doctors and parents do not and cannot know what the final outcome of the *normalization* process will be, nor can they predict its *real-life* consequences because they have no knowledge of the experiences of intersex adults. The interviews in our study demonstrate that specialized doctors neither know nor communicate with any members of the intersex community, and that there are no intersex members of ethics or other hospital committees. *Interdisciplinary teams* have no communication with intersex adults, their parents or other individuals conversant with intersexuality, reflecting the idea that doctors can only dialogue with scientists. Moreover, communication is hampered by the fragmented structure of Mexican health services, the deep cultural binarism of Mexican society—aggravated by homo-trans-intersex phobia—and the absence of specific laws in tertiary-care hospitals to protect intersex children.

During the *normalization* process, the parents of the intersex child find themselves alone facing the medical professional, thus rendering medical intervention the most likely outcome. Parents lack psychosocial support, exposure to the experiences of intersex people or information regarding the consequences of gonadectomy on the possibility of having children, something that might be achieved using assisted reproductive technology. *Normalizing* interventions are viewed as *necessary* by both doctors and parents, who believe they will make it less likely that the intersex child will be rejected in the future.

As shown in the second heading under the Results section, interaction between doctors and parents takes place in a structural context that encourages *normalizing* treatments and surgeries. The process of providing informed consent has been bureaucratized in a way that shields medical personnel from potential liability, but does nothing to protect the right to knowledge of the patient. Mexico suffers not only from a fragmented health system that prevents the monitoring of patients once they turn 18, but also from a deeply binary and misogynist society, and one that is fearful in the face of gender diversity and varying sexual orientations and preferences. Finally, Mexico must contend with ethical tensions and dilemmas in a context lacking institutions that encourage open discussion of contentious issues, clear rules for preventing abuse and the mechanisms to enforce them.

Discussion

Normalizing treatments and surgeries take place in a context in which well-being is presented as a benefit derived from *progress*, a notion Nisbet (1981) debunked as a type of *fantasy*, where sciences are considered a fundamental pillar at the service of, and promoting the happiness of, people. In the case of Mexico, *interdisciplinary medical teams* believe in this idea of technological progress and assume that they are contributing to the well-being of intersex children based on democratically made decisions, given that all team members and parents participate. However, the testimonies of intersex people point to the suffering caused by decisions made in their childhood which have affected their adult lives. This study demonstrates that interaction solely among medical personnel is insufficient, and that open discussion involving intersex people and professionals from the social sciences regarding the ethical principles that should govern these decisions is urgently needed. Even though their proposal derives from the DSD paradigm, Gillam et al. (2010) have developed six basic ethical principles that could be useful, as the authors focus attention on preventing harm.

In the case of Mexico, the informed consent process has been distorted with regard to intersexuality: the medical perspective excludes the possibility of living as an intersex person, with treatments and interventions proposed on the basis of sex and gender binarism as the only option, a perspective criticized by Machado (2009). In addition, parents are not clearly advised of the possible consequences for the child. These situations have also been reported in other countries (Gough et al., 2008; Morris et al., 2008; Roen and Pasterski, 2013). Given the pernicious effects of surgery and treatments on the lives of intersex adults, it is essential to promote more open debate about intersexuality, and such discussions must be based on total acceptance of human diversity. The process must include conversations concerning ethical issues, and should outline recommendations, laws, and public policy that would protect the well-being, human rights, and integrity of intersex people. This could help delay or avoid unnecessary medical interventions until intersex people themselves are in a position to make decisions concerning their own bodies.

Hegarty et al. (2021) showed the complexity of differentiating between *necessary* and *unnecessary* interventions. However, the discussion could be fruitful provided it starts from the premise that it is possible to live with sexual ambiguity and that binarism should not necessarily govern the diagnosis and treatment of intersex children, as Roen (2019) stated in his review on critical psychology.

It is essential to promote the dissemination of the Yogyakarta Principles launched in the form of a global charter by the United Nations Human Rights Council on 26 March 2007. Mexico was a member of the Council and is obligated to ensure that people are protected from discrimination, stigmatization and abuses related to sexual orientation or identity. Furthermore, the principles outlined in the Halifax Resolution, adopted at the 5th World Congress on Family Law and Children's Rights, delineate the nature of clinicians' fundamental ethical obligations to children including intersex newborns. The Mexican government must ensure that specialized medical personnel are familiar with and adhere to these Principles.

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