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Title:**What Mental Health Supports Do People With Intersex Variations Want, and When?****Abstract:**

Several large-scale surveys around the world show the most frequently reported mental health diagnoses among people with intersex variations include depression, anxiety and PTSD. Wellbeing risks are also high, with individuals with intersex variations citing suicidal thoughts or attempts across their life-course – specifically on the basis of issues related to having congenital sex variations. The population mostly attributed their wellbeing risks to negative social responses from others, difficulties around having undergone interventions or issues around gender/identity. In the Canadian context, there is a lack of formalized, charitable Canadian wide intersex networks, advocacy groups, universal mental health care approaches, or provincial signposting to services similar to those developed elsewhere. Using a life-cycle lens, a group of international researchers came together in a collaborative Canadian study to explore health care transitions that people with intersex variations might need or desire, at various stages of their life. A key finding highlights that transition phases have the capacity to be especially difficult in the context of mental health. Three themes in the data identified mental health impacts: worthlessness, alienation and self-esteem. However a final theme drew on integrated medicine to celebrate emerging emotional intelligence; a positive experience that had emancipatory benefits across the lifespan.

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Introduction

At least 1.7-4% of people have intersex variations that may be physically apparent preceding or at birth, or discovered later in life through testing (Carroll, 2005; Fausto-Sterling, 1993; OII Australia, 2012). Given that sex development is complex, some elements of sex are not apparent without testing and many people never test for them; current estimates of the incidence and types of intersex variations may be conservative. Intersex variations are atypical sex characteristics (OII Australia, 2012) including: chromosomes, hormones and anatomy. Many individuals with intersex variations have two or more variations (Jones et al., 2016).

In the last decade people with intersex variations have been increasingly studied or referred to as part of an umbrella group within critical research (Holmes, 2009; Pagonis, 2016). Diversity in epistemology and associated research methodology has been reported (Jones, 2018), which influences a range of disciplines and domains. The emergence and establishment of patient-oriented (POR) support units across Canada advocates for a partnered approach to developing research questions. Therefore, identifying and working with individuals with intersex is a purposeful step to exploring wellness and establishing research partnerships to co-design future studies. This article challenges older psycho-medical lenses problematising the population by foregrounding the psychological and social wellbeing of participants in a way that considers bodily autonomy a cornerstone of mental health (Davis, 2015; Jones, 2018).

There has been minimal exploration of the psychological needs and wants of people with intersex variations and a significant focus on the group in their early years (infancy and development) that drops off in adulthood and as they age (Jones, 2018). This article begins to address the gaps in Canadian research on the mental health needs of people with intersex variations, especially across their lifespan. This article first reviews the international mental

health research literature on people with intersex variations. Secondly, it details the life-cycle lens. Thirdly, it outlines the participatory and action-orientated methodology and focus group methods used to facilitate agency whereby those with intersex variations were able to discuss their mental health experiences, needs and wants against a backdrop of understanding transitions in health care. This article then discusses key findings, how they relate to existing theory and studies, and implications for the field.

Review of current literature

Literature involving individuals with intersex variations (also referred to as disorders /differences of sex development [DSD] and variations of sex characteristics) is found primarily the United States (Crerand et al., 2019; Malouf et al., 2010; Sandberg et al., 2017). Recent contributions from Europe (de Vries et al., 2019; Hegarty, Smith, & Bogan-Carey, 2019; Rapp et al., 2018), the Asia-Pacific region (Dwyer, Ball, & Barker, 2015; Henningham & Jones, 2017; Wang & Tian, 2015), Africa (Ekenze, Nwangwu, Amah, Agugua-obianyo, & Onuh, 2015; SM & I, 2016) and the Middle East (Danon, 2019; Gül, Sayar, Özten, & Eryilmaz, 2015) have also emerged, taking various theoretical standpoints. Most of the studies focus on physical health concerns and intervention. Some take a traditional medical/clinical ‘corrective’ lens, often assuming the medical need for intervention (Amarillo et al., 2016; Ekenze et al., 2015; Mutlu et al., 2015), while other studies focus on intersex variations and celebrate individual voices and narratives (MacKenzie, Huntington, & Gilmour, 2009; Sanders, Carter & Lwin, 2015). Increasingly, critical ‘Intersex Studies’ consider intersex variation through a bioethics lens, privileging the rights of people with intersex variations to body autonomy that precludes forced unnecessary treatments (Carpenter, 2018; Jones et al., 2016). Canadian literature involving individuals with intersex variations is largely linked to social justice (Holmes, 2009), at times within the LGBTIQ portfolio (Dysart-Gale, 2010) or medical discourse (Romao, Salle & Wherrett, 2012).

There have been many overt calls in the last decade for the inclusion of mental health support as a critical aspect of interdisciplinary care when working with individuals with intersex variations (D'Albertyon et al., 2015; Lev, 2006; Liao & Simmonds, 2014). Larger-scale surveys around the world show the most frequently reported mental health diagnoses among people with intersex variations include affective disorders such as depression, anxiety and PTSD (Bohet et al. 2019; Henningham & Jones, 2017; Jones et al., 2016; Lux et al., 2009). Both mental health status and outcomes have been recently reported; Bohet et al's (2019) literature review (n=18) synthesized clinical providers knowledge while Godfrey's (2020) systematic review (n=19) empirically reviewed instruments that measured global distress and mental health. Between these two reviews a lack of accord as to standardized measures in the domains of mental health and wellbeing was noted. Such variation in choice of psychological evaluation instruments raises methodological challenges, as noted by D'Albertyon et al (2018).

Wide variation in mental health concerns for individuals with intersex variations, when matched to comparison groups is reported for affective disorders, mention of suicidality, and psychiatric diagnosis (Bohet et al. 2019; Godfrey, 2020). A cross-sectional German-led dsd-LIFE study from 14 European tertiary centers reported similar outcomes from 1040 participants [mean 32.4 ± 13.6 (year range 16–75)], noting a substantial prevalence of psychiatric disorders (42.5%) i.e., eating disorders, chronic anxiety / depression, neuro developmental disorders, self-reported suicide attempts (6.8%) (Falhammer et al., 2018). While regression analysis was not statistically significant, psychiatric and mental health symptoms were prevalent within some groups i.e., individuals with Klinefelter syndrome. Recent reporting from Australia (2020) highlights that 21.3% of people with intersex variations have been diagnosed with depression; 12.9% with anxiety; 7.7% with PTSD, which in combination are reflective of previous studies. However, 19% of those 16

years or over have attempted suicide – which is a higher figure than reported elsewhere (National LGBTI Health Alliance, 2020).

From infancy to young adulthood, the influence of stress within the family unit for the individual with intersex is acknowledged. A UK study assessed the prevalence/severity of posttraumatic stress symptoms (PTSS) in parents of children with intersex (Pasterski et al., 2014). Reported PTSS was high: 31% of mothers and 18% of fathers met the threshold for cases for Posttraumatic Stress Disorder (PTSD), evidenced by high rates of PTSS. The researchers argued that it was cognitive confusion, and not emotional distress, which predicted PTSS and that direct cognitive psychological interventions may be helpful. The question remains – can early family psychosocial care reduce PTSS resulting in improved mental health outcomes for individuals with intersex, across their lifespan?

In terms of mental health across the lifespan, intersex literature makes contributions to psychogeriatrics (Tinney et al., 2015), neuropsychiatry (Gül et al., 2015), science ethics (Dreger, 2015; Hernon et al., 2014; Mohamed et al., 2015), and social psychology (Hegarty et al., 2019; Jones et al., 2016; Lux et al., 2009). Yet Tinney et al. (2015) argued that intersex people were a key sub-group for which mental health information, specifically for older people, was the most minimal.

Several contributions questioned the common dynamic in medical studies of assuming the inherent need for intervention to prevent stigma (Dreger, 2015; Hernon et al., 2014; Mohamed et al., 2015). Reporting from an Australian population study identified that intersex people attributed their wellbeing risks to negative social responses from others, and prior interventions or issues around gender/identity (Jones et al., 2016). While 44% of the group reported receiving counselling/training/pressure from institutional practitioners (doctors, psychologists etc.) on gendered behaviour, improvements in training for mental health services/workers that moved away from stigmatizing models were reported, as necessary.

The ethical and accessibility aspects of mental health and wellbeing are important with psychological care being non-stigmatizing, ‘noncategorical’ (Sandberg & Mazur, 2014), and individualized (Lee et al., 2020). Such approaches can hold individual benefit – in self and identity, as well as encourage and facilitate access to peer supports across the life course.

Applying learning from studies that have shown that social stigma around intersex variations beyond the social group is not fixed may help within therapeutic interactions as well as framing ongoing provider education (Hegarty et al., 2019; Pasterski, Mastroyannopoulou, Wright, Zucker, & Hughes, 2014). Hegarty et al. (2019) used video as an educational platform, framed either through a social or medical lens, with ninety-nine psychology students. They found the social identity themed video increased participants’ sense that intervention was more harmful; the medical video decreased their sense it was harmful. Neither video impacted stigmatizing beliefs about intersex people as a group. Whilst traditional medical approaches assume stigma is inevitable, the researchers found that people with less propensity to stigmatize are more open to learning new framings from personal experience videos.

As highlighted above, the complexity of mental health and wellbeing across the life course is influenced by a myriad of factors including; psychosocial influences - at individual and family levels, physical care and received diagnosis, nature of provider educational exposure, ethical frameworks, and stigma all of which inform individual and provider worldviews about intersex. This suggested, overall, a need for a Canadian study considering how mental health supports, that use a medicalization or a socialisation of intersex variations, may play a role in wellbeing at different age-related life stages for this population. While our study primarily focused on transitions in care in Canada, understanding mental health was perceived as a research gap by people with intersex variations across their whole lifespan.

Theory: Life-cycle Care Lens

In theorising transition for the present study reported on here, we were aware that transition-healthcare commonly focuses attention on *paediatric to adult transition*. This alone is not the panacea that ensures good outcomes for adults with intersex variations; it is only the starting point (Jones & Leonard, 2019). Transition is a dynamic and evolving area of study in that knowledge, capacity, and collaboration between all partners, i.e., individual, family as well as specialist and primary care providers, remains difficult (Leake, Koopmans & Sanders, 2020). However, the transition frame fails to address wholeness as *life-course* (Mezzich et al., 2016). One approach to address such complexity is to consider *person-centred approaches within medicine* (PCM) (Cassell, 2010). PCM reflects both health and educational needs in ways that can give agency to individuals in managing their healthcare. Furthermore, PCM is participatory in nature since patient-centred and integrated services, when equitable and informed, allow for individual agency and collaboration. Co-ordinating services around the needs of the population with intersex variations requires intersectoral action at the community level. It also requires improved care delivery through harmonizing guiding principles, evidence-based practice, and access to health and wellbeing education. Focusing on Canada, complications arise as linked to geographical factors such as the differences between urban and rural contexts provincially and nationally, and variance in population density. In addition, the lack of federal directive across provinces can weaken governance and accountability.

For individuals born with complex rare conditions such as intersex variations, understanding lifespan needs reflects the significance and interplay between early childhood events, survival into adulthood and old age as important factors in achieving long-term health outcomes. Longer life span approaches to self-management, and the burden of engaging with health care across a lifetime are shifting, with a need to “unlock community and individual resources for action” (WHO, 2016, pp. 5). A call for equity and integrated healthcare changes

the demand individuals with intersex variations have on health systems. This study focused on building understanding of service-user transition goals at three key intersex-life-cycle developmental stages broadly congruent with the development theory outlined by Erickson & Erickson (1997). These stages include:

- Young adulthood (19-30 years),
- Middle adulthood (30-50 years), and
- Maturity (50 years and older).

Understanding life course transition experiences for individuals with intersex variations at each stage of development is urgently needed to enable greater understanding of individual agency, transitional care topics, health literacy needs, and the role of health care in providing support to Canadians with intersex variations across their lifetime.

Methodology & Methods

Our purpose was to begin to understand what *Canadians with intersex variations* experienced as transition in care, synonymously with what *their healthcare providers* understood integrated intersex care to mean. We view living with intersex variations and engagement with health and mental health care, at present at least, as often interconnected phenomena given most people with intersex variations learn about their variations from professionals (Jones et al., 2016). Using a life-cycle care lens, a group of international researchers came together in a collaborative Canadian study to explore: the current nature of intersex transition services across Canada; if provincial provider or specialist medical societies or individuals adopted global standards or strategies to inform care delivery; and to listen to the immediate concerns individuals with intersex variations, or their caregivers, hold as linked to living with and responding to their own health needs while promoting their wellness behaviours.

The study took a community-driven, participatory action-orientated approach, recognizing community values and the rich knowledge individuals with intersex variations, their communities, and provider networks and teams hold. Both practical and experiential knowledge as a result of interactions and engagement between individuals with intersex variations and health and mental care providers can inform choice and decision-making and ability to enact self-care, hence a participatory approach was adopted in the study design. Cognizant that transition experiences and approaches to service models can be outside the scope of individual influence, providing the opportunity through action focused theory has the capacity to liberate the voice of those experiencing transitions in health and mental health care. Since individuals and providers within Canada have yet to be asked about intersex transition services, we had to consider how to reach marginalized groups in order to understand the influence of systems, process, and human experience.

We adopted a co-creation approach with providers and a community member which focused on stakeholder engagement processes in two provinces in Canada. Separate focus groups or one-to-one interviews, for individuals with intersex or their caregivers / providers, were planned. Focus group venues were purposefully chosen at community sites to avoid meeting in acute care settings. A choice of venues and times (morning, afternoon, or evening) were available for participants to sign up to attend and reimbursement, honoraria, and refreshments were provided. A wide range of open engagement approaches and recruitment campaigns, over an intense three month period, were used to reach out to both individuals and providers including: personal invitation to known providers, direct emails to key organisations, establishing a study website, mail shot to provider networks and speciality groups by team provider members, intersex specific support groups, community groups (i.e., LGBTQI2), patient-voices networks across British Columbia (BC), use of local radio adverts, use of social media platforms, and passive poster recruitment in acute care / community

settings. We sought to first learn from the focus groups or one-to-one interviews (offered as face to face or via the telephone) the key issues experienced as linked to intersex variations and transition health and mental health care. Thematic analysis (TA) was used with the transcribed verbatim outputs from the stakeholder focus groups and interviews (Clark, Braun & Hayfield 2015). Common codes and then themes were drawn out and examined in detail. Since TA allows for flexibility, interpretive coding, and encourages depth in thinking, coding was completed by the team using individual preferred software and /or annotation (Braun & Clarke 2014). Patterns in language and meaning were discussed and an inductive and iterative process ensued whereby much debate helped the team flow through the cyclical process of examining the data (Boyatzis, 1998).

This paper focuses on the theme of mental health and wellbeing with Canadian individuals with intersex variations as one outcome. Reporting while the study is ongoing was important for the team in light of the emerging themes. Therefore, a case study approach is adopted, from two participants - one individual in middle adulthood and one in the stage of maturity. Weaving these data together in the findings and labelling as colours, Orange and Purple – which are themselves a mix of primary colours – is aimed at protecting individual confidentiality. Excerpts are shared verbatim in order to illustrate impact and highlight metaphors of significance. Basic demographics, gender identification, and specific ages are not disclosed to maintain confidentiality.

Findings

From an ongoing Canadian Institute Health Research (CIHR) study, Ethics H19-01764 we identified two detailed and in-depth participant narratives from which we draw our current themes. Based on the aforementioned analysis methods, we found four major themes in the data from these participants with intersex variations on the topic of ‘mental health’. These included: ‘worthlessness’, ‘alienation’, ‘self-esteem’ and ‘emotional intelligence’. These

themes are addressed in the following sub-sections in their order of significance and reporting by the two participants.

Worthlessness

The pervasive and early theme for mental health for people with intersex variations in the data was worthlessness. Reporting a sense of worthlessness stemmed from experiences of insensitivity and feelings of powerlessness to change processes around them. Situating their historical narrative was important for both participants. Their experiences of what led to diminished self-value needed to be heard. The experience of discovery of variation in childhood was, for one participant, Orange, not the reason for a visit to the local rural physician for a check-up. This was *“related to some sexual abuse and anger but I was examined anyway, and my doctor was really shocked and thrilled to discover that I had a small penis”*. The physician connected with specialists to enquire about management and a decision was made for no intervention:

as long as everything was working okay, they were fine to just leave me alone and let me live my life.... he asked me if I felt more like a boy or a girl and at that point I just said girl cause that was what I was used to, but later thinking about it I didn't really see why I should have to choose at all.

The worthlessness around gender uncertainty or option to decide at an individual level was a memory that emerged again in young adulthood. For example, for Orange a further physical exam yielded similar curiosity with physicians, the decision for no intervention was chosen, with an awareness that health care follow-up later in life would be needed to support hormone levels and ensure wellbeing. As Orange noted *“I wasn't really thrilled to be doing this. And I never did do it. I just figured I would not possibly live that long, that seemed like forever [my fifties]”*. The participant navigated their life course with few encounters with health and mental health care until the stage of maturity, returning to seek medical care only to be *“stonewalled”* when:

attempting to get everything sorted..... the first doctor I went to see burst out laughing and said there's no such thing as intersex....he didn't put any of this in writing in his chart forms, he just made, [well] cast dispersions on my mental health.

Having left this encounter feeling humiliated and de-humanized, the need to seek formal professional medical and psychological notes became important as evidence of the historical narrative.

Worthlessness was also attached to the body, or its parts, that were cast by health and mental health professionals as too inadequate or too small. This was illustrated for example, Purple said:

I was told that it [my gonad] was removed because it was too small. In fact, the surgeon took it upon himself to show me the testicle in a glass vial which is one of the most distressing, the most distressing event that I've ever had in my life.

While Orange similarly offered; “[the doctors said] you must have some kind of congenital malformation, and a penis has to be of a certain size to count”. Such negative experiences elicited feelings of shame in childhood and early adulthood for participants with intersex variations.

Alienation

The second persistent theme reported across both narratives was alienation. Both participants reported that a sense of alienation arose from frequently feeling alone and unheard in health and mental health related engagements. The need to be believed, heard, treated with compassion, and kindness are not unreasonable requests in the patient-doctor dyad. When there was tension within the dialogue emotions resulted in frustration and anger. For Orange, two providers, both with increasing intensity, “disputed my claim that I could be 46xx, 46xy, which is what I was told I was. Because I didn't have any major health problems”. Such a position, argued by the individual as discordant with their knowledge from childhood, went

unheard. Resulting documentation shared with the participant's primary care provider was distressing since it undermined their sense of self "*[I felt the letter said I] couldn't possibly be who I said I was*". Indeed, the letter cited that the participant was "*[having] a mental health issue which made it totally impossible to get healthcare*" for the presenting urological and hormonal problems for which they had sought medical specialist advice. Left in physical pain the participant had to make a decision about how to find physical and emotional support. The participant found they acquired a new 'label' linked to a mental health diagnosis when the primary request had been "*asking to access services for menopause and andropause*". This resulted in an estrangement from medical care since the medical community had "*flatly refused to acknowledge or recognize or investigate any ways in which I knew that I was different and wanted care for.*"

Feeling alone was also connected to the absence of conversations with family members or providers as described by Purple:

one of the problems [was] that there weren't any conversations about it either between myself and healthcare providers or with my parents my parents felt guilty about what happened [surgery] and didn't feel like talking about it. And I felt a huge sense of shame about not being a normal body.

Such uncertainty and difficulty in having conversations lasted for two decades until eventually the participant experienced "*a breakdown*" which "*finally [resulted in] conversations with my parents and [I] found out about these different stories that we'd been told [about surgery]*". This participant noted that interactions with mental health services during phases of crisis resulted in a:

standard psychiatric diagnosis I described, about the operations and I think it would've been pretty obvious to the psychiatrist that the trauma that I was experiencing was PTSD from these childhood operations [but no]. So once again I was put in a box and not a box that recognized any of those manifestoes of my development.

It was in this stage of early middle-adulthood that the participant first heard of the term intersex. Meeting others, at a national intersex meeting, came later with a sense of

nervousness about being *worthy*, “*am I intersex enough will I be accepted part of the group*” (Purple). While the participant was accepted by the intersex community, leaving to travel home resulted in a feeling of “*isolation*”.

Self-esteem

A third theme that arose was self-esteem with both participants with intersex variations questioning their body integrity and self-doubt. The impact of emotions, how they drove self-interpretation and questioned self-belief and self-narrative influenced bodily integrity challenging the right to harmony and balance across levels of existence as described by one participant:

I was just in a really critical emergence period at that time, really beginning to admit and acknowledge who I was because I'd just forgotten for many years because I claimed one sexual identity and forgot about the other side of myself, it was really traumatizing and harrowing.

This respondent, Orange, continued to explain that:

It was really a triggering experience and it just kept on over and over and over, every time I went to a doctor, to be given this pushback refusing to give me any credit as a sole expert and observer on me, when it worked and didn't work.... its impossible to pursue my primary care needs (be)cause that's made impossible to get any mental health care for the trauma that they themselves were putting me through.

The developmental stage of either middle-adulthood or maturity allowed participants time to reflect on how struggles with body-integrity may have been better supported from a psychosocial perspective instead of a medical one. This was described clearly by Purple:

what I reflect upon is the gap between the care of the body and the care of the mind I think could've really benefited, certainly as an early teen, from some counselling around what happened. Any place where I could've gone to talk would've helped with dealing with the shame that I felt.

While the emotional labour is evident in these three themes what came to light through the analysis was the resilience. Often the reconciliatory ways in which harmony between sense of self, mind, body, and spirit are achieved can be lost or hidden in stories that are situated in narratives of trauma. The final theme is purposefully focused on the ways in which

emancipatory knowing – within and about self – continues to shape these two participants lives across their lifespan.

Emotional intelligence

A final theme of note in relation to mental health care for people with intersex variations was emotional intelligence. This was constructed by both participants in a specific and uplifting way: emotional intelligence was framed in terms of being a pathway to healing. After encounters with health care providers, participants took time to think carefully about health care and the impact such ongoing criticism or rejection reflected onto-self was causing further emotional injury. At a certain point in time, a sense of self-awareness enabled both participants to consider that the health care providers were perhaps using criticism as a primitive defence mechanism when their knowledge, opinion, or approach was questioned by a ‘patient’. For example, Orange said there was a *shift*:

[I am] not pursuing it [doctors] anymore out of a place of anger, victimization or feeling like I've been sucker-punched because I realize, as I have most of my life, that I really don't need them..... my health has always been absolutely fantastic and despite my condition which, I think is improving vastly, I actually feel better than I have in decades.

This participant went on to describe in detail the ways in which integrative approaches, complementary medicine and attention to their own mental wellness were liberated:

What's working well for me....yoga, meditation, doing mood calming. I've really had to learn how to quickly go from an over threshold state to bring myself back down. It wasn't good for me to always be in a state of panic or rage....[Looking at] what long buried issues that rise to the surface, I can see them more easily and deal with them. My own sort of visualization practice using like shamanic drumming. Bio magnetic care therapy, that's been absolutely fantastic for improving my general health overall.

Ruminating on the past encounters with health care providers with a view to ‘what ifs’ appeared to have mainly resulted in increased stress and anxiety for participants. This fuelled chronic worry which in turn impacted the participants mental health and wellness. However, both energy and enthusiasm towards ‘self’ could arise when new ways of expression were found as described by Purple:

I processed the pain, pain and the shame by writing and I got....so that's been, that's really helped. [By] breaking the silence and being able to find a way of expressing what had happened and putting it in context. And I'm still on that healing journey.

Visualization was also important for this participant as they reflected:

The main connections between the geography of the place where I had a breakdown and my body sort of mapping, as if I was unconsciously mapping my body using the geography of the towns [helped me to understand the] unconscious divide between the left and right side of my body which I've tended to.... differently.

The work of making connections between the body and the natural environment and nature, appeared fruitful in developing the capacity to help individuals see their body as a whole.

Discussion

We acknowledge that the study is ongoing, and we are reporting on one early theme. Data generated from the focus group interviews and interviews to-date warranted examination, considering the limited Canadian intersex narratives. This early reporting offers important insights into Canadians with intersex variations' experiences of health and mental health care that is currently absent in the literature.

Significantly, the data showed the impact, influence, and repercussions mental health had across the lifespan for individuals with intersex variation. Our Canadian data reflected the international findings in Europe and Australia around the prevalence of negative emotions particularly in the discovery and early life stage conceptualisations of intersex variations; where alternative affirming views or information are not provided by professionals (Jones et al., 2016; Hegarty, Smith, & Bogan-Carey, 2019; Lux et al., 2009). This related to the higher rates of internalizing symptoms i.e., anxiety and depression seen in international statistical samples of people with intersex variations (Godfrey, 2020). However, Godfrey raises caution in anticipating mental health diagnosis as a matter of course for all individuals with intersex variations, since more than a third of studies reviewed showed no statistical significance, and adoption of screening measures varies (2020, p. 13). Furthermore, difficulty exists because of

epistemological and methodological differences between different disciplinary approaches to mental health studies with individuals with intersex variation (D'Alberton et al., 2018). While necessary to broaden the scope of knowledge and deepen understanding across multiple domains, i.e., professions, social policy, justice and ethics, attention must be paid to the gap between theory and praxis.

In our current data, emotional and psychosocial support, individualized to the patient need and framed through a trauma informed lens appeared to be what both participants hoped for, within their health care interactions. This resonates with a patient-centred approach to care whereby medicine's distorted view of variation as disordered needs to be replaced from a position of emancipation, equity, and social justice (Holmes, 2009; Mezzich et al., 2016). A word of caution is needed since patient-centred has been linked to consumer citizenship from a position of 'choice' and expectations within medical engagement and discourse (Grabham, 2007). This dominant medical narrative or 'gaze' as described in detail by Danon (2019) is being challenged by activists, advocates, researchers, and supporters lobbying for a vibrant and audible patient-centred voice that allows individuals to live well, be treated with respect, kindness and compassion.

Our participants emphasised the lack of mental health care interventions and the strong potential for such interventions to have been useful at earlier points of transition into and out of health care. Until recently, much of the literature pertaining to medicalization, care, and outcome for those with intersex variation was paediatric centric (Cools et al., 2018). While psychological support may be commonplace in paediatric interdisciplinary teams, access across the life course is problematic, despite calls to action to address this (Liao & Simmonds, 2014; Roen & Pasterski, 2013). Presently, the loss of emotional support at a critical time in young adulthood and negative medical experiences at times of key transitions in adulthood, there is a risk that individuals with intersex variations will continue to feel

ignored, mis-diagnosed, and medicated. These missed opportunities to listen to those asking for timely mental health support must be noticed to support individuals with intersex variations to flourish across their lifespan.

Similar to Thyen et al.'s (2014) study, our participants, at times, experienced episodes of low-quality specialist medical care. Experiences of judgmental statements and disharmony in the individual-provider relationship led to dissatisfaction and frustration, which in combination impacted psychological wellbeing. Considering these emotions through a broader contextual lens, we heard characteristics of trauma. Disregard for the patient voice does not promote trauma-informed practices. Similar to Morland (2011) the deficit is not with the individual with intersex variation but within our health systems which are 'traumatic by design', resulting in reduced or even absent individual agency within health and mental health care interactions. Accounts of trauma are linked to physiological and stigmatizing narratives within the literature surrounding intersex variation (Ginicola, 2017; InterACT; Lev, 2006; MacKenzie et al., 2009; Malouf et al., 2010). However, what is more apparent is that across the lifespan, the risk in continuing to retraumatize individuals with intersex variations through actions, decision making (Steers, 2020) and language (Bennecke et al. 2020) remain.

In line with developmental theory, integrity and wisdom are a key aspect of reaching the stage of maturity (Erikson & Erikson, 1997). We heard this as appreciation of life and embodied experiences in these individual's with intersex variation. Developing competency in identifying, processing and regulating emotions was reported by both participants and themed as emotional intelligence. While these skills developed with maturity and becoming 'wise', a key stage in the developmental process, the adaptive benefits of social supports and networks was important. The significance of peer support is well documented in the literature (Lee et al., 2020; Jones, 2016). Here the significance included overcoming the hesitation to

engage, learning about integrative medicine, and celebrating the liberating affect knowledge, connection, and community had on resilience, coping, and mental health. As such, this study highlighted the positive potential for mental health care, which focuses on building emotional intelligence. Specifically, therapeutic work done on the experiencing and finally the letting go of the rumination process over ‘what ifs’ was important for working through trauma. Therapy done around the body and its relations to nature and its ‘naturalness’, and visualisations, particularly appeared useful in understanding and moving forward in self-conceptualisation and some of the issues identified around the theme of self-esteem. This reflects other international data on both stigma and online social groups, which showed that it was important for people with intersex variations to go through a process of reframing their intersex variations and bodies in more positive ways (Hegerty et al., 2019; Holmes, 2017). In recent years, work has been done to break down old medical practices regarding individuals with intersex variations and to honour the voices and stories of these individuals. However, at this point, Canadian individuals with intersex variations have been largely left out of the conversation, especially when it comes to their mental health needs and wants.

Conclusion

This study suggests people with intersex variations want (1) affirming mental health supports at the right life and transition stages; (2) trauma-informed and/or person-centred healthcare systems; and (3) access to integrated medicine. Particularly:

- In transitions around Young Adulthood (19-30 years), participants needed: *to feel worthy, gather knowledge about their body, and feel validated when seeking advice.*
- In Middle Adulthood (30-50 years), risk reduction was linked to: *value and feelings of worth, managing and overcoming feelings of isolation, working towards a sense of*

self-esteem, exploring new approaches to health care and building an individual framework to promote mental wellness.

- Finally, around Maturity (50 years and older): *self-wisdom and awareness supported individual emotional intelligence to flourish.*

In Canada, whilst there is currently a range of barriers in place to a systematic and widespread provision of such mental health care on location, an important next step in mental health care for people with intersex variations could look at the opportunities to build up such mental health care. Approaches include a focus on transparent peer-to-peer networks, establishing best practice standards from a position of collaborative partnership between individuals with sex variation and health and mental health providers, and exploring the feasibility of online services to promote equity in access to care. Canada is well placed to learn lessons from the global intersex variations literature; with federal and provincial creativity perhaps now is the time to address health and mental health care with this population.

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