

Student Article: Hearing their voices, acknowledging their pain: Intersex 'treatment' experiences and the impact on self.

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I am a Massage Therapist working in private practice in Wellington and enrolled in the PGDipHealSc programme, endorsed in Pain and Pain Management, at the University of Otago. I developed an interest in learning about pain several years ago, after starting to see more people with chronic pain at my clinic. After completing my postgraduate diploma I intend to enrol in the Master's programme. The following is an overview of a piece of academic work I submitted for the Psychosocial and Cultural Aspects of Pain paper I completed in 2020. I want to explore this area in greater depth in my Master's thesis. I also co-edit *Massage NZ Magazine*.

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Background

This is a story of the right to bodily integrity, of identity (and loss), of decisions made about gender and what is 'normal' that have far reaching consequences on physical and psychosocial wellbeing, and the impact of pain on self. It is also a story of the need for change and acceptance, for inclusive, culturally safe and person-centred care. My clinical work with an intersex client prompted me to want to develop a greater understanding and awareness of how childhood experiences of 'gender-normalising' surgical interventions may influence one's lived experience of chronic pain as an adult.

The term *intersex* is an umbrella term referring to normal variations of biological and/or physical sex characteristics. Variations can affect external and internal genitals, hormonal and/or chromosome patterns.¹ There are at least 40 different variations and most are genetically determined.² Examples include Complete Androgen Insensitivity Syndrome (CAIS), Swyer Syndrome which is a form of Gonadal Dysgenesis, Congenital Adrenal Hyperplasia (CAH) and Klinefelter Syndrome. Such variations are present in around 1.7% of the population.⁴ This is similar to the prevalence rate for those born with red hair.⁵ Based on this, we might estimate numbers to be around 85,000 live births in Aotearoa/New Zealand; however, because of issues related to consistency in the recording of differences of sex development, including what is recorded and when, it would not be a reliable assumption and in fact Mitchell⁶ notes that prevalence figures are not kept in New Zealand.

Old terminology included the terms *hermaphrodite* and *pseudohermaphrodite*^{7,8} which are offensive to intersex people. Newer terms include *diverse sex development and differences of sex development* and for some the preference is to use the name of the specific diagnosis.³ Such variations in children have, since the mid-20th century, been treated under a model developed by John Money, which became known as the ‘Money Protocol’.^{7,9-11} Money was a New Zealand psychologist working at Johns Hopkins University in the 1950s and 1960s. His theories on gender identity and nurture over nature proposed that children with variations of sex be ‘fixed’ through what has been termed ‘*gender-normalising surgery*’, which often involves the removal or reshaping of external and/or internal genitalia to make a child’s appearance conform to binary gender stereotypes. Surgery, combined with ongoing hormone treatment and child-rearing that reinforced the ‘assigned’ gender, was believed to create a ‘normal’ and stable gender and sexual identity. It is worth noting that similarities between gender-normalising surgery and female genital mutilation (FGM) practices have been drawn.⁹

According to anecdotal evidence and lived experience accounts, outcomes of gender normalising surgery are poor, with the effects of childhood surgeries often resulting in chronic pain.^{7,12} A major problem is the lack of unbiased and rigorous studies on long-term outcomes including psychosocial outcomes for intersex people^{7,11-13} and many studies exclude any form of patient satisfaction as an outcome measure.¹⁴ Many intersex advocacy and support groups strongly advise against surgery until puberty, when the person can give their full informed consent, unless surgery is needed for lifesaving reasons. This view is starting to appear in some medical literature.¹⁴ A review of literature and documentaries on the subject, combined with interviews I carried out with two intersex people, led to several key themes emerging. Borrowing from concepts of thematic analysis, I explored these themes which gave rise to questions highlighting what needs to change in healthcare and professional practice. From there I offer suggestions for how this could be done.

Participants

Mani Mitchell (they/them), age 68, is Executive Director of the Intersex Trust Aotearoa New Zealand (ITANZ), an educator, counsellor and change agent in this area. Georgia Andrews (she/her), age 28, is active in LGBTQI+ rights.

Emerging themes

• Secrecy and shame

Often diagnostic and surgical information has been withheld by clinicians.¹⁴ Parents have often been told to conceal information from intersex children, which reinforces a sense of shame and guilt within the family.^{10,12,15,16} Children grow up with a sense of shame and humiliation about their bodies, harbouring a sense of being different that must be hidden.¹⁷ These views are often reinforced by attitudes of health professionals and practices such as medical photography, teaching rounds, unnecessary observations and examinations^{6,12,18} that removes the intersex person’s bodily autonomy.¹⁶ The result is that, as children, intersex people may learn to keep pain experiences to themselves.

“I had the first surgery when I was age one – laparotomy – I have no memory (adult recall) of that surgery – what I am aware of, a developing awareness and fear of that huge scar – it was a symbol of that ‘thing’ that could not be talked about.... I was very self-conscious of that scar... of trying to hide it. When I did try and talk to Mum about it – she said to tell people it was an appendix scar.” (Mani,68)

Question: What might this mean for intersex people with chronic pain needing to access health care? If they have grown up with a sense of shame about their diagnosis and treatment, and been subjected to further shaming from gender-biased or uninformed health professionals, how might this impact their capacity to feel safe and have their needs met without fear of humiliation or discrimination?

• “Fixing a problem”

A common theme in the literature is the idea that intersex people’s bodies are not ‘normal’ so must be ‘fixed’ to fit the binary stereotype and solve the ‘problem’.¹⁶ However, this pathologizes variations of sex. Often more surgeries are needed to correct problems created from the initial procedures. Adverse physical and psychosocial outcomes include: chronic pain, scarring and contractures, urinary problems, the need for ongoing hormone replacement therapy, impaired sexual function and sensation, loss of reproductive function, relationship difficulties and enduring trauma and mental suffering.⁹⁻¹²

“My next surgery was age 8 – that was the so called normalising surgery to make my body, which had NOTHING wrong with it – look more like what society considers ‘female’ bodies should look like... The surgery left me with a genital area that looks more ‘normal’

superficially... there are lots of scars... and – the surgeon was skilful – however, the area does not work normally – I cannot experience ‘normal sex’ – I sometimes experience very deep and out of the blue nerve pain.” (Mani)

Question: If children’s bodies are surgically altered to fit an idea of what constitutes normal, what might this mean for trauma-related pain when a person is constantly reminded of those past experiences?

- **Trauma and central sensitisation**

Post-traumatic stress disorder (PTSD) is a commonly discussed outcome of childhood normalising surgery. Literature mentions experiences such as non-consensual physical examinations of genitalia, invasive procedures and medical observations having similarities with characteristics of child sexual abuse – traumatic experiences that have led to PTSD.¹⁴ In studies on paediatric medical trauma, figures for children developing PTSD symptoms range from 10-30%.^{19,20}

Research indicates those with PTSD have an increased risk of chronic pain conditions and the more traumas a person has, the bigger the impact on their physical wellbeing.²¹ Links have been made between central sensitisation (CS), PTSD and environmental stressors,^{22,23} including stress related to childhood trauma.²⁴

I was interested to know if CS might be a factor for intersex people who had traumatic medical experiences as children, and as adults now experience chronic pain. In a recent study looking at the relationship between trauma exposure, PTSD symptoms and CS, McKernan et al.²³ noted that as trauma exposure increases, patients experience greater CS (widespread pain, pain intensity, and polysomatic complaints) and that PTSD symptoms account for a substantial portion of the link between traumatic experiences and CS. To look at this, I had Mani and Georgia fill out the Central Sensitisation Inventory and interestingly both had scores in the severe range. While this represents a tiny sample, it would be interesting to know if this is common among a larger group of intersex people.

“Physical examinations with the gynaecologist and endocrinologist. At age 16, not been in a relationship, never had intimate exams before and I was not familiar with my own body. My first intimate experiences were on the examination table in clinical settings with these professionals.I developed a stress response to touch from examinations. I would dissociate during medical examinations.” (Georgia, 28)

“I have always dissociated – been disconnected from that part of my body (genital area) and while I have done lots of work on ‘returning’, feeling okay – this area still remains ‘tight’ the muscles often painful to touch.” (Mani)

Question: Could it be valuable to consider CS/PTSD when working with intersex clients with chronic pain?

- **Words and treatment encounters as nocebo**

Words and rituals in therapeutic encounters have been shown to impact both the patient’s brain and treatment outcomes resulting in placebo or nocebo effects. Negative verbal suggestion may result in worsening performance and reinforce unpleasant symptoms. A study of surgeons and anaesthetists²⁵ found that the nocebo phenomenon frequently occurred in doctor-patient communication (verbal and non-verbal); reinforcing unpleasant symptoms such as pain, fear, apprehension and nausea in their patients.

The context that healthcare takes place in also cannot be underestimated in terms of how it affects therapeutic effectiveness. Factors including: patient-clinician relationship; clinician beliefs, behaviour and communication style; patient beliefs, expectations and previous experiences; treatment features such as nature of the encounter, type of touch and level of invasiveness; and treatment setting including the physical environment, accessibility, inclusiveness and staff approachability – all influence patient outcomes.²⁶ If health professionals do not have sufficient experience or understanding of intersexuality and their beliefs and biases negatively influence how they interact with intersex patients, might this affect therapeutic outcomes? Research looking at the lived experiences of intersex people in Israel appears to support this.¹⁸

“I was told I was not a ‘normal’ female” (Georgia)

Question: Could factors such as past treatment encounters, the reinforcement of shame and secrecy, the use of negative words in therapeutic settings and the lack of clinician knowledge be nocebic factors for intersex people seeking treatment for chronic pain?

- **Feeling unsafe**

Studies on lesbian, gay, bisexual, trans, queer and intersex (LGBTQI) people highlight discrimination, health inequalities and barriers to accessing healthcare as a reality. Minority stress and heteronormativity impact mental and physical health outcomes.^{27,28} Examples include negative interactions with health

professionals, long appointment wait times, and systems that promote non-binary exclusion. A New Zealand report, 'Counting Ourselves: the health and wellbeing of trans and non-binary people in Aotearoa New Zealand'²⁹ showed that 36% of participants avoided seeing a doctor out of fear of disrespect or mistreatment, and 13% had been asked invasive or unnecessary questions about being trans or non-binary, unrelated to their reason for seeking healthcare.

As a result of their treatment experiences, intersex people may feel unsafe and have difficulties trusting health professionals. This might impact their capacity to seek treatment when needed, which can have further health consequences.

"I don't want to get an ultrasound in (location specified) now.... I had to have a D and C surgery, I had to go to Auckland for this because the specialists there are more understanding and knowledgeable... It's disruptive having to go elsewhere, also costly." (Georgia)

This raises the issue of cultural competence and safety, which are increasingly being discussed in the health sector. Cultural safety addresses clinician-patient power imbalances, promotes critical self-reflection, encourages acceptance of diversity, promotes patient autonomy and focuses on equity.³⁰ Aspects we might consider important for intersex people seeking healthcare. The New Zealand Medical Council notes that cultural safety has benefits for

people across multiple cultural dimensions, including gender; however, there are no established universal standards to ensure consistency of cultural competence across professions in New Zealand/Aotearoa.

Question: What might these negative experiences mean for intersex people when trying to find health professionals who provide affirming, culturally safe trauma-informed healthcare?

- **What my pain means**

The latest International Association for the Study of Pain (IASP) definition of pain acknowledges that pain is personal, shaped by biopsychosocial factors and that a person's lived pain experience should always be respected. Pain means different things to all of us. It is multifactorial, influenced by beliefs, attitudes, past experiences, expectations, culture and biology. The reflections shared by Mani and Georgia echo the reality that many intersex people live with. The result of a medical approach that still pathologises variation and (re)constructs children to fit in a binary paradigm.

"I think it's complex and layered" (Mani)

"... Pain gives awareness of my body, pulls me back to grounding" (Georgia)

Drawing these strands together, we can see the pain experiences of intersex people as a dynamic interaction of multiple elements. I offer up a possible way of looking at these in figure 1.

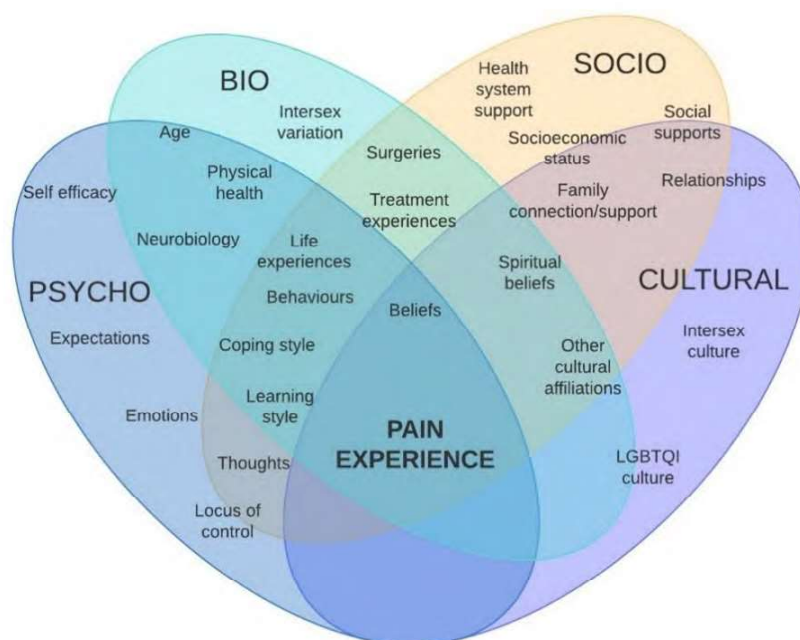


Figure 1. A biopsychosociocultural model of intersex people's pain experiences

What needs to change?

Several points have emerged from my exploration.

- The dominant medical narrative needs to shift from heteronormative to one that accepts variations of sex as normal. Surgeries that alter sex characteristics of infants, children and adolescents without full informed consent of the individual should end.
- Course curricula in medical and allied health professional training need to include more information on sex variation and gender inclusion at undergraduate level. Continuing professional development requirements laid out by our professional bodies also need to ensure this is part of best practice and cultural safety.
- Organisations need to remove barriers to healthcare for intersex people at service level. Record-keeping systems should allow people to self-identify and physical environments should be more inclusive and accepting of diversity. An excellent example where this happens in Aotearoa/New Zealand is the Physio Spot model implemented by Willis Street Physiotherapy in Wellington.³¹
- At the practitioner level, we need to do several things. Be mindful of our language - watching our biases and being aware of our own beliefs and cultural views. Avoid unnecessary and probing questions during history-taking and avoid making assumptions about someone's gender based on their appearance. Instead, ask them how they identify and prefer to be addressed (i.e., they/ them, she/her, he/him). Be clear with intersex clients about what will happen during treatment. Always gain informed consent, especially when touching the client in any area that may trigger traumatic memories. A shared-decision making approach gives the power back to the client, focusing on their goals; crucial for intersex people who have experienced a lack of bodily ownership and trauma.^{3,16} Providing compassionate and trauma-informed care helps build trust and foster therapeutic alliance. Taking a biopsychosocial perspective in treatment should be the gold standard as it acknowledges the multifactorial nature of a person's pain. The over-arching approach throughout the health system should be patient-centred informed care.
- Finally, more research looking at the outcomes of childhood gender normalising surgery on adults needs to be done. This will help health professionals better understand the psychosocial impact it has on intersex people in terms of chronic pain, raise awareness of the issues and achieve greater leverage for change across the healthcare sector.

I end with a quote from Davidian^{9(p21)}, "We need to acknowledge these voices, to recognise the bodies that have been normalised as sites of lived experience, and take into account what that lived experience means."

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