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# Towards equity & inclusion: a critical examination of genetic Counselling Education on Intersex Healthcare

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## Abstract

**Background** Intersex describes a diversity of individuals with variations in sex characteristics (VSC), reflecting underlying differences in reproductive anatomy, hormones, and/or genes and chromosomes. With a shift towards socially-conscious clinical practices, genetic counsellors (GCs) are increasingly needing to provide comprehensive care to individuals with VSC and their families. However, the current quality of training provided to genetic counsellors on intersex health is unclear.

**Methods** Qualitative interviews were conducted between Jan-Feb 2021 with 20 current and graduated students of Canadian GC training programs to assess the quality of GC education on intersex health topics. An agency-based model of VSC health as proposed by Crocetti et al. was used to guide the inductive thematic data analysis.

**Results** Results revealed three key themes: limited discussions on psychosocial considerations when caring for intersex individuals, enthusiasm for integrating more intersex training into the curriculum, and personal initiative in ensuring equity and justice in the care of individuals with VSC.

**Conclusions** These findings demonstrate existing knowledge gaps in the GC curriculum, with a need to increase the profession's overall awareness on intersex issues. GC training programs have an opportunity to meet the desires of students while promoting person-centered and validating healthcare for the intersex community.

**Keywords** Intersex, Genetic counselling, Genetic counsellors, Education and training, Variations of sex characteristics

## Introduction

Intersex variations and variations of sex characteristics (VSC) are umbrella terms used to describe individuals with congenital variations in sex characteristics and/or reproductive anatomy, reflecting underlying variations in genitalia, gonads, hormones, or genetic differences [1, 2].

Most notably, it includes differences in sex chromosomes or single genes. The vocabulary surrounding intersex, disorders of sexual development (DSD), and variations of sex characteristics (VSC) has evolved, reflecting community perspectives and priorities [3] however medical texts often prefer the term DSD or will refer to the specific congenital variation falling under the intersex umbrella. It is estimated that intersex individuals represent approximately 1.7% of the general population [1, 4]. Variations in sexual characteristics can be detected at different life stages (prenatally, at birth, during puberty, and adulthood) and healthcare providers (HCPs) engagement with intersex individuals can occur anywhere along this

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trajectory. Individuals with VSCs are culturally stigmatized, and report human rights violations and pathologization worldwide. These experiences translate to medical communication where many individuals report negative experiences as a result of their intersex status including misinformation and the concealment of personal medical information, [5] contributing to a culture of “secrecy and shame” [4, 6], infringing on human rights of bodily integrity and self-determination, [7] and perpetuating the lack of social visibility of the intersex community [8, 9].

Stigmatization may be perpetuated through apologetic or judgment-ridden language by HCPs at the time of identification of an intersex trait. In studies conducted by Jaramillo et al. [10] and Streuli et al. [11] they demonstrated that styles of pathologizing versus non-pathologizing communication by HCPs strongly influenced the decisions made by parents or parental proxies regarding the care of children with VSC. Continued stigmatization of VSC can stem from a lack of HCP awareness of potential trauma, uses of inappropriate terminology, [12] or knowledge gaps in understanding the needs of individuals with VSC [13]. Various advocates, allied health professionals, and international human rights bodies have called for movement away from a purely biomedical model of intersex, which centres around a dialogue of intersex variations as “abnormalities” or “disorders”, towards more neutral and accepting language and attend to psychosocial needs [9]. Moreover, the communication should focus on the health concerns, if relevant, rather than merely emphasize physical differences compared to the statistical norm. To complement this shift, patient-centred and rights-based models that emphasize the use of non-pathologizing language are encouraged [14, 15].

Recommendations for improving intersex care often include the formation of multidisciplinary HCP teams to guide individuals with VSC and their families [6, 16–19]. Within these teams, genetic counsellors (GCs) are suggested to take on roles in pediatric settings, such as educating patients and families on genetic etiologies of VSCs, providing outreach resources for children and adolescents with VSC, and providing parents with communication tools like letters to explain VSC to family members [20–22]. Genetic counselors facilitate individuals understanding and adaptation to the medical, psychological, and familial implications of genetic contributions of particular differences that may impact health [23]. For intersex adults, GCs can also facilitate discussions about reproductive goals and fertility. Additionally, genetic counsellors have opportunities to encounter VSC topics in a prenatal setting. With the increasing availability of non-invasive prenatal genetic screening (NIPS), the detection of some VSC conditions related to sex chromosome aneuploidies are likely to increase [24]. Recent studies on NIPS for sex prediction call for guidance on

pretest counseling from professional organizations, continuing education focused on sex and gender-diverse approaches to avoid stigma, anxiety and psychological harms [25, 26]. This furthers the increasing need for GCs to be aware of social issues surrounding VSC and provide context specific, non-directive counselling [27, 28].

Previous research has explored the perceived levels of competency and comfort of GCs when working with sexual orientation minorities such as gay, lesbian, bisexual patients, [29] or gender identity minorities such as transgender and non-binary patients [30–34]. While intersex variations are independent of sexual orientation and gender identity (SOGI) research highlights the challenges of developing rapport and effective communication when professionals lack of vocabulary and ease utilizing the terminology [35]. Barnes, Tuite, and Sheehan all reflect on the lack of universally accepted standards to accurately represent the uniqueness of individual identities in healthcare settings, particularly with regards to the use of symbols in drawing pedigrees and family history intake during a genetic counseling (GC) encounter [31, 33, 36]. However, an important portion of intersex individuals do not identify themselves as belonging to a SOGI minority group. Furthermore, the distinct needs of individuals with VSC are not specifically examined in these studies, with both Barnes and Sheehan commenting on the need for intersex-focused research in genetic counselling settings in the future [31, 33]. Broad themes encompassed in these studies also include the importance of using validating language, the responsibility of the counsellor to create a safe space for discussion, and the widespread desire for more education in working with these patient populations. Therefore, training focused on these topics would be valuable to GCs and students.

An initial approach to address the need for intersex-focused research in GC is to assess the current state of intersex education provided to GCs during their training. Despite calls for continuing education and guidance from professional organizations including the 2023 Accreditation Council for Genetic Counseling (ACGC) standards, there are no specific requirements on the provision of training addressing the needs of situationally marginalized groups such as individuals with VSC [37]. Integrating the social and biomedical models of intersex health such as Crocetti et al.’s agency-based model will inform the analysis to examine the sociocultural constructions of medical treatment and management of intersex health and how this related to GC training in this space. This qualitative study aims to assess the experiences of Canadian GCs and students regarding their education and training (psychosocial and medical) on intersex individuals’ healthcare, related topics of variations of sexual characteristics and nuances of the specific counseling settings (prenatal, newborn, puberty and adulthood). Without a

clearer understanding of the current knowledge gaps in VSC education, it is challenging to specify training competencies for GCs to provide patient-centred and validating healthcare for this patient community.

## Methods

### Study design

This study utilized an interview approach with thematic analysis to assess the richness of participants' responses [38]. The approach was chosen as it compliments early stages of research with limited coverage in the existent field, while individual interviews allow for detailed discussions of the participant's personal experiences, opinions, and reflections [39]. An agency-based model of intersex, or VSC health, as proposed by Crocetti et al. was used to guide the analysis [9]. It integrates both the social and biomedical models of intersex health to address health issues concerning individuals with VSCs, as well as the sociocultural constructions that guide the medical treatment of individuals with VSCs. Social model of intersex health is inspired by critical disability theory, which challenges the biomedical pathologization of intersex individuals, and recognizes that the 'disabling' aspect of intersex embodiment is a direct outcome of societal norms, prejudice, and discrimination [40].

### Positionality statement

The authorship team includes authors who identify as queer, disabled, people of color, and as a parent of a nonbinary child. The authors also have a range of clinical, academic, legal and advocacy involvement with LGBTQIA+ communities. The manuscript was supported by Social Sciences Research Council grant # 435-2018-0626 (Toward effective health communication with intersex Canadians: A study of ethical and legal challenges).

### Ethics approval

Ethics approval for the study was obtained from McGill University's Research Ethics Board in Winter 2020 (REF #20-11-054).

### Eligibility criteria

Eligible participants included current students and recent graduates of Canadian genetic counselling programs. "Recent graduates" were defined as genetic counsellors who completed their training within the 5 years prior to the conduction of this study, including individuals from the graduating class of 2015. Exclusion criteria included having participated in the pilot interviews conducted during the design stage of the study.

### Participant recruitment

Participants were recruited via purposeful sampling through email blasts sent by the Canadian Association of Genetic Counsellors (CAGC) to members registered on their listserv, as well as via emails from the Program Directors of Canadian genetic counselling programs to current students and alumni. The initial recruitment email included an invitation to connect with the researcher. The researcher contacted each participant to provide more information regarding the background of the study and a consent form. Participants were then scheduled for an individual interview in English on the video conference platform Zoom.

### Data collection

Between January to February 2021, the researcher conducted 20 individual interviews using Zoom with participants in the location of their choice. Individual interviews lasted between 23 and 59 min (median: 39.8 min) each and were audio recorded. Throughout the interview process, care was taken to check in with the participants, to ensure they felt safe, and reduce the possibility of participant discomfort in discussing details related to intersex topics or related gender, sex, and sexuality minorities. Participants were extended the opportunity to decline answering any question or could withdraw from the study at any time without explanation.

### Interview guide

The semi-structured interview guide (see [Appendix](#)) was based on a review of existing literature exploring the experiences of genetic counsellors, [29, 30, 32, 33] training related to counselling considerations for SOGI minorities, and intersex issues in general. Similar to Zayhowski et al., 2019, the interview guide provided structure for the formal interview, with open-ended questions and prompts allowing participants' responses to follow trajectories of relevant topics as they emerged [41]. The interview guide was piloted by GC students who closely resembled the study's intended demographic to maximize the content validity, assess the appropriateness of questions and estimate approximate interview length [42]. The final guide included 14 questions on the following topics: (a) education received and/or desired regarding intersex healthcare, (b) participants' awareness of intersex issues, and (c) personal or extra-curricular experiences contributing to awareness of intersex issues. Questions related to participants' demographics such as age, gender identity, pronouns, and student status (e.g., first-year, second-year, or recent graduate) were also asked.

### Data analysis

Recordings of each interview were saved to an encrypted and password-protected laptop and sent for transcription by a third-party transcription service. Resulting transcripts were reviewed for accuracy, and participants' names as well as any identifying information was deleted to maintain confidentiality. Transcripts of the interview were not returned to participants for comment or correction. Transcribed data from individual interviews were then uploaded into NVivo Version 20.6.1 (2020). The coding team consisted of the lead researcher (A.A.), and two members of the research team with extensive familiarity in qualitative methodologies (N.P. and M.C.). A thematic codebook was developed using an inductive approach by independently identifying emergent concepts and highlighting representative quotes across the data set [43]. Coding of the transcripts occurred independently. Together, the team reviewed the coded transcripts. Once completed, the coding was compared to the codebook and differences were reconciled through iterative discussion to reach a consensus and identify overarching themes and subthemes.

An inductive thematic analysis was used, as it permitted the examination of patterns in participants' perspectives and the generation of unanticipated themes without the application of a pre-existing framework [44, 45]. The lead coder (A.A.) reviewed the raw data and assigned initial codes to recurrent patterns in the participants' responses. These codes were then reviewed by the secondary coders (N.P. and M.C.) and the codes were organized into broader themes that relate to the research questions. Participant checking was not employed in this project as there was limited time for the student led project. This report presents the emergent themes and how they relate to existent intersex education literature.

## Results

### Participant characteristics

A total of 20 participants enrolled in the study, comprising 3 first-year students, 6 second-year students, and 11

recent graduates across 5 GC programs in Canada. The counselling programs were distributed between four provinces (two in Québec, one in each of Manitoba, British Columbia, and Ontario). All demographic information is listed in Table 1.

### Themes identified

The three major themes identified through thematic analysis include: (1) limited discussions of psychosocial aspects of intersex identity during training (2) enthusiasm towards integration of training specific to intersex issues into the curriculum and (3) collective responsibility of GCs in ensuring equity and undoing historic harms in the care of individuals with VSC.

### Psychosocial aspects of intersex identity during training

Participants noted that the medical aspects of intersex were formally covered in course learning objectives and were discussed in depth. However, discussions on the psychosocial aspects of intersex identity and the impact of stigma occurred primarily in informal settings and were often initiated by interested students (rather than indicated by the curriculum). Most participants ( $n=19$ ) believed that medical topics related to intersex conditions (such as factors influencing diagnosis or clinical management) were addressed in formal lectures. Notably, the topics were predominantly conveyed using language of disorders of sex development (DSD) and taught by medical professionals (geneticists and/or GCs). Regarding clinical experience, several participants ( $n=11$ ) shared that they had limited or no exposure to cases involving intersex conditions and/or variations of sexual characteristics. By contrast, discussions on psychosocial issues related to intersex identity, ethical considerations (e.g., patient autonomy, self-determination, and bodily integrity), adaptations in counselling strategies emerged in informal group discussions, and debriefing clinical cases with fellow students were raised through student-led presentations ( $n=13$ ). Many participants ( $n=19$ ) commented that intersex topics were included within the broader context of training related to SOGI minority groups. However, it meant that intersex issues were rarely, if ever, treated as a distinct entity in formal training. Notably, three participants recounted instances during training when a GC student experienced resistance and backlash from medical residents and physicians in response to a presentation delivered by a peer GC student. The presentation sought to analyze an article which criticized certain practices in the care of infants or fetuses with congenital adrenal hyperplasia (CAH), a condition that can be categorized under the umbrella of intersex. All three participants described feeling uneasy with the situation, with one participant saying that they felt it was

**Table 1** Population characteristics

Demographic Characteristic	Count (n)
Total Number of Participants	20
Self-Reported Gender Identity	Woman (19) Female (16) Cis female (1) Woman (2) Man (1)
Age Range	25 years old or younger (6) 26–30 years old (11) Over 30 years old (3)
Education Status	First-year students (3) Second-year students (6) Recent graduates (11)

unfortunate that the burden of initiating discourse on potentially charged topics often fell onto students.

#### ***Integration of intersex-specific training into the curriculum***

All 20 participants expressed positive attitudes about incorporating more intersex topics into training, and a diversity of responses emerged from participants upon being prompted to expand on these sentiments of support towards additional training in this domain. Some wanted a curriculum that provided formal introduction to intersex topics, as well as addressing misconceptions of what intersex is and is not. A few ( $n=11$ ) cautioned on assuming incoming students would have a baseline knowledge of intersex topics and the lived experiences of intersex individuals (due to the increasing social advocacy of the intersex community), as it assumes that students already understand how to approach these topics with patients. Interestingly, a few participants ( $n=10$ ) touched on how the assumed transferability of strategies for counselling from one patient population to another may create unintentional gaps in training. These responses reflected on adjustments in counselling approaches when working with different marginalized populations - participants shared that counselling considerations for groups such as SOGI minorities, patients (or parents of a child) with Down syndrome, or the disability community may have been covered in classes, but no explicit considerations specific to intersex counselling were included in training.

Participants proposed novel and diverse formats of training and education devoted to intersex issues (such as role-playing, simulated sessions, or workshops), training regarding language considerations, pedigree nomenclature to represent diverse patient identities, as well as opportunities for advocacy and affirming care in clinical settings (e.g., terminology used in medical documentation, inclusiveness in questionnaires and forms, etc.). Overwhelmingly, all participants placed a high degree of value in directly learning from the intersex community to have a better understanding of the perspective of this patient group. A few participants ( $n=5$ ) suggested opportunities for programs to invite patient representatives and/or intersex advocates to speak and present to students.

#### ***Ensuring equity and undoing historic harms in the care of individuals with VSC***

Participants reflected on the roles of GCs in advocacy and undoing historic harms experienced by the intersex community, tying it to equity and responsibility to provide services to an underrepresented population which faces stigmatization and systemic barriers to quality healthcare.

#### **Confidence**

Participants identified opportunities for GCs to be involved at many points in an intersex individual's care throughout their lifetime (prenatal, pediatric, adult and fertility genetics). Many ( $n=13$ ) respondents detailed various considerations in a counsellor's role in the prenatal setting when discussing intersex traits and variations of sexual characteristics with prospective parents. "We can go into a counselling session with someone who is from a different culture and have some idea of values and issues that we might want to bring up and see if that's influencing decision making or, you know, accepting or adjusting to a diagnosis." All participants described feeling confident in their ability to provide non-directive counselling, regardless of whether they had previously participated in the care of an intersex patient.

#### **Uncertainty**

However, some identified areas of uncertainty in their approach or delivery of information. One participant commented that "it is not a challenge to be non-directive, but in some cases, it can be more complex," acknowledging that they would feel a level of discomfort if a couple expressed wanting to terminate a pregnancy based on variations of sexual characteristics, without the presence of significant medical complications. A separate respondent expressed that a similar situation would create a conflict with their internal values, sharing that they would be "torn between wearing my counselling hat and my advocacy hat."

#### **Mitigating strategies**

Many participants ( $n=13$ ) expressed a desire to spend time thoroughly preparing for a consultation involving intersex in a prenatal setting. Almost half of the participants ( $n=9$ ) emphasized the dilemma of wanting to present a more balanced and nuanced perspective on the quality of life of intersex individuals or those with VSCs, without having had a previous exposure to this information in training or in clinical practice. Several participants ( $n=16$ ) anticipated the types of strategies they might use to address these challenges in a GC session. For example, being aware of how tone and language affects the decision-making process when discussing VSC topics, how a couple might perceive a child with VSC, or how that person or family may go on to interact with the healthcare system. Other participants commented on possible benefits of "front-loading" assessments of their patients' values and beliefs at the beginning of a session to best adapt to their needs ( $n=2$ ). One respondent expanded on this, stating that it was important to be aware that discussions which challenge patients' sociocultural beliefs on sex and/or gender binary can be polarizing. Finally, a few participants ( $n=3$ ) warned against over-emphasizing



intersexuality as a dimension of a person's identity and/or "creating a centrepiece" out of variations of sexual characteristics as this may perpetuate stigmatization, despite an underlying intention to be open and inclusive.

## Discussion

### Summary of findings

These interviews elucidated the perspectives of current students and recent graduates of Canadian genetic counselling programs regarding the quality of education on care for intersex individuals. Participants generally reported satisfaction in the medical aspects of intersex education provided within the curriculum. However, the education on VSCs was situated in the biomedical model of care, focused on the disordered aspects of an individual, and characterized by using DSD terminology. This focus on pathologization reflects the societal constructs of "othering", discrimination, and prejudice that could be mediated by integrating social and psychosocial approaches to healthcare. This narrow approach to instruction can lead to missed opportunities for GC students to engage in personalized care, develop cultural competence, recognize opportunities to ameliorate health inequalities and advocate for patients' human rights. However, according to our participants, discussions about psychosocial aspects, issues tied to social identities, and the impact of stigma occurred primarily in informal settings and were largely driven by student interests. "If I hadn't had that one lecture by a second-year student who took the initiative to do it, I don't think we would have received the education that we did" remarked one participant on their Intersex training. Though there can be arguments made that counseling skills can be transferred to multiple counseling situations excluding these topics from the curricula places a burden on CGs to learn the material on their own and deprives them of opportunities of working with groups for whom engagement with the medical establishment is for many already fraught. [46] This knowledge gap is reflected in the most recent Accreditation Council for Genetic Counseling (ACGC) standards. Categories for required curriculum content related to psychosocial topics are defined (e.g., sensitivity and competency in the context of multiculturalism, disability awareness, etc.), but there are no specific requirements on the provision of training that addresses the needs of situationally marginalized groups such as individuals with VSC [37]. In response to this division in training, all participants expressed support for formal integration on intersex topics into the curriculum. The participants' identification of existing knowledge gaps and their further interest on resources for intersex management is consistent with other studies where GCs have been assessed regarding training opportunities to

provide more comprehensive care to other minority groups [32, 36].

Participants noted the current inadequacy in training on psychosocial aspects of intersex issues and recommended adding lectures or workshops to rectify this knowledge gap. This would provide opportunities to incorporate existing teaching infrastructure into training, such as the eQuality virtual module, developed by the University of Louisville School of Medicine [47]. The module touches on issues faced by SOGI and intersex communities and continues to be updated via continuous input by the patient populations in question [47]. Additionally, participants attributed a high level of value to learning about the lived patient experience and gaining a better understanding of the quality of life for intersex individuals. As described in some of the challenges to counselling in the prenatal setting, the ability to provide a balanced perspective when counselling about intersex can be facilitated by exposure and encounters with intersex individuals and patient advocacy groups. Intersex community training would be invaluable in that one community embodies a range counselling contexts (prenatal, at birth, puberty, and adult) with the concomitant variation in terminology and communication associated the age and culture of the patient. Further, positive interactions with healthcare providers by this community helps to build trusting relationships necessary for quality care. Thus, training that is centered on the voices of the intersex community is necessary for GCs to encourage patients and prospective parents to develop a more nuanced understanding of the situation. This is also observed in literature commenting on the training needs of healthcare providers regarding intersex issues [27].

Lastly, participants noted that discussions about intersex topics during training are often lumped into discussions about SOGI minorities. Many respondents questioned this practice as it may treat these groups as a monolith population, lacking clarity or distinction between these possible dimensions of personal identity. While the intersex community is commonly included in the popular "LGBTQIA2S+" acronym and may share important social trajectories with SOGI minorities, [3] the needs of intersex individuals are still distinct from these groups [48]. Intersex people ultimately face unique challenges in medical settings which warrant individual concern. Concerns raised by participants are in line with recommendations described by Parent et al., outlining how some advocacy groups have called for awareness of these differences and highlighted the importance of treating the needs of marginalized groups with careful distinction [49].

### Study limitations

There are several limitations to this study. First, it is a qualitative study drawing from a diversity of participants across Canada from eight separate cohorts. Due to the relatively small number of participants, perspectives detailed in this study may not be representative of all Canadian GC students. Second, enrollment into the study was voluntary, which may contribute to a positive response bias and the views may possibly reflect those with a vested interest in the topic and those with more available time to participate. In parallel, the interpretation of participants' responses is also subject to the researchers' viewpoints and understanding. However, the development of a codebook, and having multiple independent reviewers were employed to minimize researcher bias. Participant experiences reflect that of current students and recent graduates in the field. Separate research is needed for middle or late career GCs currently practicing, regarding their readiness and quality or educations on intersex, and possible supplementary continuing education opportunities. Finally, while the population of interest in this study is GCs and students, the topic of intersex education implicates the larger intersex community which has historically been underrepresented in medical settings and by extension, research as well. Therefore, it is essential that in addition to research data, any changes to the GC training curriculum be centered around intersex voices and perspectives. Such a perspective was sought in another study.

### Conclusions

In summary, this study has identified gaps in the Canadian GCs' training curriculum related to intersex issues and described best practices to foster social awareness in person-centred care for intersex individuals. Through interviews, genetic counselling students and recent graduates reflected on their experiences during training regarding care of intersex individuals. Thematic analysis revealed that gaps in training further perpetuates of the stigma and marginalization experienced by the intersex community. Participants reported adequate training on the medical aspects of intersex, but inadequate training on psychosocial aspects of intersex identity and social stigma (which were relegated to informal or student-initiated settings). In response to this apparent division in GC training, participants expressed support for a more formal integration of intersex topics into the curriculum. A major challenge raised by participants was uncertainty in approaching discussions of identification of VSC with patients or parents, particularly in a prenatal setting. Overall, these findings demonstrate the need for additional training so that GCs can provide nuanced and affirming psychosocial support in the care of intersex individuals. To achieve this, the educational gaps related

to intersex topics must first be bridged. GC training programs have an opportunity to address these gaps in the broader context of promoting person-centred and inclusive care that is more accessible to the wide diversity of patients and families seen by GCs.

### Abbreviations

ACGC	Accreditation Council for Genetic Counseling
CAGC	Canadian Association of Genetic Counsellors
CAH	Congenital adrenal hyperplasia
DSD	Disorders of sex development
GC	Genetic counselling
GCS	Genetic counsellors
HCPs	Healthcare providers
SOGI	Sexual orientation and/or gender identity
VSC	Variations in sex characteristics

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12909-024-05898-x>.

Supplementary Material 1

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### Author contributions

Conceptualization: YJ, AA; Data curation: AA; Formal analysis: AA, NP, MC; Funding acquisition: YJ; Investigation: AA; Methodology: AA; Project administration: YJ, NP; Resources: AA, KH; Software: AA, NP, KH; Supervision: YJ, NP; Validation: AA, KH, MC, NP; Visualization: AA, KH; Writing-original draft: AA, KH; Writing-review & editing: KH, NP, AA.

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### Data availability

Redacted transcripts of the interviews are available from the corresponding author on reasonable request.

### Declarations

#### Ethics approval and consent to participate

Ethics approval for the study was obtained from McGill University's Research Ethics Board in Winter 2020 (REF #20-11-054). Informed consent was obtained from all participants as required by the REB. Data was de-identified and the author received and archived written consent for all data used.

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare no competing interests.

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## References

- OHCHR. Background Note Human Rights Violations Against Intersex People [Internet]. [Cited 2023 Sep 17]. <https://www.ohchr.org/sites/default/files/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsAgainstIntersexPeople.pdf>
- OHCHR, Free and Equal Campaign Fact Sheet - Intersex [Internet]. [Cited 2023 Nov 17]. <https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf>
- Vilorio H, Nieto M, Law A. The spectrum of sex: the science of male, female, and intersex. London; Philadelphia: Jessica Kingsley; 2020. p. 156.
- InterACT HR, Watch (Organization), editors. I want to be like nature made me: medically unnecessary surgeries on intersex children in the US. Amsterdam: Human Rights Watch; 2017. p. 179.
- Grinspan MC, GATE - Global Action for Trans Equality. 2019 [Cited 2023 Aug 9]. The Road to Hell: Intersex People, Sexual Health & Human Rights - GATE. <https://gate.ngo/the-road-to-hell-intersex-people-sexual-health-and-human-rights/>
- Frader J, Alderson P, Asch A, Aspinall C, Davis D, Dreger A, et al. Health Care professionals and Intersex conditions. *Arch Pediatr Adolesc Med*. 2004;158(5):426.
- Hegarty P, Donnelly L, Dutton PF, Gillingham S, Vecchiotti V, Williams K. Understanding of intersex: the meanings of umbrella terms and opinions about medical and social responses among laypeople in the United States and United Kingdom. *Psychol Sex Orientat Gen Divers*. 2021;8(1):25–37.
- Lundberg T, Hegarty P, Roen K. Making sense of 'Intersex' and 'DSD': how laypeople understand and use terminology. *Psychol Sexuality*. 2018;9(2):161–73.
- Crocetti D, Monro S, Vecchiotti V, Yeadon-Lee T. Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health. *Cult Health Sex*. 2021;23(4):500–15.
- Jaramillo C, Nyquist C, Riggan KA, Egginton J, Phelan S, Allyse M. Delivering the diagnosis of sex chromosome aneuploidy: experiences and preferences of parents and individuals. *Clin Pediatr (Phila)*. 2019;58(3):336–42.
- Streuli JC, Vayena E, Cavicchia-Balmer Y, Huber J. Shaping parents: impact of contrasting Professional Counseling on Parents' decision making for children with disorders of Sex Development. *J Sex Med*. 2013;10(8):1953–60.
- Dickens BM. Management of intersex newborns: legal and ethical developments. *Int J Gynecol Obstet*. 2018;143(2):255–9.
- Donald C, Ehrenfeld JM. The opportunity for Medical Systems to reduce Health disparities among Lesbian, Gay, Bisexual, Transgender and Intersex patients. *J Med Syst*. 2015;39(11):178.
- Taskforce ALC, Harper A, Finnerty P, Martinez M, Brace A, Crethar HC, et al. Association for Lesbian, Gay, Bisexual, and Transgender issues in Counseling competencies for Counseling with Lesbian, Gay, Bisexual, Queer, Questioning, Intersex, and Ally individuals: approved by the ALGBTIC Board on June 22, 2012. *J LGBT Issues Couns*. 2013;7(1):2–43.
- Jones T. Intersex Studies: a Systematic Review of International Health Literature. *SAGE Open*. 2018;8(2):215824401774557.
- Roan K. Intersex or diverse sex development: Critical Review of Psychosocial Health Care Research and indications for practice. *J Sex Res*. 2019;56(4–5):511–28.
- Sandberg DE, Gardner M, Callens N, Mazur T. The DSD-TRN Psychosocial Workgroup, the DSD-TRN Advocacy Advisory Network, and Accord Alliance. Interdisciplinary care in disorders/differences of sex development (DSD): the psychosocial component of the DSD-Translational research network. *Am J Med Genet*. 2017;175(2):279–92.
- Mouriquand PDE, Gorduza DB, Gay CL, Meyer-Bahlburg HFL, Baker L, Baskin LS, et al. Surgery in disorders of sex development (DSD) with a gender issue: if (why), when, and how? *J Pediatr Urol*. 2016;12(3):139–49.
- Casey RK, Trotman G, Damle L, Menzel M, Gomez-Lobo V. Prenatal diagnosis and management of disorders of sexual differentiation. *J Pediatr Adolesc Gynecol*. 2014;27(2):e57–8.
- Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, Baratz A, et al. Global disorders of Sex Development Update since 2006: perceptions, Approach and Care. *Horm Res Paediatr*. 2016;85(3):158–80.
- Gomez-Lobo V. Multidisciplinary care for individuals with disorders of sex development. *Curr Opin Obst Gynecol*. 2014;26(5):366–71.
- Accord, Alliance, Intersex Society of North America. Clinical Guidelines for Management of DSDs in Childhood. Consortium on the Management of Disorders of Sex Development [Internet]. 2006. <http://www.dsdguidelines.org>
- Resta R, Biesecker BB, Bennett RL, Blum S, Estabrooks Hahn S, Strecker MN, et al. A new definition of genetic counseling: National Society of Genetic Counselors' Task Force Report. *J Genet Couns*. 2006;15(2):77–83.
- Yoshii K, Naiki Y, Terada Y, Fukami M, Horikawa R. Mismatch between fetal sexing and birth phenotype: a case of complete androgen insensitivity syndrome. *Endocr J*. 2018;65(2):221–5.
- Stevens C, Llorin H, Gabriel C, Mandigo C, Gochyyev P, Studwell C. Genetic counseling for fetal sex prediction by NIPT: challenges and opportunities. *J Genet Couns*. 2023;32(5):945–56.
- Kamoun C, Rossi W, Kilberg MJ. Ethical concerns surrounding sex prediction using noninvasive prenatal screening from pediatric endocrinologists' perspective. *J Genet Couns*. 2023;32(5):937–41.
- Saulnier KM, Gallois H, Joly Y. Prenatal genetic testing for Intersex Conditions in Canada. *J Obstet Gynecol Can*. 2021;43(3):369–71.
- Marteau M, Nippert T, Hall I, Limbert S, Reid C, Bobrow M. Outcomes of pregnancies diagnosed with Klinefelter syndrome: the possible influence of health professionalst. *Prenat Diagn*. 2002;22(7):562–6.
- Glessner HD, VandenLangenberg E, Veach PM, LeRoy BS. Are genetic counselors and GLBT patients on the same page? An investigation of attitudes, practices, and genetic counseling experiences. *J Genet Couns*. 2012;21(2):326–36.
- Berro T, Zayhowski K, Field T, Channaoui N, Sotelo J. Genetic counselors' comfort and knowledge of cancer risk assessment for transgender patients. *Jnl Gene Coun*. 2020;29(3):342–51.
- Barnes H, Morris E, Austin J. Trans-inclusive genetic counseling services: recommendations from members of the transgender and non-binary community. *Jnl Gene Coun*. 2020;29(3):423–34.
- Zayhowski K, Park J, Boehmer U, Gabriel C, Berro T, Campion M. Cancer genetic counselors' experiences with transgender patients: a qualitative study. *J Genet Couns*. 2019;37(4):1092.
- Sheehan E, Bennett RL, Harris M, Chan-Smutko G. Assessing transgender and gender non-conforming pedigree nomenclature in current genetic counselors' practice: the case for geometric inclusivity. *Jnl Gene Coun*. 2020;29(6):1114–25.
- Rosenwohl-Mack A, Tamar-Mattis S, Baratz AB, Dalke KB, Ittelson A, Zieselman K, et al. A national study on the physical and mental health of intersex adults in the U.S. Useche SA, editor. *PLoS ONE*. 2020;15(10):e0240088.
- Carpenter M. Intersex human rights, sexual orientation, gender identity, sex characteristics and the Yogyakarta principles plus 10. *Culture. Health Sexuality*. 2021;23(4):516–32.
- Tuite A, Dalla Piazza M, Brandi K, Pletcher BA. Beyond circles and squares: a commentary on updating pedigree nomenclature to better represent patient diversity. *Jnl Gene Coun*. 2020;29(3):435–9.
- ACGC - Accreditation Council for Genetic Counseling. Practice Based Competencies: ACGC [Internet]. 2019. <https://www.gceducation.org/practice-based-competencies/>
- Creswell JW, Creswell JD. Research design: qualitative, quantitative, and mixed methods approaches. Fifth edition. Los Angeles: SAGE; 2018. 275 p.
- MacFarlane IM, McCarthy Veach P, LeRoy BS. Chapter 8: conducting qualitative genetic Counseling Research. *Genetic Counseling Research: a practical guide*. Oxford University Press; 2014.
- Reaume G. Understanding critical disability studies. *CMAJ*. 2014;186(16):1248–9.
- Cohen D, Crabtree B. Qualitative Research Guidelines Project [Internet]. 2006. <http://www.qualres.org/HomeSemi-3629.html>
- Leon AC, Davis LL, Kraemer HC. The role and interpretation of pilot studies in clinical research. *J Psychiatr Res*. 2011;45(5):626–9.
- Clarke V, Brown V. Thematic analysis. *Encyclopedia of quality of life and well-being research*. Dordrecht, The Netherlands: Springer; 2014. pp. 6626–8.
- Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness Criteria. *Int J Qualitative Methods*. 2017;16(1):160940691773384.
- MacFarlane IM, McCarthy Veach P, LeRoy BS. Genetic Counseling Research: A Practical Guide [Internet]. Oxford University Press; 2014 [Cited 2023 Aug 9]. <http://www.oxfordmedicine.com/view/https://doi.org/10.1093/med-9780199359097.001.0001/med-9780199359097>
- Wang JC, Dalke KB, Nachnani R, Baratz AB, Flatt JD. Medical Mistrust mediates the relationship between nonconsensual intersex surgery and Healthcare Avoidance among Intersex adults. *Ann Behav Med*. 2023;57(12):1024–31.
- Holthouser A, Sawning S, Leslie KF, Faye Jones V, Steinbock S, Noonan EJ, eQuality: a process model to develop an integrated, comprehensive medical education curriculum for LGBT, gender nonconforming, and, health DSD et al. *MedSciEduc*. 2017;27(2):371–83. <https://doi.org/10.1007/s40670-017-0393-5>.



48. International Lesbian, Gay, Bisexual, trans and Intersex Association. Minorities Report 2017: attitudes to sexual and gender minorities around the world [Internet]. Geneva: ILGA; 2017 Oct [cited 2023 Aug 9]. [https://ilga.org/downloads/ILGA\\_RIWI\\_Minorities\\_Report\\_2017\\_Attitudes\\_to\\_sexual\\_and\\_gender\\_minorities.pdf](https://ilga.org/downloads/ILGA_RIWI_Minorities_Report_2017_Attitudes_to_sexual_and_gender_minorities.pdf)
49. Parent MC, DeBlaere C, Moradi B. Approaches to Research on Intersectionality: perspectives on gender, LGBT, and Racial/Ethnic identities. *Sex Roles*. 2013;68(11–12):639–45.

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