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Review

The psychology of people with variable sex characteristics/intersex

Peter Hegarty

Abstract

Psychological research on people with variable sex characteristics (VSC)/intersex is broadening from the traditional exploitation of this population to ask nature/nurture questions about sexuality and gender. Healthcare for this population has been highly controversial, prompting research on psychological outcomes, the life-span development of adults with VSC, and distress trajectories of parents of children with VSC. Psychological research on clinical psychologists' roles in multidisciplinary care teams, and on decision making about medical pathways informed by those teams, both inform the evaluation of contemporary healthcare. Research is broadening to consider schoolchildren with VSC, elite athletes with VSC, and public understanding of VSC. The growing interdisciplinary field of intersex studies provides critical resources for psychologists.

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Edited by **Phillip Hammack** and **Liam Wignall**

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Keywords

Variable sex characteristics (VSC), Clinical psychology, Critical psychology, Social and cultural psychology, Intersex studies.

Introduction

Some people have *variable sex characteristics* (VSC) that vary from the typical alignment of chromosomes, hormones, and genitals that signify “sex.” Also called “intersex traits,” and “differences” or “disorders of sex development” (hereafter DSD), no “umbrella term” is preferred by everyone with VSC [1]. These term name

biological categories, meaning that they refer to sex characteristics not gender identities, but these terms do not name natural kind categories, with clearly defined necessary and sufficient features that determine category membership or non membership. There is no single essential sex characteristic that all people who might be covered by any umbrella term might share. Rather these categories are defined by diverse *differences from* typically aligned genetics, hormones, and anatomy, and the extent of difference required to determine category membership is contestable. A primer on sex development for psychologists is available elsewhere [2].

The United Nations estimate that 0.05%–1.7% of the population have VSC. Estimates vary because experts use different concepts, whilst laypeople with VSC are often kept silent [3]. Research psychologists have long exploited people with VSC as ‘natural experiments’ to test nature/nurture theories about sexuality, gender, criminality and cognitive abilities. Psychologist John Money’s (1921–2006) influential 1950s protocols integrated clinical psychology with paediatric endocrinology, assuming that (1) gender identity is plastic only during infancy, (2) quick surgery should align genital appearance to assigned sex to support parent child bonding, and (3) secrecy is the best way to address the risk of stigma [4,5].

Money’s protocol presumed that if your VSC became known, you would not be loved by others or yourself. Patients who endured these protocols challenged them in the 1990s, prompting clinical medicine to respond with the “Chicago consensus statement” a decade later. This consensus first acknowledged that Money’s assumptions lacked evidentiary support in science, second promoted multidisciplinary teams (MDTs) delivering patient-centred care, and third gave parents responsibility for making medical decisions affecting their children [6]. Then, patient advocacy diversified. Some advocates, then and now, allied with healthcare professionals towards reform, whilst other advocates extended healthcare professionals far less trust [7]. The United Nations and other international human rights bodies have since described early surgery on minors as infringing human rights. Two hospitals in the USA have recently ceased performing particular surgical practices on children [8]. In broad terms, the psychologies of people with VSC are situated in this history of contested

medicalization, whilst all other psychological issues have been relatively neglected by researchers.

Well-being among adults with VSC

1990s intersex activists pointed out that psychological effects of early surgeries had never been properly studied, and research on adults' well-being remained underdeveloped. A recent review of studies of depression in Turner's syndrome found the statistical effect sizes to be too variable to test for statistical significance [9]. Recently, a large collaboration between DSD clinics across Europe found the Quality of Life (QOL) of adolescents and adults with VSC to be close to average [10]. Single clinic studies continue to be published that report low QOL from a diversifying range of countries, including Turkey and Egypt. QOL likely vary in this population not only due to VSC themselves, but also due to experiences in and beyond healthcare settings, and the sense that people make of those experiences.

Recent qualitative and mixed-method studies described personal growth among LGBTIQ adults with VSC experiencing psychotherapy in Britain [11], a support group for adults with Androgen Insensitivity Syndrome in Australia [12], and patients transitioning from paediatric to adult healthcare providers in Canada [13] and in the Netherlands [14]. All four studies describe adults with VSC who develop new perspectives on their lives, bodies and experiences. All authors call the field to listen to such narratives, rather than assume that the effects of VSC are all-determining or all negative.

Researching the outcomes of controversial surgeries performed on children can be difficult because cases are rare, reporting is poor, and there are far fewer controls who have not had the prescribed surgeries. A recent large European study of people with VSC who had experienced early surgery found that women were more satisfied than men, but factors such as selection bias may have influenced its conclusions [15].

A hypospadiac penis has a natural urethral opening somewhere down its shaft which is moved towards the tip by surgery. Because hypospadiac penis is very common, effects of surgical interventions are better researched. Two-thirds of parents experience mild post-surgery regret and about one-fifth experience severe regret after choosing hypospadias surgery for their sons. Half of post-surgery complications emerge more than a year after surgery, after many follow-up studies conclude. Medical practitioners may underestimate negative sequelae when advising parents about hypospadias surgery [16].

Parental distress

Parents can experience complex distress and anxiously search for *certainty* when a child's VSC becomes known. One multi-clinic USA collaboration found that about two-

thirds of parents were "resilient," with no elevated distress, whilst one-fifth "recovered" from initial distress in the year after electing for surgery. Far fewer parents showed chronic or elevating distress in that year, whilst mothers reported more distress than fathers overall [17]. The same research collaboration found that levels of illness uncertainty predicted parents' depression and anxiety in the year after infant surgery [18]. Medical interventions may cause distress because parents lack sufficient time to process difficult emotions, and VSC that pose no health risk can be framed as disordered in healthcare settings [19]. In one USA clinic, parents given time for conversations with adults with VSC often reported changing their view of the future for their own child with VSC [20]. Access to private healthcare and other material resources, may predict which parents experience more or less common and profound distress [21].

Psychologists should weigh critiques of "damage-centred" narratives when reading studies on adults' long-term outcomes and parent's distress [22]. Evidence of psychological damage here may not empower families directly, but could limit their power to effectively represent their own and other families' interests and experiences.

The marginalization of clinical psychology in multi-disciplinary teamwork

The Chicago consensus named psychologists and psychiatrists as essential members of the MDT, leading researchers to examine psychologists' availability to patients and parents. DSD MDTs are typically led by paediatric endocrinologists, are not close knit, and often position psychologists and psychiatrists only as consultants [23,24]. A recent Freedom of Exercise study of the English National Health Service found a minority of DSD teams operating with no input from psychologists or psychiatrists at all [25].

Nonetheless, clinical psychologists who work in paediatric MDTs are the psychologists with the greatest professional experience of working closely with this population. Liao and Roen (2021) interviewed DSD MDT members to better understand psychologists' positions within teams [26]. Some medical professionals described psychologists' roles accurately. Others had never met the psychologist in their MDT, or didn't know what the psychologist did. Psychologists described their MDTs as characterized by conflict and groupthink and as causes of parents' distress. The authors expressed concern that psychologists remained marginal to many MDTs dominant biomedical cultures, and that some psychologists were expected to soothe parental distress caused by those MDTs. Some paediatric endocrinologists recognize that marginalizing psychologists means that true multiprofessional care is impaired for patients [23].

Clinical psychologists could advocate by drawing medical professionals and human rights experts with opposing constructions of reality into meaningful dialogue [27]. Human rights principles and sexual and gender minority frameworks have informed recent healthcare advocacy principles and could guide clinical psychologists' advocacy [28].

The social psychology of medical decision making

Psychologists know that decisions made under uncertainty, including medical decisions, are subject to various cognitive biases. Culture frames healthcare and decisions about the best interests of children with VSCs. In South Africa, traditional healers may practice infanticide on intersex children [29]. In Israel, genital surgery is strongly mandated [30]. In India, parents may strongly prefer boys over girls [31]. In Aoterea/New Zealand, Maori understandings may offer holistic correctives to Western individualized medicine [32]. In Europe, medical professionals working in MDTs may vary in their beliefs about the necessity of the interventions that their teams perform [33]. Social and cultural frameworks always contextualize how healthcare is organized, and children's social and cultural contexts are talked about variably as part of medical decision-making [33]. Psychologists should be alert to ethnocentric assumptions that cultural only influences "their" healthcare delivery and not "ours."

In cultural contexts influenced by the Chicago consensus, the framing of reality that occurs between healthcare providers and parents determines how children's best interests are understood. Conversation analysis shows that healthcare professionals in the USA can communicate to parents that irreversible surgeries are good options even when those same professionals are uncertain about what's best. This can happen merely by describing the surgeries as effective and available [34]. Such qualitative work illustrates how illness uncertainty meets discursive framing to construct what children's best interests seem to be in a cultural context. Making decision making more principled seems difficult; carefully developed decision support tools have not been extensively used in practice [35].

School and sporting contexts

Clinicians are often uncertain about how much children with VC are at risk of being bullied at school [33]. This is understandable, as developmental psychologists have rarely researched such children's school experiences. Adults with VSC often recall negative school experiences, including dissociation, self-disgust, feeling different, and intrusive attention [36,37]. Parents concerns may focus on schools' changing facilities, whilst their children describe broader school-related concerns

[38]. Educational psychologists and school counsellors lack standards for supporting children with VSC [37,39].

A *whole school approach* assumes that at every level of a school's functioning that there is a responsibility to proactively care for children with VS who may or may be visible [40]. This approach seems difficult, but necessary, as many students with VSC do not know or use the word "intersex," but still want close friends to know enough about their variation to give support when it's needed [41]. Repeated medical visits require absences from school, interrupt vacation time, and need to be explained, bringing particular stress. Sex education curricula can misrepresent and insult students with VSC [42].

Holistic educational interventions might reduce bioethical demands on MDTs. For example, hypospadias surgery is performed partially out of concern for bullying [16,33]. A whole-school approach might respond to such risks by fixing the school environment rather than attempting to fix a child's body [40].

Intersex is visibly debated in elite sports. In 2011, the International Association of Athletic Federations (IAAF) limited women with high circulating testosterone levels or *hyperandrogenism* from participation in women's competitions. This policy lacked supporting evidence. 2018 IAAF regulations specifically excluded women with 46-XY genotype and differences of sex development from five events, citing new evidence of correlations between androgen levels and elite women athlete's performance. That evidence contained material data errors [43]. The application of the 2018 AIAFF regulations to exclude intersex South African athlete Caster Semenya have been legally contested. Despite public interest in this sporting controversy, empirical studies on intersex athletes and coaches are lacking [44]. Educational psychologists might consider how the IAAF's controversies impact the school and sporting engagement of ordinary young people with VSC. Biological psychologists should expect research on hyperandrogenism to remain politicized.

New directions in "intersex studies:" adding I to LGBT?

The contemporary literature contains helpful reviews of LGBTQIA + research that document a lack of research on people with VSC [44]. It also contains several publications using the LGTQIA + rubric with no substantive discussion of intersex or people with VSC whatsoever. Some LGBTQIA + research in USA and European contexts could move past token inclusion by incorporating a historically grounded understanding of the related marginalization and silencing of sexual and gender minorities and people with VSC in psychology and elsewhere [4,5].

Research on intersex shaped contemporary transgender medicine [4,5], but the norm towards surgery on VSC contrast with norms delaying surgery for trans youth rests on multiple contradictions [45]. The interdisciplinary field of “intersex studies” is expanding (see recent special issues of *Sex Education, Culture, Health, & Sexuality*; *Psychology of Sexualities Review*, and *Transgender Studies Quarterly*). It promises new understanding of how these histories intersect with lived experiences of racism [46–48].

Finally, the attitudes of laypeople have long assumed to be so stigmatizing that they justify elective surgeries to correct VSC. Recent research in the USA and UK suggests that secular people, politically liberal people, LGB + people and people who endorse gender binary beliefs less are more supportive of psychological and social methods of creating inclusion for people with VSC and are more negative regarding surgery on infants with VSC [49,50]. This research also promises a more empirical description of socio-cultural context, revising Money’s original assumption that people with VSC can only expect stigmatization from the general public.

Declaration of competing interest

The author is a member of the American Psychological Associations current sitting Task Force on differences of sex development, the international network Psychosocial Intersex International (PSI International) and is a member of the Executive Committee of the UK charity Interconnected (ICON) UK. The views herein are his own and he reports no conflict of interest for this article.

Data availability

No data was used for the research described in the article.

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- * of special interest
- ** of outstanding interest

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