

Editorial

Intersex embodiment: when health care means maintaining binary sexes

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ABSTRACT. The treatments carried out with intersex children for the purpose of helping them live in a normatively gendered world have raised increasing levels of controversy in the past decade. This paper outlines key debates that are taking place highlighting the relevance of critical approaches to evidence. It points to the value of working across disciplines and epistemological frameworks in order to fundamentally re-think existing clinical practice in terms of ethical concerns and in terms of the reported experiences of intersex people.

Additional keywords: treatment, gender, ethics, evidence, queer, interdisciplinary.

Introduction

One of the more controversial and challenging ways in which issues of sex enter into the health arena concerns the care of intersex people. ‘Intersex’ has come to refer to people who, due to chromosomal, hormonal and anatomical anomalies, have sexual features that do not conform to ‘male’ or ‘female’ norms. Dilemmas that this raises for intersex people themselves are how to: (i) live as gendered beings in a world that frequently expects that we all fit within a binary gender system, and (ii) access optimal health care.

A raft of texts has emerged discussing intersexuality in terms of incidence,^{1–3} aetiology and diagnosis,^{4,5} treatment practices and outcomes,^{6–11} historical understandings,¹² social psychological critiques,^{13–17} and ethics.^{18–21} A clear debate has been established among intersex people, clinicians who work with intersex people, and social scientists. The debate centrally concerns the reliance upon Money’s 1950s theorising as the basis for current treatment practices.

Money and colleagues proposed that the sexual reassignment of atypically sexed children would be possible if carried out before a critical age, and if the child was raised unambiguously within the gender role consistent with their new sex.²² While Money’s ideas about this are still being asserted,²³ there is a growing understanding that the way intersex infants and children are treated medically needs to be addressed.

The focus of concern is not on medically necessary treatment but on treatments carried out for cosmetic effect — hormonal and surgical treatments that often take place when the person concerned is too young to give consent, that seek

to normalise the sexed appearance of the intersex body to make it look more ‘male’ or ‘female’.

Dilemmas and debates

A key dilemma concerns the possibility that the treatment offered may not only be inadequate but may cause harm. Some research suggests that the process of going through repeated treatment procedures leaves some intersex people fearful and untrusting of health care professionals.^{21,24,25} There is also concern that ‘normalising’ treatment renders intersexuality invisible and maintains it as shameful: something that needs to be hidden or erased. This is counterproductive from the points of view of those seeking to build positive identities and communities around notions of sexual diversity.

Connected with this concern is the debate about whether it is ethical to carry out ‘normalising’ treatments or, conversely, whether inaction (not offering such treatment) is ethically sound. Treatment is supported by the proposition that genitalia that look unambiguous are necessary for the development of a healthy, integrated gender identity and by the concern that children whose sexual features are visibly different will face extreme harassment and humiliation among their peers.

These concerns connect closely with the various roles and motivations of clinicians and of parents involved in making treatment decisions on behalf of intersex children. Parents’ role in the decision-making hinges partly on their understanding of what the treatment may entail in the long term. When parents consent to normalising treatment, to

what extent are they aware that (1) their child's body may still have a substantially atypical appearance after treatment and (2) treatment may lead to complications whose impact continues for many years? Parents (and clinicians) may also be making decisions in the context of homophobic fears and sex-normative attitudes. In the case where parents find it intolerable to raise an atypically sexed child, is it ethical practice for clinicians to cosmetically alter that child's genitalia in order to facilitate the parent-child relationship? To what extent is it the role of a clinician to challenge a decision that is based on homophobic/queerphobic or sex-negative prejudices?

These questions only make sense within the current socio-political context where there is an acknowledgement of the diverse range of 'queer' expressions of identity and embodiment emerging through literature by and for intersex, transgender, bisexual, lesbian, and gay people, among others. This wider context has seen increased challenges to normative assumptions about gendered expression and sexed embodiment. The changing socio-political context also concerns the recognition of patients' perspectives and rights.

Another aspect of the political context of these debates concerns the rise of evidence-based medicine, which brings with it increasing demands upon clinicians to ground clinical practice in a specific kind of epistemological frame. There have been repeated calls for more evidence that the current practice does (or does not) work well enough to justify its continuation but the validity of any given piece of evidence is hotly contested.²⁶ The way the debate is framed is affected by the relative status of different kinds of 'evidence': scientifically validated 'evidence' about which surgical techniques work from a clinical perspective; qualitative research 'evidence' drawing from the experiences of those living with surgically altered bodies; and the 'evidence' offered by intersex people who choose to speak out publicly about their concerns.

In weighing up the debates, motivations, and concerns indicated here, questions that emerge include: Are the teasing that may be faced by an intersex child at school, and parenting challenges involved in raising an atypically sexed child, necessarily worse than the physical and psychological pain that may result from repeated medical procedures? How might the various concerns about, and critiques of, current practice be synthesised and a way forwards be formulated? To what extent will new practices reflect a substantial philosophical and epistemological shift (rather than just improved clinical techniques)?

Various changes in understanding and practice are already underway. In some contexts, there is now a clear understanding that maintaining secrecy (not telling intersex children about their condition) is not a useful practice.²⁷ Among some clinicians, there is an understanding that intersex adults do have something useful to say in this debate.

One of the dilemmas faced as these complex debates are being articulated is that there is too little genuine cross-pollination of ideas across the disciplinary and professional lines. Thus, despite more than a decade of highly articulate social science and activist intersex literature being available, a recent review of work in this field²³ still reviews surgical approaches with only minimal acknowledgement of concerns about those approaches. My grouping of 'social scientists' and 'intersex authors/activists' in these paragraphs is intended to reflect the fact that some of the highly articulate voices coming from the social sciences on this topic are, indeed, the voices of intersex people themselves, for example^{19,28–34}. Typically, when clinical texts do draw on social scientists' and intersex authors' texts, they tend to refer briefly to the concerns being raised but rarely engage in more depth with the complexities and wide-ranging implications.^{7,35} This concern is raised in more detail by Myra Hird.¹⁶ Similarly, while social science texts on intersex may have an interest in psychological well-being and in surgical outcomes, they are not working with these ideas from clinical points of view and therefore typically engage with clinical literature in fairly limited ways. Each party is writing for a different audience and from a different epistemological base, and there is much talking past one another. Despite the existence of the impasse I am suggesting here, there are outstanding exceptions where researchers working within clinical disciplines take up social scientists' arguments and intersex activists' concerns in detail.^{18,21,25,36}

Some (perhaps many) clinicians are understandably wary of any implication that they should become political activists — using their professional positions to attempt consciousness-raising exercises with parents who may be terrified or horrified by having an atypically sexed child. It may seem more appropriate to surgically alter the child's body than to work with the parents' attitudes towards sexual diversity. What gets overlooked is the fact that the treatments associated with gender assignment are themselves 'political.' They are political in the sense that they are imbricated in the societal power relations through which our understandings of sex and gender are constructed. Clinical processes and clinicians themselves are, like everyone else, implicated in the greater 'political' process of making 'gender' work as it does in our society. The decision to try and forge bodies and identities within heteronormative and gender normative parameters is not apolitical nor is its success clearly indicated by research evidence.

What kind of dialogue can clinicians, social scientists, and intersex activists optimally have? While the literature on this topic suggests an impasse (and a lack of engagement across disciplinary and professional lines) innovative work is underway to promote dialogue among key parties. An example of this is the work of Liao, Creighton and colleagues through University College London Hospitals.

Future directions

While some commentators argue for withholding cosmetic surgery until the child is old enough to give consent, I suggest that this kind of change is not at the heart of what is needed. Another way of considering future directions for this debate and this area of clinical practice is by focusing on the more subtle, complex, and dynamic aspects rather than by proposing a fixed, rigid stance. I am proposing: more attention to dialogue and to the process of changing understandings and practices. Attention to the idea that any clinical practice in this area is inherently political. Attention to the need for an intellectual space where clinical, ethical, social, psychological, philosophical and political issues can be raised in conjunction with one another. Attention to the need for that intellectual space to be regarded as valid — as providing an interdisciplinary method through which new kinds of evidence may emerge to guide new approaches to practice. Attention to the urgency of listening to intersex activists and academics and not putting aside their concerns as extreme and unrepresentative. Attention to the day-to-day realities of clinical practice and the constraints that clinicians face — including the need to continue providing consistent and reliable care for intersex people and their families while being involved in complex debates about that care.

The way forward that I am envisaging concerns relationships (the patient–clinician relationship, the parent–child relationship, and interdisciplinary relationships), and epistemological shifts (towards valuing new kinds of evidence and theorising) and shifts in understanding about the risks and merits of reconfiguring the sexual features and gendered identities of young people to conform with (hetero)normative, binary sexes and genders.

The debates I have highlighted here resonate with the original dilemmas posed: how intersex people are to live and, more specifically, access optimal health care in a world that demands normatively sexed embodiment. Living in a world of binary genders and accessing health care are entirely intertwined — most intersex people are ‘gendered’ (as boys or girls) through the health care they received as children. The extent to which this clinical process *facilitates* or *hinders* living in our world of binary genders is still an open question.

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