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Résumé de l'article

Les personnes présentant des variations intersexuelles se situent en dehors du binaire sexuel normatif homme/femme pour diverses raisons. Ces personnes sont fortement stigmatisées et discriminées dans les sphères juridiques, médicale et sociale. Dans cet article, nous analysons les manifestations de cette discrimination dans le contexte des soins de santé et nous émettons l'hypothèse que les approches de soins centrés sur le patient (SCP) et de prise de décision partagée (PDP) sont mal pratiquées avec les personnes intersexuées. Un examen narratif de la littérature actuelle permet de présenter les preuves d'une pratique inadéquate des SCP et de la PDP, ainsi que leurs répercussions sur les personnes intersexuées et, dans le contexte pédiatrique, sur leurs parents. La désinformation des parents de personnes intersexuées par les praticiens médicaux favorise la perpétuation d'interventions chirurgicales inutiles. Nous proposons des stratégies pour améliorer les soins médicaux aux personnes intersexuées, notamment une meilleure adhésion aux directives de la SCP et du PDP ainsi que la normalisation socioculturelle de l'identité intersexuée. Les perceptions actuelles des interventions chirurgicales pratiquées sur les nourrissons et les enfants intersexués doivent mieux correspondre aux risques pour la santé physique et psychologique fondés sur des preuves. Toutes ces stratégies s'inscrivent dans le cadre de la préservation de l'autonomie et de l'intégrité physique des personnes intersexuées et de la garantie que leur bien-être reste au coeur de leur prise en charge dans le contexte médical.



ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

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Marilou Charron^a, Katie Saulnier^{a,b}, Nicole Palmour^a, Hortense Gallois^a, Yann Joly^a

Résumé

Les personnes présentant des variations intersexuelles se situent en dehors du binaire sexuel normatif homme/femme pour diverses raisons. Ces personnes sont fortement stigmatisées et discriminées dans les sphères juridiques, médicale et sociale. Dans cet article, nous analysons les manifestations de cette discrimination dans le contexte des soins de santé et nous émettons l'hypothèse que les approches de soins centrés sur le patient (SCP) et de prise de décision partagée (PDP) sont mal pratiquées avec les personnes intersexuées. Un examen narratif de la littérature actuelle permet de présenter les preuves d'une pratique inadéquate des SCP et de la PDP, ainsi que leurs répercussions sur les personnes intersexuées et, dans le contexte pédiatrique, sur leurs parents. La désinformation des parents de personnes intersexuées par les praticiens médicaux favorise la perpétuation d'interventions chirurgicales inutiles. Nous proposons des stratégies pour améliorer les soins médicaux aux personnes intersexuées, notamment une meilleure adhésion aux directives de la SCP et du PDP ainsi que la normalisation socioculturelle de l'identité intersexuée. Les perceptions actuelles des interventions chirurgicales pratiquées sur les nourrissons et les enfants intersexués doivent mieux correspondre aux risques pour la santé physique et psychologique fondés sur des preuves. Toutes ces stratégies s'inscrivent dans le cadre de la préservation de l'autonomie et de l'intégrité physique des personnes intersexuées et de la garantie que leur bien-être reste au cœur de leur prise en charge dans le contexte médical.

Mots-clés

intersexe, communication médicale, soins centrés sur le patient, discrimination, stigmatisation

Abstract

Individuals with intersex variations fall outside the normative sex binary of male and female for various reasons. These individuals are highly stigmatized and discriminated against in the legal, medical and social spheres. In this paper, we analyze manifestations of such discrimination in the healthcare context and hypothesize that Patient Centred Care (PCC) and Shared Decision Making (SDM) approaches are improperly practiced with intersex individuals. Through a narrative review of current literature, we present evidence of improper practice of PCC and SDM and its effects on intersex individuals and, in the pediatric context, their parents. Misinformation by medical practitioners to parents of intersex individuals promotes the perpetuation of unnecessary surgical interventions. We propose strategies to improve intersex medical care, including better adherence to SDM and PCC guidelines as well as the sociocultural normalisation of intersex identity. Current perceptions of surgical interventions done on intersex infants and children need to better align with evidence-based physical and psychological health risks. All these strategies are part of preserving the autonomy and physical integrity of intersex individuals and ensuring that their well-being remains at the heart of their care in the medical context.

Keywords

intersex, medical communication, patient-centred care, discrimination, stigmatization

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INTRODUCTION

*Taylor is an infant born with true gonadal intersex, a variation where the individual has both ovarian and testicular tissue. Though Taylor's immediate health is not threatened, the attending medical team recommends that Taylor receive genital surgery so that their genitals conform to a typically female appearance. Taylor's parents experienced anxiety around the social expectation and pressure regarding the disclosure of their child's sex. They worry Taylor could experience stigma from having an intersex variation. Taylor's parents are hesitant about the surgery; they feel like they do not have enough information to make the best decision for their child, because Taylor's best interest was not sufficiently discussed. Surgical complications and alternative approaches have not been discussed. They feel rushed and uncomfortable about making decisions and announcements, causing them great distress.*¹

Anne Fausto-Sterling and Amnesty International estimate that up to 1.7% of the population could have intersex variations² (2,3). Intersex is an umbrella term used to designate individuals whose categorization within the normative sex binary of male and female is contested (4). In medical terms, the presence of intersex traits – often referred to in medical

¹ The scenario presented in this vignette is purely fictional. Any resemblance to actual persons, living or dead, or actual events, is purely coincidental.

² The percentage of the population described as having an intersex variation is widely contested, in part because there is still debate as to what qualifies as an intersex variation and because many people who may have intersex traits go undiagnosed (1,2).

contexts as a disorder/difference of sex development (DSD)³ – can designate individuals with differences in genitalia (6), sex chromosome aneuploidies (4), and various other congenital conditions (7).

Individuals with intersex traits – whom we refer to as “intersex individuals” in this paper⁴ – experience increased discrimination and stigma in the sociocultural, legal and medical spheres compared to those who do not have such traits (4,8,9). One of the behaviours that intersex advocates condemn is the practice of early so-called “cosmetic” – or otherwise medically unnecessary⁵ and/or unproven as to their functional beneficence – surgical interventions on intersex infants. They argue that such interventions strip these infants of their (future) bodily autonomy (i.e., their ability, once sufficiently mature, to decide whether to undergo such interventions) and human rights (e.g., to bodily integrity), because they are not yet capable of consenting and most such surgeries are not medically urgent (11,12). Moreover, in Canada, as in a majority of countries, intersex individuals do not benefit from explicit legal protection against such surgeries (13).

An approach that was predicted to lower demands for medically unnecessary surgery and to improve intersex patient outcomes was Patient/Person-Centred Care (PCC)⁶ (9). The goal of this approach is to encourage medical practitioners to consider their patients’ values, culture, preferences, and specific situations, and to exhibit compassionate, respectful, and empathetic behaviours (15). Above all, PCC involves the establishment of a relationship between patients and healthcare workers (15). Theoretically, this is the established best practice for intersex patients and their families (7,9). However, the results expected from PCC are not often achieved (9). In fact, in North America, surgery is still a common standard of practice and the default approach in intersex medical care (6,9,16,17), with practically no changes in the frequency of surgeries since the 2006 *Consensus Statement on the Management of Intersex Disorders* (9,17).

Due to dissatisfaction with current medical practice related to intersex individuals, several intersex activists have called for a moratorium on medically unnecessary surgeries done on intersex infants and children before they have reached the age of consent (18). Other activists have called for a shared decision-making (SDM) approach, while considering the best interests of the child and promoting their participation in decision-making about treatment in an age-appropriate manner (18). Here, we describe SDM as a collaborative process between patients and practitioners to reach agreement on a given clinical decision that is consistent with the best available clinical evidence as well as the patient’s given preferences (19). SDM is encompassed in PCC approaches where clinical evidence is low to justify one treatment over another, or when optimal treatment outcomes are largely dependent on patient preferences (19), as is often the case for intersex individuals.

These observations raise questions about intersex discrimination (in the medical and social context) and the application of PCC. How does intersex discrimination – for example, unnecessary genital surgeries, and gonadectomies, interfere with receiving adequate, culturally appropriate healthcare? How does this discrimination affect how patient-centred care with intersex individuals is practiced and perceived? Can concepts from patient-centred care truly be the solution to intersex discrimination issues? There is often no proof of the beneficence (i.e., net benefit or all things considered improvement to well-being) of medically unnecessary (e.g., cosmetic) surgery during infancy; in fact, evidence currently suggests these practices cause more harm than good (20,21). Therefore, we contend that the continuation of medically unnecessary surgery on intersex infants and children is deeply ingrained in the maintenance of a normative sex and gender binary (5,12,21-24). This leads to worse clinical outcomes for intersex individuals due to their social discrimination (5,12,21-24). Our hypothesis is that PCC is not in and of itself flawed, rather that it is inappropriately practiced for intersex individuals (9). Moreover, poor application of SDM in the case of intersex surgical decision-making due to coercion, misinformation and omissions on the part of medical practitioners is reported (25).

METHODS & RESULTS

A narrative literature review on intersex stigma, intersex medical practice and PCC and intersex was conducted. Research was done using Google Scholar and Morgan Carpenter’s *Intersex Bibliography* (26). For articles of particular relevance to the topic, we used a snowballing method. Since intersex literature is scarce, especially regarding long-term studies of intersex outcomes (6) and psychological investigations (20,24), no geographic restrictions were applied on the included articles. Search queries on Google Scholar were the following: *Patient-Centered Care AND Intersex OR DSD*, *Intersex OR DSD AND “soc* stigma”* (This search query produced no result as of August 5th, 2021), *Intersex OR DSD AND stigma*. Search results were restricted to articles published from 2016 onwards. Cited documents from years prior to 2016 were taken from Morgan Carpenter’s *Intersex Bibliography*, where no time frame was applied due to scarcity of published relevant quality studies.

A snowballing method was applied to the following articles: Timmermans et al. (9), Crissman et al. (29), Ravendran and Deans (27), and Leidolf et al. (28). In the case of Leidolf et al., the article was not included here due to outdated data, but

³ Due to the harmful social implications surrounding the term DSD and the stated preference of the community for using intersex (5), we refrain from its use throughout the paper.

⁴ This term, too, is sometimes contested, as some people with intersex traits may, nevertheless, identify within the gender/sex binary and consider themselves simply as male or female; others may self-identify as an “intersex male” or “intersex female,” and still others, simply, as “intersex.” By referring to “intersex individuals” we do not mean to exclude any such identifications – the term is used as shorthand for “individuals with intersex traits”, however they may self-identify.

⁵ For this article, we refer to the Brussels Collaboration on Bodily Integrity’s definition of medically unnecessary genital cutting, which refers to genital cutting when there is no “serious, time-sensitive threat to the person’s well-being” and/or when the intervention is not “the least harmful feasible means of changing the bodily state to one that alleviates the threat” (10).

⁶ While there are some differences between Patient-Centred Care and Person-Centred Care (14), we have judged these two terms to have enough similarities to be used interchangeably in this paper.

articles citing their research for follow-up studies were used. These articles were chosen because the research conducted was of central importance to the research question, specifically articles about the application of PCC for the intersex population (9) or the psychosocial effects of intersex medical treatment or identity, for individuals (27,28), and parents (29). A total of 38 articles were identified, read and one article was rejected due to lack of relevance to the research question.

DISCUSSION

A History of Intersex Medical Treatment

The recurring, widespread practice of intersex “cosmetic” genital surgery started in the 1950s (8,16,30). A movement of silence and non-disclosure was led by psychologist John Money up until 2006; during this time, it was believed that gender identity development relied on unambiguous genitalia and was an entirely environmental phenomenon that could be modified through education (8,31). These beliefs led to decades of cosmetic surgery on intersex infants, where parents were often uninformed regarding the nature of the surgery, coerced into giving permission (proxy consent) for specific treatments, and intersex individuals were virtually never informed of their diagnosis (8,12). The goal of these surgeries was mostly cosmetic, that is, to make the genitalia appear more stereotypically masculine or feminine with less regard towards function than normalized appearance (8).

The standards of practice were formally changed in the 2006 *Consensus Statement on the Management of Intersex Disorders* (7,8,17). Disclosure of intersex differences became the standard of care, and the proxy consent of parents necessary before proceeding with surgery, which had not been the case previously (7,8,17). The beneficence of psychosocial support and support groups for parents and intersex individuals was recognized (7). However, infant “cosmetic” surgery was and is still considered the standard of practice and encouraged among members of the medical field, making it the normalized treatment and outcome (7,8,16,17). Presently, medical practitioners are not required to defend the medical necessity of surgery on intersex infants to their licensing bodies before proceeding, since it accords with the standards of practice (8,17). Nevertheless, the goal of surgery has shifted to prioritize better functional outcomes over (what the surgeon and/or parents may perceive to be) better cosmetic outcomes (7,24). While perspectives in bioethics and human rights were addressed in the Lee et al. (7) review of the 2006 consensus, we argue that they were not given enough weight. The bulk of the paper is largely centred on technical approaches to surgical practices rather than the respect for patient (future) autonomy and for the principle of non-maleficence of these surgeries, detached from intersex individuals’ perspectives.

Medically unnecessary surgeries (e.g., chiefly intended for cosmesis) performed on intersex infants are now recognized by a growing number of international organisations and experts as a violation of the human right to bodily integrity as well as the right not to be discriminated against on the basis of one’s sex characteristics, while also undermining the individual’s future bodily autonomy (2,11,12,16,32). Best practice guidelines of a growing number of hospitals and human rights groups advise against any type of medically unnecessary surgery performed on intersex children (2,12). Nonetheless, such surgeries persist (6,9,16). In most cases this is not out of immediate medical urgency (i.e., to preserve or restore a straightforwardly physical function, such as the ability to pass urine), but for what the doctors/parents regard as aesthetic improvement, which they assume will be conducive to the psychosocial well-being of the child (12). However, as noted, this assumption is without an evidence base, whereas the evidence that is available suggests that many intersex individuals are psychosocially (as well as physically) harmed by medically unnecessary surgeries, a situation that is often exacerbated by resentment over not having been given a choice in the matter (12,20-22,24). Accordingly, intersex activist groups still fight to have such surgeries postponed until the intersex individuals themselves can provide informed consent (9).

Intersex Patients as Discriminated and Stigmatized Individuals

Here, we use the definition of stigmatization provided by Hegarty et al., who describe stigmatized traits as ones that diminish a person’s value in the minds of those who do not possess the trait (5). We would add to this definition the notion of internalization of stigma, which occurs when possessing a trait diminishes an individual’s personal sense of worth (33-35). As intersex traits have been shown to be highly stigmatized, it is important to understand that negative perceptions of intersex individuals are socially determined, rather than being grounded in, or fully justified by, more basic facts about their embodied status (36). Moreover, these negative perceptions affect medical care, for example, by framing surgery as a way to “ease the distress of parents” or to “prevent bullying in the future”, outcomes for which these procedures have been widely ineffective (26,37,38). It is inaccurate to think of intersex individuals as needing medical treatment solely because they do not have external genital appearances that conform with the socially normative sex and gender binary (12). The status of being intersex in and of itself is a naturally occurring and mostly non-life-threatening variation in human sex (4,12,22); the perception of intersex as a “problem that needs fixing” is a cultural phenomenon, enforced by current medical treatment paradigms and a strong societal reliance on male and female sex and gender identity (4,12). When medical issues do occur, such as salt-wasting in individuals with classical congenital adrenal hyperplasia (CAH), the need for a medical treatment should not be considered a special sort of “problem” with intersex differences (22). As a parallel, typically male or female phenotypes are not problematized for the presence of sex-linked disorders and diseases, such as prostate or breast cancer, respectively (22). As such, when we discuss difficulties and increased mental health risks experienced by intersex individuals, we should speak of “an issue of stigma and trauma, not gender” (5). Table 1 summarizes the different common challenges lived by intersex individuals throughout their lives.

Table 1. Summary table of common challenges lived by people with intersex variations (and their parents) at different stages of life and the different support and intervention methods proposed

| Stage of life | Challenges encountered | Support/Intervention |
|----------------------|--|---|
| Birth/Infancy | <ul style="list-style-type: none"> • Parental distress • Surgical decisions • Child's inability to consent • Social pressure (including pressure to announce child's sex) | <ul style="list-style-type: none"> • Counselling • Support groups • Information and options regarding different care paths • PCC and SDM (with parents) • Allowing time for decision-making and discussions |
| Childhood | <ul style="list-style-type: none"> • Surgical decisions • Genital examinations (potentially traumatic) • Development of gender identity • Child's inability to consent • Social pressure in school/community to conform to a sex and gender role | <ul style="list-style-type: none"> • Counselling • Support groups • Age-appropriate involvement in care: child's assent • Allowing time for decision-making and discussions • Recognition by educational institutions of intersex youth needs |
| Teenage years | <ul style="list-style-type: none"> • Mental health complications • Social challenges • Development of gender identity • Surgical decisions and hormonal treatment • Social pressure in school/community to conform to a sex and gender role | <ul style="list-style-type: none"> • Counselling • Support groups • Involvement in care: PCC and SDM • Giving time for decision-making and discussions • Recognition by educational institutions of intersex youth needs |
| Adulthood | <ul style="list-style-type: none"> • Mental health complications • Social challenges • Long-term effects of surgery and hormonal replacement (e.g., pain, discomfort) • Reproductive complications (e.g., infertility) • Surgical decisions (less common) • Discrimination: institutional, work, social, medical • Health complications unrelated to intersex variation not recognized by professionals | <ul style="list-style-type: none"> • Counselling • Support groups • Involvement in care: PCC and SDM • Giving time for decision-making and discussions • Consultation with intersex community • Development of inclusive environments |

While a given intersex individual may not experience all these challenges or may experience them to varying degrees, they are the ones commonly reported by the intersex population as a whole. Moreover, this list is not exhaustive, and many more challenges can be experienced by intersex people and their families.

A study by Crissman et al. reported that 68% of parent respondents feared that their child would be stigmatized due to their intersex status, on top of reporting high stress and anxiety from the intersex diagnosis (28). Two of the four major domains of anxiety and fear were related to disclosing information about their child's differences or the announcement of the child's sex (and therefore, expected gender) and intersex variation diagnosis to friends, family, daycare and school staff, or other relevant caretakers of the infant (29). This suggests an intense and persistent pressure to rear children in a way that conforms to the normative sex and gender binary (27). This could potentially have harmful affects on intersex individuals, since their conformity to that model is contested; these harms are likely aggravated where there are fewer educational and support resources to adequately care for intersex individuals (27). These issues are relevant for ensuring the adequate practice of PCC, because addressing parental fears and educating them on intersex variations are some of the key goals of this practice (9,15,38).

The pressure to conform to the normative sex and gender binary, erasure of intersex variations and discrimination against intersex individuals has also been reported in the school system. In an Australian survey of 272 intersex individuals, participants were invited to report on the discrimination they faced in the school system (36). Participants reported that school environments were the least likely to support intersex individuals and advocate for non-discrimination. Most participants in the survey reported being targets of heavy bullying by students and staff members. Moreover, 92% of individuals reported receiving no information about intersex variations in their high-school curricula. Instead, they reported strong enforcement of binary explanations of sex and gender. Not only do these curriculum choices ignore the existence of intersex individuals, they may contribute to increased drop-out rates and psychological distress among such individuals. Indeed, participants in the survey experienced an 18% drop-out rate for intersex individuals, as compared to the overall Australian drop-out rate of 2% (36). Sixty percent of participants also reported having had suicidal ideation, indicating significant distress in this group. The study author called for increased understanding of school environments regarding the medical and social needs of intersex individuals to ensure they are not unjustly penalized due to their variation (15). It is important to note that these phenomena were reported

despite Australia being one of the few countries with explicit legislation to protect intersex individuals from experiencing discrimination (37). In Canada (and other countries) where no such explicit legislation exists (13), we can hypothesize that similar problems may occur, but research regarding this topic has yet to be conducted.

One of the ways in which intersex erasure and enforcement of the normative sex and gender binary has a potentially harmful impact is on health-related quality of life (HRQoL) measures, defined as a method to measure perceived health status and the way in which it affects quality of life (27,39). HRQoL scores are consistently lower for intersex individuals in the domains of psychological/psychosocial problems such as anxiety, depression, obsessive-compulsive disorders (OCD), psychoticism, suicidal ideations, etc. (21,24,27,36). Intersex individuals, especially those having undergone multiple surgeries, are more likely to report negative body image, fear of rejection, fear of not meeting sexual partner's needs, reduced sexual sensation, feelings of devaluation, social isolation, and of feeling discredited (20,21). Since there is no indication that intersex variations biologically predispose individuals to psychological and psychosocial risks, decreased HRQoL scores and reports of self-harming behaviour suggest that environmental and sociocultural factors predispose them to such health risks (5). Decreased HRQoL measures suggest that intersex individuals experience discrimination and stigma in their everyday lives (27). For PCC practice, this indicates that particular attention should be paid to the psychological well-being of intersex individuals (4,15).

A survey of women with congenital adrenal hyperplasia, one of the most common intersex variations, was conducted to identify experiences of stigma in their social and sexual lives; 66% of participants reported experiencing stigma in their overall social experiences, while in the medical context, 27% of participants reported stigma, and in their sexual lives, stigma was reported by 20% of participants (33-35). The social stigma experienced in these contexts took many forms, such as explicit negative interactions with peers, anticipation and coping behaviours, as well as internalized stigma as a result of difference, regardless of surgical outcome (33-35). In the sociocultural context, evidence suggests that intersex individuals, whether or not they have undergone surgery, are highly stigmatized and discriminated against (8).

Intersex Medical Practice and its Repercussions

Overall, the current climate surrounding intersex medical treatment has remained surgically-focused (6,9,16). However, findings report a decrease in the invasiveness of surgical interventions since the 2006 change in practice guidelines (6). In 2014, there was a tendency to prefer "minor" surgeries (e.g., non-invasive or minimally invasive procedures) over major surgeries (e.g., gonadectomies, major genital reconstruction) (6). It was suggested that a more directive approach by surgeons may explain part of the clinical approach at the time (38).

What is most concerning are reports that medical practitioners were aware that their framing of cosmetic intersex genital surgeries (i.e., that promote aesthetic conformity of genitals) as medical emergencies was contrary to practice guidelines issued in the 2006 consensus statement, yet they continued to perform them (17,22). More recently, medical practitioners studied by Timmermans et al. also demonstrated awareness of the controversy and risks of surgery yet continued to be significantly biased in its favour (9). Further, no proof of the physical beneficence of early surgeries (apart from rare cases of life-threatening variations) or of their psychological beneficence has emerged (11,16,22). This suggests that the persistence of surgical practices on intersex infants is influenced by the perception that bodies that do not clearly conform to socially normative expectations around a sex binary are negative (4,12,22).

Many studies report that genital examinations, especially when undergone repeatedly or done by a group of doctors and medical residents, were particularly aversive and even traumatizing to intersex individuals (27,29,33). Often done for the purposes of educating medical students and practitioners, and without regard for the consent and privacy of intersex individuals (including minors), these group examinations have been shown to have long-lasting effects on psychological well-being, potentially accentuating feelings of stigma and shame and can also lead to healthcare avoidance later in life (4,33). The use of negative and stigmatizing language to describe intersex variations reinforces negative interactions between medical professionals and this community (22,37,40). These studies highlight differential treatment of intersex individuals and a deviation from medical best practice, and thus the importance of the principles of patient privacy and confidentiality (41).

From the existing evidence, intersex surgical decision-making does not fully adhere to best practice guidelines issued by expert groups for PCC and SDM (9,22). SDM should be the favoured process in these circumstances since intersex surgical decision-making is both preference-based and has low evidence to justify surgical intervention over non-intervention (19). Moreover, the lack of evidence indicates a need for more research on the consequences of surgical interventions and information regarding preferred care pathways for intersex individuals (40).

Medically unnecessary genital surgeries during infancy and childhood carry risks and can lead to both mental and physical harm (21). Intersex individuals who have undergone such genital surgeries report impaired bodily experiences, such as reduced genital sensations, urination difficulties, loss of fertility, and pain during penetrative sex, all which can lead to additional surgeries and put them at risk of complications (12,21). A less well-known area of concern is the harms associated with receiving anesthesia in early life, which may potentially harm brain development (25). Some surgeries can also disturb hormonal balance, leading intersex individuals to have to rely on hormonal therapy throughout their lives (12).

Often, medical professionals attempt to justify these risks by bringing up the psychological and psychosocial harms which they assume will be associated with having a mismatch between genital appearance and assigned social gender group

membership, and the need to relieve parental stress (25,37,42). However, studies have shown that having external genital appearance align in the way prescribed by the dominant culture to one's assigned social gender (or adopted/developed gender self-identification) is neither necessary nor sufficient for well-being (18). Indeed, self-esteem in children does not seem to reliably relate to atypicality, meaning that feeling atypical does not cause them significant distress (20). By contrast, manifestations of social pressure, such as examinations and surgical procedures, have been found to be a significant source of distress (20). Moreover, patients with hypospadias that have remained untreated in childhood typically do not seek corrective surgeries in adulthood (20,43). This indicates that they may be satisfied with the appearance of their external genitalia – or at least, do not regard surgical interventions to change such appearance as being worth the risks or other potential downsides – and that it may not affect their psychological well-being (20,43). Finally, parental distress is reported to remain high after surgical procedures, indicating that surgery does not substantially relieve all parental anxiety (27,37). Therefore, the justifications for favouring genital surgery on intersex infants are insufficiently supported by scientific evidence and are inadequate to support their use in the medical management of intersex individuals, especially infants and young children. More attention should be given to the well-documented risks of surgeries.

These reports suggest that medical examinations and other traumatic practices should be kept to a minimum and done only if medically necessary (44). Better adherence to SDM guidelines can greatly improve patient outcome and satisfaction with treatment (45). For intersex treatment the importance of a multidisciplinary team and varied perspectives on intersex care is essential (38), especially the role of culturally-aware psychologists and the support they offer (27,44). Preferences for information disclosure should be established during the SDM process (38). Parents consistently report a lack of information during decision-making procedures, especially regarding sexual development (18,20,25,29,38). Physicians should be aware that they violate SDM when they withhold information from parents (38).

Further, healthcare practitioners should engage emotionally with decision-makers and address sources of anxiety and psychological distress before any surgical decision is made (38). Proposing genital surgery to ease parental worries before a child is mature enough to voice their own opinion violates SDM and informed consent, because parents may not be in the appropriate state of mind to make these decisions (25,38). In the SDM process the intersex child is considered an active participant, making it necessary to wait for them to be of appropriate age to at minimum provide their assent, opinions and sentiments, and assent regarding procedures (18,23). Physicians should be attentive to the fact that their positions of authority can create power imbalances and that voicing their opinions without considering patients' and their parent's concerns can easily become coercive (4,38). All options, both surgical and non-surgical, should be presented to patients (24,37,38). Finally, SDM should always focus on the well-being of the intersex child, instead of being parent-centred (9,23,37).

Parental Choice and Coercion

The main objective of intersex medical management is to ensure that the best interests of the child are protected (18,23,37,46). According to Wiesemann et al. (18), safeguarding the best interests of the child involves four main criteria: 1) the intersex child should be recognized as a major participant in decision-making; 2) psychological support to ensure a good parent/child relationship should be prioritized; 3) practitioners and parents should recognize that sex-typical appearance of genitalia is neither necessary nor sufficient for the well-being of the child; and 4) the child's bodily integrity should be considered and preserved to keep their options open for the future (18,20,23,37).

For cosmetic genital surgery to occur, proxy consent of the parents must be obtained (9). Davis and Murphy determined from interviews with medical professionals that they often purposefully created ambiguity and framed surgeries as medically necessary for intersex children (22). Medical practitioners, rather than using a SDM process, biased parental decision making by restricting information presented to them (22). Such processes were reported to shift the onus of the responsibility to the parents. This may result in adverse consequences for the child's health and is unjustified since most lay people do not have sufficient knowledge on intersex variations to make a truly informed decision (22). Bennecke et al. (44) reported that 82% of surveyed parents were given a surgical recommendation, despite this not being indicated in the best-practice guidelines nor supported by the literature. Timmermans et al. (9) recently reported that in recordings of surgical decision-making appointments between parents and a medical professional, genital surgery was framed as necessary and beneficent for intersex individuals; consciously through the information relayed, and unconsciously through clinicians' attitudes and choice of words thus swaying parental decisions towards the surgical approach. Both studies indicate that parents often felt pressured to make decisions (9,22). Moreover, parents consistently reported feeling medical communication was difficult and that information regarding their options and their child's health status, especially in the fields of social and sexual development, was lacking (18,20,25,29,38).

Consequently, most studies regarding parental surgical decision-making report that they felt the surgery was "obvious and necessary". Properly used, the SDM approach would present all treatment options (advantages and disadvantages) and parents would be aware of non-surgical alternatives and the debate concerning surgery (5,25,29,47). In fact, Roen and Pasterski (20) reported that most parents were unaware of non-surgical options nor were they informed of the debate, limitations, and possible consequences of intersex surgeries. Instead, many parents believed that surgery was taken as an effective protective measure for their child, even when it was not a necessity (46). These results are supported by Crissman et al. (29), who reported similar parental attitudes, as well as a strong wish to normalize their child's genital anatomy and the belief that surgery would resolve social complications for their family. Though recent research shows violations of informed consent and impaired medical communication, assessment of parental attitudes is absent (9). Further, Sanders et al. (46)

report a lack of consideration for what the child as an adult might want. As such, Timmermans et al. conclude that current intersex healthcare practices are “parent-centred” rather than patient-centred (9).

Streuli et al. (47) tried to identify how healthcare professionals’ attitudes could influence parental choices for their intersex children. They asked undergraduate students to choose a treatment option for an imagined intersex child after being exposed to one of two introductory/diagnostic videos: one depicted an actor playing the role of a physician, who presented intersex variations in a highly medicalized way, while the other, using the same actor, depicted a psychologist, who presented intersex as a naturally occurring bodily variation and did not stress immediate need for medical procedures (47). Both scripts were approved by relevant medical professionals and a multidisciplinary group of relevant experts, including intersex activists. Results indicate that students exposed to “the medicalization” video tended to choose surgery significantly more often than those who had seen the psychologist video, while those who had seen “the psychologist” video tended to opt out of surgery. Moreover, participants reported being largely unaware of the impact the presentation methods and presenter’s attitude had on their decisions. These results suggest that intersex medical practices and surgical decision-making are highly prone to bias (47). For PCC and SDM, this means that a strict code of conduct should be observed by medical practitioners to ensure that non-directive counselling occurs during the decision-making process (9,37,46). Additionally, Schweizer et al. (21) report that parents who received psychosocial care and a more detailed communication and informative process tended to opt out of surgical interventions.

Intersex medical treatments affect the individual, their parents, and their relationships. Significant correlations were found between how intersex individuals perceived the parental care they received and measures of insecurity, suicidal thoughts, body image perceptions and psychological distress signs, all of which are important components of HRQoL (21). These results suggest that parents play an important role in shaping the psychosocial development of their intersex children (21,48). When combined with reports that repeated surgical interventions – often seen in intersex care – affect parent-child bonding, concern should be heightened (20,48).

The priority of parents is to protect their child, and this encompasses the child’s privacy, mitigating negative social experiences, and consideration for the child’s future relationships (46). Rolston et al. (49) identified that intersex parents’ main worries were for their children’s future and the stigma these children may face. Not understanding these worries or unrealistic responses to them could easily lead to coercion or exploitative patient (decision-maker)-practitioner relationships (29,38). Parents experience high stress and anxiety when receiving an intersex diagnosis for their children (42,44), which can lead to post-traumatic stress disorder (37). They also reported feelings of isolation during the process (29). These studies highlight the importance of showing parents compassion and support during the decision-making process, an essential component of PCC (15). Psychological support may still be lacking in this area, and not systematically offered despite recommendations that it be provided (44).

RECOMMENDATIONS

Better adherence to SDM guidelines, better access to psychosocial supports and descriptions of intersex differences framed according to current scientific evidence could ameliorate parental experiences with intersex healthcare (29,37). A starting point is to educate medical professionals on SDM and adopt a PCC approach that is culturally sensitive to sex and gender diversity, with non-directive language, and which includes presenting non-surgical alternatives (19,45). Reports from NGOs and international law opinions, which view unnecessary/cosmetic surgical practices as unethical, should be available to parents in the decision-making context (24). Deferral of surgery and non-surgical management of intersex differences should be framed as realistic options for parents, options that are consistent with current scientific evidence and SDM procedures (27,37).

CONCLUSION

Since intersex individuals face discrimination and stigma, and are thus a vulnerable population (8), ensuring that PCC and SDM are considered part of the standard of care in the intersex context is especially important and has the potential to greatly improve outcomes (45). Ensuring that parents are equipped to protect the best interests of their children requires improvement in the transparency and objectivity of the decision-making processes (24). Unlearning beliefs about the sex and gender binary is an essential step toward truly achieving PCC standards for intersex individuals (15).

Combatting stigma towards intersex variations requires systematic change in: 1) education through curricula that includes intersex variation and a discrimination-free environment; 2) the medical field, with improved communication for self-disclosure around sex and gender, such as preferred pronouns; and 3) the legal domain, where widespread acceptance of a third sex and gender status, namely “X”, could improve intersex and the broader LGBTQIA2S+ communities’ experiences. However, the intersex community has acknowledged that, while a third sex and gender status could be helpful in challenging the normative sex and gender binary embedded in legal documents, it would be insufficient in addressing the systemic institutional problems they face (50). In the treatment of intersex individuals, a move away from a binary gender identity as a measure of well-being in childhood, and towards a focus on aspects of communication, family, healthcare, support from peers, body image perceptions, and the enjoyment of bodily pleasures is proposed (4,18). Measures of well-being specific to intersex experiences, such as access to group support and members of their community should be considered (20). Moreover, there is a pressing need for professionals who specialise in intersex-related medical and psycho-social challenges to be part of their multidisciplinary care teams (27).

Finally, in movements where there is a strong sense of pride associated to an identity, such as the LGBTQIA2S+ community, attitudes tend to move away from medicalization and more towards social acceptance (5). To reduce the impact of stigma and the over-medicalization of intersex variations, we should move towards a more fluid model of sex and gender, reflective of the genetic and psychosocial reality, especially among medical professionals who care for intersex individuals (5,42). In so doing, we move toward embracing variety in the way sex and gender are expressed (22,42).

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None to declare

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