

‘You’re basically calling doctors torturers’: stakeholder framing issues around naming intersex rights claims as human rights abuses.

Abstract

In this article we address activist, patient advocate and medic perspectives on framing intersex, variations of sex characteristics (VSC) and Disorders/differences of Sex Development (DSD/dsd) medical treatment as human rights abuses. Problematic aspects of intersex medical treatment have increasingly been highlighted in national debates and international human rights bodies (IHRBs). Some intersex activists have framed aspects of intersex medical treatment as human rights abuses since the 1990s. Other stakeholders in shaping medical treatment, such as patient advocates and medical professionals, are not always content with human rights framing, or even the term intersex. In order to address the different perspectives in this arena we provide background on the primary rights claims that have arisen followed by key human rights framing of these claims. We provide a short discussion of activism styles, looking at pan-intersex social movements and variation specific patient associations as different styles of health social movements (HSMs). The analysis of stakeholder perspectives on the use of Human Rights strategy in health areas provides a useful case study for medical sociology and policy in general.

Keywords

Intersex; DSD/dsd; Human Rights; Health Social Movements; Evidence Based Activism

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Introduction

In this article we will be addressing European activist, patient advocate and medical practitioner (MP) perspectives on framing intersex¹ medical treatment as human rights abuses. Problematic aspects of intersex medical treatment have increasingly been highlighted in national debates and international human rights bodies (IHRBs) (Bauer et al. 2019; Ghattas 2019). While specific attention is focused on the surgical ‘normalization’ of infant genital form, critique is also directed at all forms of normalizing procedures that take place before the age of consent² (Chase 2013; Davis 2015; Carpenter 2016). Some intersex activists have framed aspects of intersex medical treatment as human rights abuses since the 1990s (Dreger and Herdon 2009; Bauer et al. 2019). Other stakeholders in shaping medical treatment, such as patient advocates and MPs, are not always content with human rights framing, or even the term intersex (see Cools et al 2006). Differences between activist and advocate mobilization strategies have been addressed in a US context (Preves 2005; Davis 2015), yet the EU offers different histories in this arena, which are strongly influenced by international collaboration.

In order to address the different perspectives in this arena we draw on interviews with 40 activists, advocates, MPs and policy makers (from the UK, Switzerland and Italy), the budding field of intersex social sciences, as well as academic discussions surrounding health social movements (HSMs) and embodied health movements (EHMs) (Brown et al 2004). We first provide background on the critique of childhood intersex medical practices, reassuming the primary rights claims that have been moved by intersex activists and patient advocates, followed

¹ We will be using the terms intersex, variations of sex characteristics (VSC), Disorders (or differences) of Sex Development (DSD for disorder and dsd for differences), or ‘syndrome’ specific terms as the different stakeholders use them in context. However, intersex or VSC are the terms most utilized by IHRBs.

² Including hormone treatments but also stigmatizing or lacking medical communication, invasive unnecessary exams and other aspects of treatment in medical settings.

by key human rights framing of these claims. We then provide background on HSMs and EHMs, followed by a short discussion of activism styles, looking at pan-intersex social movements and variation specific patient associations as different styles of HSMs.

Drawing on qualitative data in the form of interviews and participant observation with intersex activists, patient association advocates, policy representatives and medical professionals, as well as published material, our findings examine shared aims and areas of tension in naming aspects of intersex medical treatment human rights abuses. Our analysis indicates that tension does not rest as much on the rights claims in-of-themselves, but rather on the tactic of appealing to IHRBs and the strong emotional register of human rights terms such as ‘harmful practice’, ‘torture’, ‘inhuman or degrading treatment’ and ‘violence’.

We address a research gap regarding different styles of activism and advocacy used to address intersex, DSD, dsd and VSC, focusing on the various perspectives on naming aspects of this medical practice as human rights abuses. By analysing intersex activist, patient advocate and medical professional perspectives together we intend to highlight key similarities in aims that are obscured by differences in framing and strategy. To gain a deeper understanding of the positioning dynamics, and how they might be addressed, we utilized an adapted model of Benford and Snow’s (2000) framing of social movements. In this manner we hope to contribute to theoretical work on movements and biosocial activism, as well as the implementation quandaries expressed by some of the policy makers.

Background

Intersex is an umbrella term that can be defined as being born with bodily sex characteristics that do not conform to standard binary definitions of male or female, sometimes entailing

biological material from both ‘sexes’ (OHCHR Factsheet). Commonly used statistics indicate 0.3% and 2% of infants are born with intersex traits (Lee et al. 2006), yet many nations do not collect this data (or render it transparent)³. This number fluctuates greatly if hypospadias, Klinefelter’s Syndrome (KS), Turner’s Syndrome (TS), and Congenital Adrenal Hyperplasia (CAH) are considered within the intersex trait umbrella (see Griffiths 2018). Many health activists in this arena use variation specific medical terminology such as the abovementioned ‘syndromes’, as opposed to an umbrella term.

Medical fascination with the gendered body grew through the 1800s. While medical practitioners were in disagreement as to which biological trait firmly represented an individual’s sex, consensus grew regarding the need to establish all bodies as either male or female (Dreger 1998). In the 1950s the US John Hopkins medical center consolidated a medical approach that was rapidly adopted in that it filled a vacuum in treatment consensus (Karkazis 2008). Commonly known as the Optimal Gender of Rearing (OGR) model, the new protocol located genital form and parental consensus as primary drivers in consolidating gender identity. In practice this meant surgically transforming genital form and hormonally shifting gendered bodily markers in early childhood to conform to one (often stereotyped) gender style, in order to enforce parental confidence in their child’s assigned gender, which in turn would (in theory) enforce the child’s own gender identity. While the Hopkins team initially advocated informing parents, clinical practice soon developed which involved misleading parents and individuals about the nature of their treatment, yet again to consolidate the individual’s gender development.

MPs reversed their ethical position regarding disclosure to parents towards the 1990s, as laws surrounding informed consent developed. However, even today, there is a lack of clear protocol

³ Data collection and data validity is a recurrent theme in both national and international debates.

for informing individuals or involving minors in decision-making. Gardner and Sandberg (2018) discuss “two future possibilities” in elective body modifications for intersex minors: a moratorium on proxy decision making; or enhanced shared decision-making (SDM). However, SDM is generally intended as between MPs and parents (legal surrogates for the child), not between MPs and young patients (Timmermans et al 2018). While in other medical arenas guidelines indicate that children be involved in healthcare decisions that regard them, parents decide for elective procedures *and* disclosure in most DSD centres.

Many medical arenas continued to use the stigmatizing and inaccurate term pseudo-hermaphrodite well into the early 2000s, or focused on variation specific terminology. The medical term Disorders of Sex Development (DSD) was coined in 2006. Many national contexts jumped terms from pseudo-hermaphrodite to DSD without ever using ‘intersex’ in clinical settings. The term DSD is contested by many social activists as incorrectly applying the stigmatizing term ‘disorder’ to mere physical variation, but was rapidly adopted by most medical teams across the world as well as several patient advocacy associations (Feder and Karkazis 2008: 33-6). Some MPs and patient advocates use differences of sex development (dsd). Davis (2011) argues that the new term consolidated medical authority over VSC as something that needed fixing, an idea that had been threatened by intersex activism. Variations of sex characteristics (VSC) is also used in human rights work (as well as in some policy circles) with the aim of establishing ‘sex characteristics’ as a protected legal category that can only be modified by consent of the individual concerned, and not parents (see Carpenter 2018).

The rise of intersex activism after the 1990s led to numerous published testimonies on negative impact of the secrecy and shame resulting from intersex medical treatment, as well as harmful long-term physical and psychological outcomes (Chase 1998; Holmes 2000; Preves 2003; Davis and Feder 2015; Interface project; among many others). Private facing patient association

collaboration with medical allies has also led to scientific publications regarding the damage of secrecy (e.g. D'Alberon 2010). Medical protocol has shifted somewhat regarding diagnosis communication (at least for parents), but appears stagnant and undecided regarding the ethics of elective interventions in childhood that may cause harm in adulthood (Ernst et al 2018; Liao et al 2015; Liao et al 2019). Childhood interventions, which range from genital surgery to gonadectomies to hormonal treatments, can have long-term negative impacts on self-esteem, sexual sensation, sexual pleasure, reproductive capability, continence, and gender self-determination.

Many of the first intersex organisations were variation specific HSMs (Baratz et al 2014), including some that mainly represented parents. In particular, Androgen Insensitivity Syndrome (AIS) groups were quite critical regarding unnecessary non-consensual procedures, the lack of informed consent and stigmatizing invasive exam procedures (Dreger and Herndon 2009; Davis 2015). Italian patient associations began forming in the mid-2000s. The birth of the Intersex Society of North America (ISNA) in the 1990s inaugurated public facing tactics and initial human rights framing with the introduction of the term 'Intersex Genital Mutilation' (IGM). This new form of activism sought to end 'shame, secrecy and unwanted genital surgeries', making 'normalization' surgical procedures their first line of criticism.

The term IGM also refers to other unnecessary and harmful medical practices - which are also addressed by health advocates. These include, but are not limited to:

- all forms of normalizing procedures, including gonadectomy and hormonal therapy, without full and repeat informed consent
- stigmatizing, coercive, and/or deceptive medical communication (such as fictitious cancer risks)

- stigmatizing and traumatizing invasive medical exams and photography for the purpose of research instead of treatment.
- selective termination of intersex foetuses and/or infanticide
- damaging gender-normalising prenatal interventions
- the lack of medical research on overall and long-term health
- the lack of medical health services for adults
- the lack of psychological and peer support for parents and families

IHRMs' attention to intersex medical treatment is due to extensive lobbying by International networks of intersex activists. The above aspects of intersex medical treatment are increasingly being addressed as serious Human Rights abuses, with verdicts from numerous IHRBs (see Ghattas 2019). In 2015 the Malta Gender Identity, Gender Expression and Sex Characteristics Act, and in 2017 the Yogyakarta Principles plus 10 specifically included 'sex characteristics' as a protected category. The most significant Human Rights frameworks that have been applied to IGM, and intersex in general, by different IHRMs are:

1. Harmful practices
2. Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
3. Integrity of the person
4. Access to justice
5. Involuntary medical experimentation
6. Violence against children
7. Right to life
8. Coercive sterilization;
9. Right to health

10. Rights of the Child

11. Anti-discrimination laws that include sex characteristics

The request for protective legislation, a moratorium on surgery, and strong emotional register of human rights terms such as ‘harmful practices’, ‘torture’, ‘inhuman or degrading treatment’ and ‘violence against children’ is where we found the largest difference in perspectives.

Styles of activism. HSMs and EHMs.

The biomedical management of intersex variations increasingly faces numerous forms of political mobilization. The fact that patients are often new-borns or minors complicates the issue of informed consent, and data (Jones 2016; Jones 2018) shows that while medical interventions are often heralded as successful by MPs, the subjective experience of medicalization is negative. The evaluation of intersex treatment is misaligned between medical stakeholders, parents and patients.

Beyond this foundational misalignment, that results in competing interests of medical authorities and patients, activism and advocacy around intersex rights claims have taken different forms, from public facing actions such as protests and awareness campaigns, to closed groups that offer peer-support and negotiate the role of the ‘patient expert’ while demanding better health care. While there might be overlapping membership and strategies, there continues to be differences in approach between patient advocates, who push for better medical care founded on long-term medical data and collective subjective experience, and intersex activists who no longer believe in medical self-reform and therefore push for criminalization of non-consensual, unnecessary

practices. In addition, there can be significant differences in perspectives between patient associations led by individuals, and those led by parents (proxy agents).

Intersex, DSD/dsd and VSC health social movements (HSMs) are not unique in having multiple styles of action. Every HSMs has a ‘style of militancy’, which is characterized by the mobilization of complex social practices: the emotional content; the composition of the group; relationships with allies; conflicts regarding protest goals; and so forth. In this arena differences are also found not only in naming the umbrella category (intersex, dsd, VSC) but also in identifying groups as activists or advocates (particularly in the English language context of the UK).

Davis addresses a shift in US intersex advocacy from ‘confrontational mobilization strategies’ towards ‘unobtrusive mobilization strategies’ such as “discursive politics” and “occupy and indoctrinate tactics” (Davis 2015, 49)⁴. Instead, international human rights lobbying has grown as a strategy for European intersex activists since 2008 (Bauer et al. 2019), refocusing tactics on legal objectives, which include prohibition and/or criminalization. Tension around this strategy rise to the surface as IHRM proclamations increase in number and critique.

Most national legal frameworks, with the exception of Malta⁵, allow parents to choose unnecessary ‘normalizing’ cosmetic interventions for their children with VSC. National policies and IHRMs proclamations on patients’ rights, children’s rights and disability rights increasingly mandate involving the child in healthcare decisions that concern them, as well as the need to uphold respect for bodily integrity (Bauer et al. 2019; Ghattas 2019). Davis and Murphy address the lack of the application of pre-existing protections to intersex infant bodies as a ‘state of exception’ justified by the presence of bodily difference itself (Davis and Murphy 2013). Intersex

⁴ The shift addressed by Davis reflects the dominant players in the US.

⁵ Gender Identity, Gender Expression And Sex Characteristics Act; However, with the absence of criminalization within the new law, parents may still take their children to the UK for ‘normalizing’ cosmetic surgeries.

activists cite the lack of change in medical practice as the precise rationale behind their appeal to supranational structures such as IHRBs, while patient associations and medical professionals appear divided as to the value of such an appeal (Bauer et al. 2019; Lundberg et. al. 2019: 371). Some patient group representatives and medics have claimed that IHRBs who have addressed intersex rights claims have not listened to patient associations, and are misinformed by LGBT organizations (Cools et al. 2016). National policy makers seem unclear how to create regulation guided by IHRBs due to these unresolved tensions.

In framing the experience of health and wellbeing as a matter of moral individual responsibility, the biomedicalization of (western) society (Clarke et al. 2003) has also expanded the opportunities for lay actors (individual and collective) to interact with the medical field. The study of HSMs beyond individual case studies, is a well-established tradition in medical sociology and proves the significant impact of HSMs on larger dynamics in health policy, care provision and scientific medical research (Brown & Zavestoski 2004). HSMs are fairly recent invention of collective actors, the American Cancer Society, founded in 1913, is one of the oldest groups, yet it is argued that HSMs currently comprise significant engines of change in bio-medicine (Conrad 2005). Brown et al. (2004) suggest a typology of HSMs based on modes of action organized around: access to health care (in general), *health access movements*; social stratification (i.e. gender, race, sexuality) of access to health services, *constituency-based health movements*; or a disease/illness experience (specific to a medical category), including disability or contested illnesses, *embodied health movements* (EHMs). In this framing, intersex, VSC and dsd movements are all *embodied health movements* in that they

“introduce the biological body to social movements in central ways... typically include challenges to existing medical/scientific knowledge and practice...[and] often involve

activists collaborating with scientists and health professionals in pursuing treatment, prevention, research and expanded funding” (Brown et al. 2004: 54-55).

Callon and Rabeharisoa (2008) propose a typology that instead reflects relationships with establishments: auxiliary associations; partner associations; or opposing associations. This is useful for addressing an initial aspect of difference between activist styles in this arena. Patient associations can be either auxiliary or partner associations, whereas pan-intersex social activists are generally seen as opposing associations.

Both public facing activist groups and private facing patient advocacy groups enact forms of evidence based activism in that they mobilize ‘patients’ experience as a legitimate body of ‘experiential knowledge’ (Arskey 1994; Borkman 1976) on their conditions, and became what Epstein refers to as ‘lay experts’ (1995), or as Rabeharisoa and Callon highlight, ‘experts in experience’ (2002: 62). While activists have a stronger de-medicalization framework, both of these stakeholder categories acknowledge, and address in different manners, a problematic overlap of physiological and social issues in medical treatment. However, VSC patient groups rarely *publicly* critique biomedicalization. As found in Lindee’s (2005) study of patient associations, many groups in this field may welcome new genetic research. Intersex activists instead contest that the continued focus on diagnosis only enhances the medicalization of intersex variations at the cost of real health concerns.

In order to address perspectives on human rights framing of rights claims, we also took into consideration Benford and Snow’s methodology (2000) for analyzing social movements, simplifying it to look at rights claims and tactics. Benford and Snow’s methodology is designed to unpack the “shared understanding of some problematic condition or situation they [SMO] define as in need of change, make attributions regarding who or what is to blame, articulate an alternative

set of arrangements, and urge others to act in concert to affect change” (Bedford and Snow 2000: 615).

The collective action is divided into four framework categories, which, curiously, are given more typically medical terminology (the *diagnostic framing*; the *prognostic framing*; the *frame resonance*; and the *motivational framing*). Initially, applying Bedford and Snow’s frame analysis, by forcing simplifications, helped highlight the similarities between groups. For instance, in the *diagnostic frame*, most activist and advocate groups identify a mix of social prejudice and medical practice as the root problem to be addressed. However, where intersex activists first address the normative parts of intersex medical treatment, patient associations first address health care specifics. Along with this subtle difference in the *diagnostic framing*, there were significant differences in the *prognostic framing*, or rather in the tactics and strategies groups used to address the issues they identified as most pressing. In the following we will primarily address the simplified adaption that focuses on rights claims (diagnostic frame) and tactics (prognostic frame).

Methods

This article is informed by an analysis of published position statements and interviews with intersex activists, patient advocates, MPs and policy figures in the UK, Switzerland and Italy. The qualitative material was collected as part of an EU funded research project on Intersex, Citizenship and Human Rights (EUICIT)⁶.

⁶ EU Marie Skłodowska-Curie grant agreement number 703352.

Empirical material was collected between February and December 2017 in the UK, Switzerland and Italy. Nineteen qualitative interviews were conducted in the UK, six in Switzerland and fifteen in Italy, for a total of 40 interviews.

	UK	SW	IT	Total
DSD team medic	1	4 (2 also policy)	5	10
Intersex activist	7	2	4 (2 also patient ad.)	13
Patient group advocate	4	1	3	8 (10)
Intersex allied activist	1	0	2	3
Policy representatives	6	See above	1	7 (9)
Total	19	6	15	40

The qualitative research period also included 3 months of participant action research (Reason and Bradbury 2001) with the international intersex activists *Zwischengeschlecht/StopIGM*. Several DSD-team MPs declined to participate in the qualitative study, yet referred the researchers to published material in which their views on the subject were expressed. The statement papers and published material we reference is by no means exhaustive, but yet are fairly representative of the significant issues posed in the empirical data.

All of the participants were informed of the aims of the research project, given different options regarding anonymity and participating in an open data pilot program, signed informed consent forms, and were given the option to withdraw and review the interview transcripts for three months after the date of the interview. The qualitative data was analysed using NVIVO and adopting a

thematic analysis approach (Braun et al., 2014) informed by research on social studies of medicine and science, social health movements, political science, gender and sexuality, citizenship and human rights. The project received ethics approval from the EU funding body, the University of Huddersfield and the UK HRA (Health Research Agency).

Pushing for human rights framing

Intersex activists' mistrust of medical self-reform, and critique of the medicalization of VSC, has led the drive towards human rights framing and tactics. Intersex activists are generally in support of HR framing of intersex rights claims, as well as the pursuit of punitive national legislation and a moratorium on childhood intersex surgeries. In this section we examine the relevance that is given to IHRB framing by intersex activists.

While changes can be seen in certain arenas of intersex medical treatment (primarily regarding communication), key rights concerns such as unnecessary childhood medical procedures undoubtedly continued to be practiced across most of the globe (see Monro et al. 2017; Carpenter 2018). Precisely this continued practice has led intersex activists to appeal directly to IHRMs to denounce Intersex Genital Mutilation (IGM) as a serious violation of non-derogable human rights. The appeal to IHRMs has the intention of raising public awareness about intersex rights claims and creating grounds for national legislative protections. An international, collaborative and strategic approach has enabled the intersex movement to obtain numerous recommendations from IHRBs in less than two decades⁷. In turn, most intersex activists increasingly utilize HR framing, or have participated in NGO reports to IHRBs themselves. Some intersex activist groups such as

⁷ For more detail see <http://intersex.shadowreport.org/>

Zwischengeshlecht/StopIGM have turned the majority of their energy to human rights lobbying, utilizing strategic analysis of human rights conventions and articles, such as ‘harmful (cultural) practices (Bauer et al 2019) and ‘torture’ to address intersex rights claims, indicating they “found all the requirements”.

By strategically studying existing human rights protections incorporated in international human rights conventions, activists hope to break what Davis and Murphy refer to as ‘states of exception’ (Davis and Murphy 2013) in children’s rights within VSC medical treatment. Our interview data shows HR framings such as ‘torture’ and ‘harmful treatment’ are increasingly replicated by intersex activists. As one participant stated “it does amount to abuse and in some instances, *torture*” (Dr Jay Hayes-Light; UK Intersex Association - UKIA).

In 2015 the CRC (Convention on the Rights of the Child) recognized IGM as constituting a harmful practice like FGM for the first time⁸, referring to the CRC-CEDAW Joint General Comment 18/31 “on harmful practices”. Building on this CRC verdict, in 2015, CAT recognized IGM as constituting ‘Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment’, and recommended that Switzerland take legislative measures⁹. Intersex activists draw on these verdicts in framing future activism strategies.

Human rights framings that have softer emotional registers than ‘torture’, such as ‘bodily autonomy’ are also used strategically, occasionally linking intersex to better known human rights issues such as FGM. As Dawn Vago of IntersexUK states “The most pressing Human Rights, it would be the bodily autonomy, it would be not being operated on unless it was medically necessary”, indicating that IGM is similar to FGM.

⁸ CRC/C/CHE/CO/2-4. 2015: paras 42-43.

⁹ CAT/C/CHE/CO/7. 2015: para 20.

However, even activists who have contributed to NGO reports to IHRBs are unsure the impact these declarations will have at a national level. Holly from IntersexUK indicates that:

“its very difficult for a government to acknowledge that its healthcare service abuses people and commits...crime... actually the UK were found to be in breach of International Human Rights Law and the NHS in all UK countries was the NHS bodies within all UK countries were condemned for crimes against the child (CRC 2016 review of the UK)”

As another activist cautions: “I believe that they [IHRB proclamations] are fundamental but not sufficient in and of themselves.” (Alessandro Comeni; OII-IT, OII-EU)

A legal ally emphasized that legal reform seems to be “one of the big drivers” in European intersex activism, as opposed to the Chilean reform model which was in collaboration with the Chilean NHS. In explanation he stated: “I think there’s so much distrust within the community [...] of the medical profession, they don’t trust the medical community to deliver that, even if they paid lip service to the idea, which they haven’t, they still don’t believe it.” (Micheal; Genital Autonomy)

Some intersex activists in fact expressed frustration that the 2006 and 2016 guidelines did not appear to have much impact on key rights aspects of medical practice such as childhood surgery rates (see Monro et al 2017). The request for legislation also reflects a fear of appropriation (as discussed regarding mental health activism; see Penney and Prescott 2016) of the positive rhetoric promoted by patient associations into guidelines that do not concretely deliver on patient autonomy.

IHRBs are increasingly seconding the call for a moratorium on surgery. In 2016 the UN, the Council of Europe (COE), the African Charter on Human and Peoples' Rights (ACHPR), and the Inter-American Commission on Human Rights (IACHR) issued a Joint Statement for Intersex Awareness Day indicating that:

“States must, as a matter of urgency, prohibit medically unnecessary surgery and procedures on intersex children. They must uphold the autonomy of intersex adults and children and their rights to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment. Intersex children and their parents should be provided with support and counselling, including from peers. [...]”.

In the beginning of 2019, the European Parliament adopted a resolution on the rights of intersex people¹⁰ which refers to the numerous conventions that have been used to address violations of intersex human rights, and specifically “Strongly condemns sex-normalising treatments and surgery; welcomes laws that prohibit such surgery”. While intersex activists argue that these decrees should be binding for states that have ratified the conventions, few states are actually moving to create legislation.

As indicated earlier, the strong emotional register of ‘torture’ claims, and the call for legislation is not a tactic shared by all invested subjects. In the following section we address the diverse perspectives of patient associations within their generally private facing tactics.

‘It’s not our focus’. Variation specific patient group perspectives.

While variation specific groups support the rights claims evoked by IHRBs proclamations, our participants were from un-engaged with HR framings, to critical of the tactic itself. In the following we unpack the primary issues (not in remit; fear of confusion with LGBT+; strong emotional register) that patient group members indicated lead them away from directly engaging with HR framings.

¹⁰ B8-0101/2019

Most variation specific patient groups focus their energies on peer-support (see also Baratz et al 2014), cultivating medical allies and the specific issues related to their situation (for example: high termination rates for Klinefelter's syndrome; unnecessary early gonadectomies for Androgen Insensitivity Syndrome). Patient group members were interviewed regarding the membership of the group, primary activities, and primary rights claims in collaboration with available published material. Participants were also asked their opinions on the rights claims elaborated earlier in the article, as well as human rights proclamations. It is important to note that in this arena patient groups may be organized by individuals with VSCs, parents, or a combination of the two. In order to highlight the divergence of opinions on human rights proclamations and strategies we also include a brief discussion of published responses to the US Human Rights Watch report 'As nature made me' which emphasize the positions we found in Europe.

In the UK, Switzerland and Italy we found that adult run patient groups address human rights strategy as outside of their remit, while they might support the rights claims embedded in the tactic. Specific issues arose regarding statements that added intersex to the 'LGBTIQ+' acronym, making intersex appear as an identity as opposed to a physical variance. Some group members were also wary of strong language that would alienate medical allies and institutions. Several patient groups had members who also participated in intersex activist groups, and therefore endorsed HR tactics in a separate setting. Parent run groups instead ranged from very critical to surprised about HR tactics and framings.

Even if interpretations of the intersex experience have been foundational to the field of LGBT studies and queer theory (e.g. Butler 2004), in the political arena, framing intersex rights within the LGBT rights struggle umbrella can create tension and confusion for intersex activists, patient advocates, MPs and policy makers alike (see Carpenter 2018; Bauer et al 2019; Cools et al 2016). At the same time, LGBT+ movements are among the strongest supporters and funders of intersex

rights and activism. HR declarations such as the Yogyakarta Principles plus 10 use the specific terminology of ‘sex characteristics’. Yet addressing these rights claims within the context of gender identity and sexual orientation rights claims can divert intersex rights discussions surrounding bodily autonomy to the historic medical obsession with gender assignment, or an overlapping of gender, sexuality and the body (which form part of the historic justifications of intersex cosmetic medicalization).

In fact, some medics focused their discussion of intersex human rights framing on third gender requests even when questioned specifically about ‘bodily integrity’ or ‘harmful practices’. Others reiterated parent’s fears that children with VSC were more at risk of becoming gay or trans. Members of an Italian CAH parent association also drew the conversation around to third gender markers when addressing IHRB statements, stating, “our girls are normal”; while ignoring ‘bodily autonomy’, ‘harmful practices’ or ‘torture’ claims.

VSC run patient groups were sceptical about framing intersex as an identity, yet wanted to support members who might be also LGB or T. An Associazione Italiana Sindrome Insensibilità agli Androgeni (AISIA) member indicated, “the majority of AISIA’s people don’t identify with an intersex condition”, yet went on to clarify: “[AISIA] supports them in this sense... it’s not against the fact that the ‘I’ would be included together with LGBT, however, it [AISIA] doesn’t entirely identify with this type of area” (Alice; AISIA).

In a similar manner Klinefelter Syndrome Association UK (KSA) member indicated they would like to support members with gender variation, while it is not their primary focus, “I think over the time, we’ve come to realise that not all XXY people are male and that we need to adapt our policies to be able to assist everyone not just males.” (Paul; KSA).

Patient groups were primarily focused on peer support activities and cultivating medical allies who will not only listen to their evidence (ie EBA), but use it to re-frame scientific research

questions and represent patient experiences as valid scientific evidence¹¹. This situates patient advocates as ‘change agents’ and/or ‘reformers’ in Moyer et al’s (2001) analysis of social activism roles. All groups were involved in specific collaborative projects which involved donating either their time or biological material (i.e. genetic databases; hormonal research). Therefore, their tactical focus is not on human rights claims, while they were supportive of the rights claims themselves. A representative of Androgen Insensitivity Syndrome Support Group UK wrote that they supported HR claims such as bodily autonomy (and were opposed to unnecessary surgeries), but that they did not develop HR framings because there was a lack of interest from the member base. Individuals in chronic care for co-morbidity (i.e. salt-wasting CAH), instead, indicated that not all feel comfortable with direct criticism of MPs¹². As one intersex activist (who had also founded self-help groups) indicates:

“the other thing is, self-help groups and particularly parents, they are dependent on the doctors. When you have your gonads taken out, you need a prescription for the rest of your life. You don’t want to upset your doctor, who you are dependent on, for giving you the prescription. The parents with small children, maybe the children will need medical health, so they don’t want to upset the doctors. But if you only talk nice with the doctors, they don’t listen to you.” (Daniela Truffer; Zwischengeschlecht/StopIGM)

As stated earlier, the groups that most oppose HR framing (in particular claims of torture, CIDT and harmful practices) and/or a ban of unnecessary genital surgery, generally are led by, or are strongly focused on parents. Highlighting the difficulty in this area, a member of a parent oriented support group that is otherwise opposed to ‘normalizing’ interventions indicated that their group

¹¹ For example see D’Albertyon 2010.

¹² See discussion in Davis (2015; pp. 87-115) on claiming DSD and a medicalized identity as opposed to intersex ‘radical’ identity.

didn't feel that it could afford to only 'preach to the converted' when giving support to parents who might come from very socially normative positions. Framing parents who had already had surgery performed on their child as 'torturers' would preclude any other support they might be able to give the parent and their child.

Some other parent-oriented groups actively defend their right to choose for childhood surgeries. In 2016 the US organization Human Rights Watch (HRW) began research for a campaign promoting intersex rights. As indicated in the HRW report¹³, in February 2017 the patient association CARES Foundation launched a call to action¹⁴ in defence of parental rights to choose early childhood genital surgery. The call to action cited the National Geographic program, "Gender Revolution" by Katie Couric as "inaccurately and misleadingly characterized CAH, describing girls born with CAH "not clearly male or female" and criticizing the parental decision for early surgical intervention". They question the American Medical Association proposal "to end parents' rights to make a decision regarding surgery on their child and require a child's consent prior to such surgery". In addition, they criticize the Human Rights Watch campaign stating it "is actively fighting parents' rights to make decisions regarding early surgical intervention comparing it to female genital mutilation". Similar to the COE response paper, this parent-led patient association states: "These entities have not asked how CAH patients and their families feel about these issues and they need to hear from you.", without however address the human rights claims made by those who oppose early childhood elective genital surgery.

Many Congenital Adrenal Hyperplasia (CAH) associations worldwide do not consider CAH intersex (while several intersex activists have had this diagnosis experience), or even part of the

¹³ <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us>

¹⁴ <http://www.caresfoundation.org/wp-content/uploads/2017/02/1CALL-TO-ACTION-Nat-Geo.pdf>

dsd umbrella¹⁵. However, CAH girls are one of the largest groups in the umbrella category to be subject to either clitorectomies or clitoral reductions, as well as decades of psychological research that confused gender stereotyped behaviour (primarily toy object choice and physical activity levels) with gender identity and sexual orientation (Fausto-Sterling 2000). CARES message is specifically pro-parental choice in a manner that leans towards condoning surgery in a way that instead a parent-led group such as dsdfamilies does not¹⁶. Representatives from an Italian parent-focused CAH group told of their surprise when they learned that childhood genital surgery was a contested issue¹⁷.

On the other end of the spectrum, the US *AIS-DSD* association released a joint statement with *InterACT: Advocates for Intersex Youth* in full support of Human Rights Watch's analysis and condemnation of medical unnecessary surgeries. AIS-DSD, like AISIA, is a mixed adult and families group, with strong adult leadership.

In our study, variation specific patient associations were in favour of the rights claims embodied in IHRB declarations, unless the groups were parent focused. Yet they did not embrace this strategy as a primary focus, occasionally reflecting what Davis (2015) refers to as 'unobtrusive mobilization strategies' that operate behind closed doors. In the next section we look at the perspective of MPs on human rights framing, including being referred to as 'torturers'.

Torture: Medical perspectives

¹⁵ As is the case for the Italian groups.

¹⁶ see for example <https://www.dsdfamilies.org/parents/raising-child-surgery>

¹⁷ The active erasure of criticisms of genital surgery from CAH adults on a Italian CAH internet forum has been noted in the past (Crocetti 2011).

Medical practitioners obviously have specific concerns regarding naming current practice as human rights abuses. In the following we examine statements on IHRB framing of intersex from MPs, many of whom also claim to otherwise support the rights claims they represent. Many MPs feel uncomfortable at being called torturers by IHRM language, while they are essentially following international medical protocol. As the UK healthcare practitioner stated: “Whereas I think the IGM kind of claim, they just go ‘not a chance’ [...] If IGM is abuse and torture and mutilation and the medics absolutely do not see it as that, that where the hell do you go?”.

The 2016 updated DSD best practice statement (Lee et al. 2016) that serves as international protocol now references IHRB statements and the controversial nature of early cosmetic procedures, indicating:

“Although parents are responsible for consenting to interventions believed on the basis of available evidence to be in the best interests of their child, their right to consent to non-medically necessary irreversible procedures that may adversely affect the child's future sexual function and/or reproductive capacity has been questioned, particularly when such parental decisions preclude the child's ability to be involved in decision making.” (Lee et al 2016: 176)

However, the guidelines remain non-directive, merely stating: “Physicians working with these families should be aware that the trend in recent years has been for legal and human rights bodies to increasingly emphasize preserving patient autonomy.” (Lee et al 2016: 177). There is, however, a growing body of statements from MPs, professional associations and even former US Surgeon Generals condemning the practice of medically unnecessary childhood cosmetic procedures¹⁸. Yet,

¹⁸ EG NASPAG Position Statement on Surgical Management of DSD https://c.ymcdn.com/sites/www.naspag.org/resource/resmgr/pdf/s/NASPAG_Statement_on_DSD_PES_.pdf; Palm center report authored by three ex US Surgeon Generals <https://www.palmcenter.org/publication/re-thinking-genital-surgeries-intersex-infants/>

in our study, even MPs that support the rights claims embodied in Human Rights statements are often reluctant to endorse appealing to Human Rights Bodies *as a tactic*.

An Italian practitioner, who indicated that in their perspective most medical procedures could be postponed until the age of consent, voiced concern that legislation would translate into no care at all, stating: “When I hear the word “genital mutilation”, I’m a bit puzzled to tell you the truth, because it seems to me like labelling a whole movement [...]. My fear is that it might go too far [...] who will support these people?” (IT Psychologist centre 2).

Another Italian practitioner instead questioned both a moratorium on surgery “I mean, why can’t the genitals be operated on?” (IT Urologist centre 1), and childhood bodily autonomy, “honestly, in Italy a 14 year old kid is not ready to make such a decision...if we are raising the issue of people not being able to go home alone in middle school, how do you think they can make decisions about surgery?” (IT Urologist centre 1).

Some practitioners were also concerned about ‘gender’ issues in IHRB statements. Requests to postpone genital surgery and other ‘normalizing’ interventions were seen by some medics as merely relevant to gender assignment, responding: “Germany’s third sex strategy, the society here is not ready for that...putting disorders of sexual differentiation on the same level as transgender people is completely incorrect” (IT Endocrinologist centre 3). In this manner, some medics appear to assume that the request for bodily integrity and autonomy is *only* related to ‘incorrect’ gender assignment, thereby confusing non-surgical pathways with social requests for third-sex markers or transgender issues. Most activists clarify that autonomy regarding genital form is a distinct issue from gender identity and gender assignment. Other MP comments added the critique that IHRBs proclamations are ‘lumping everything together’ or ‘confusing issues’. And yet, some also felt that

the appeal to legislation might actually be welcomed by some practitioners: “I think one of the surgeons has said to me this needs to be a law, if someone tells me not to do it, I can’t do it, I won’t do it.... I went so you just don’t want to have to make the decision, you just want like, you want someone else to say no” (UK DSD team)

The medics who participated in our study mirrored the cautious awareness of IHRB proclamations found in the 2016 guidelines, the surprise at being called torturers found in the Society of Paediatric Urologist’s (ESPU/SPU) standpoint on surgical management of DSD (Mouriquand et al. 2014: 8), as well as the fear of intersex being confused with LGBT issues found in the medic and patient association co-authored *Response to the council of Europe human rights commissioner's issue paper on human rights and intersex people*.

Similar to patient associations, MPs also shared many of the rights concerns embodied in the IHRB statements. While cautious regarding a moratorium on surgery and important issues such as bodily integrity, all MPs were keen for a national review of practice, the establishment of national protocol, and better data collection. While we find it important to also address MP stakeholder perspectives on human rights framing, the unequal hierarchical relationship in knowledge authority between MPs and SHMs does need to be acknowledged, and individuals and families may only be exposed to a biomedical pathological framework.

Conclusions

Appeals to IHRB are a relatively new strategy in intersex activism, which have rapidly gained traction, while providing ambiguous concrete results. The diverse opinions portrayed regarding this strategy can mask (e.g. in policy discussions) an underlining agreement regarding the need to align medical practice with ongoing rights claims. The analysis of stakeholder perspectives on this

strategy provides a useful case study for medical sociology and policy in general. On a broader theoretical level, this study suggests that sociological research on HSMs and EHMs must be sensitive to dynamics within the emergence of novel activism styles more common in other arenas (such as human rights activism), such as how subtleties of disagreements over strategy can mask agreement surrounding the rights claims themselves.

Attention must be paid to positioning within HSMs, addressing whether members are directly implicated or proxy (parents) stakeholders. In addition, as HSMs increasingly gain authority in the institutional playing field, medical sociology will increasingly need to unpack the emergence of appropriated activist/advocate policy rhetoric versus actual clinical change. Further research beyond the scope of this article may also draw out how broad mobilization frames based on strong emotional registers, such as ‘torture’ claims, possess the ability to travel, resonate, be adapted and translated across diverse HSMs.

Articles such as the *Response to the council of Europe human rights commissioner's issue paper on human rights and intersex people* highlight stakeholder tension regarding human rights strategy. Yet our data indicates that the tension largely resonates around the appeal to IHRB as a strategy in itself (including the use of LGBT+ framings) and the high emotional register of ‘torture’ and harmful practices’ framings. VSC led patient groups primarily indicated that they felt human rights strategy to be outside of their remit, while they supported the rights claims they represented. Parent led patient groups had more criticism or caution around human rights framing, particularly in the case where members might have chosen ‘normalizing’ surgery for their own children.

There is little consensus among MPs and medical associations regarding intersex rights claims. In fact, the global best practice statement (Lee et al 2016) mentions IHRB proclamations, while maintaining a certain distance from any prescriptive position, particularly regarding parental choice for surgery. Other individual medics and medical associations have clearly come out on the

side of human rights framings such as bodily integrity. Our participants in particular were sceptical about the utility of legislation and high emotional register terms such as ‘torture’, advocating for internal medical self-reform. However, international intersex human rights strategy arose in response to delusion with medical self-reform tactics, and therefore very specifically seeks to force international and national bodies to examine why certain VSC medical practices seem to elude otherwise consolidated human rights standards in medical care. In this direction, IHRB requests for better data collection and nation reviews of practice appear to be welcomed by most medics.

As argued elsewhere (Bauer et al 2019), IHRB merely provide softlaw that individual nations may or may not choose to legislate on. However, the numerous IHRB proclamations have certainly brought intersex rights claims to international attention. These proclamations, however, are most welcomed by those who also primarily use the term ‘intersex’ and seek prohibitive legislation as part of their aims.

We argue that while stakeholders seem divided regarding IHRB proclamations, there is underlying agreement regarding rights claims. The lack of consensus among MPs regarding childhood ‘normalizing’ treatments, as well as international guidelines that differ to national laws on parent rights, are clear signs that medical self-reform do not have the key to resolving the issues raised by both intersex activist and variation specific patient associations. Clear national policies that address gaps in human rights protections can move forward by addressing the rights claims themselves, dismantling the existing ‘states of exception’ (Davis and Murphy 2013).

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