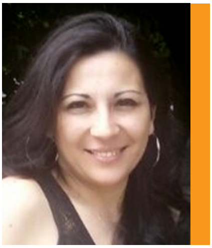
SECTION 7.2



Michelle Cilia

TITLE

The Current Situation of Intersex Persons in Malta: Shifting away from the Medical Paradigm towards Social Justice.

AIM AND BACKGROUND OF THE STUDY

An intersex person is born with physiological variation/s in the reproductive and sexual characteristics that typically fit within the archetypal normative male-female classification of human anatomy. These include people with atypical external or internal reproductive organs and/or having different sex chromosomes or hormones, which may be either apparent at birth or else manifest themselves later in life, usually around time of puberty.

Traditionally, intersex persons' management was based on a concealment-centred medical model, comprising of a range of medical and surgical procedures aimed at immediate reconstruction of the perceived anatomical abnormality. Hence, medical personnel advocated these non-therapeutic interventions as corrective measures required to achieve cosmetic and aesthetic alignment with the normative sex binary. It was not until the early 1990s that activists, through international networking and political lobbying, heightened public and professional consciousness and stirred discussion. The provision of new knowledge exposed the lived experiences of intersex persons who underwent these traditional unconsented normalisation medical and surgical procedures at a young age. Apart from enduring a series of physical and sexual irreversible negative short and long-term consequences, the overarching reality of these testimonies was a deep sense of humiliation, violation of their person and intense psychological scarring. Other issues unveiled by these lived testimonials included the authenticity of the parental informed consent; the realm of deceitful information giving; difficulties faced when attempting to access one's childhood medical records; stigmatization and secrecy of the experience; as well as the rejection of the sex assigned at birth.

In light of this new data, the traditional medical approach has been questioned on bases of human rights, ethical issues, and psychological and physical abuse. On a global level, there is currently exponential awareness calling for the movement away from the physical aspects of diagnosis and alternatively look at the realm of intersex in all its complexity. The way forward proposed is a person-centred social model that views intersex conditions as merely an anatomical variation, and not a medical problem. This paradigm shift emphasizes on the discontinuation of conventional practices of uninformed, non-consensual, unnecessary, irreversible sex-altering medical interventions and treatment. It focuses on truthful information giving and informed choices, the provision of interdisciplinary psychosocial support and counselling, full access to medical records, legislative changes and increased societal awareness.

In March 2015, Malta was the first nation to outlaw unnecessary normalization procedures on intersex babies, in the passage of the Gender Identity, Gender Expression and Sex Characteristics (GIGESC) Act. This Act also implies that an interdisciplinary team will be appointed to ensure decision-making is based on the child's best interests, as well as a working group to review the existing medical treatment protocols. Moreover, this legislation states that expert psychosocial support should initiate from time of the child's diagnosis and extended as required**.** Apart from medical aspects of the intersex persons' management, this law furthermore allows parents to postpone the inclusion of a sex marker on the birth certificate until gender identity is determined and includes simplification of administrative procedures to amend gender identity, if necessary.

Despite having such progressive law in place, locally, the topic of intersex is quite novel and intersex persons' experiences are still hardly ever heard of. Moreover, no studies were previously carried out to explore this issue within the Maltese society. In view of this, this small-scale qualitative study aimed to yield practical knowledge regarding the current paradigm and to increase further understanding and dialogue about the situation of intersex persons' management in Malta, following such historical legal reform.

METHODOLOGY

Data was obtained through six in-depth face-to-face audio-recorded semi-structured interviews. A self-constructed interview guide comprising of set of open-ended guided questions was used to steer the conversation and frame discussion. Expert sampling method was employed to recruit with six experts from the local medical and social field, whilst thematic analysis was employed to analyse the raw data.

KEY FINDINGS

One overarching theme emerged being '*In limbo*'. A number of intertwined concepts emerged from this main theme and these were further classified under four sub-themes and their respective sub-headings, as per table below.

Table: Theme, sub-themes & sub-headings

In Limbo	1. Being Invisible	In the Abstract In Absentia In Hiding
	2. Being in Between	Inconceivable Indistinct In Evolution
	3. Being in Divergence	In Variation to In Deviation from In Silos
	4. Being in Suspense	In Stasis Indeterminate In a Vacuum

Primarily, this study brought into light the fact that intersex is not an abstract concept or simply a rare physiological condition in isolation. Indeed, it is a tangible, multi-dimensional, emotionally and socially challenging lived experience of human-beings and their loved ones. A two-sexed selective cultural context left this cohort of people in hiding, shrouding this experience with secrecy, stigma and shame. Locally, this social invisibility reflects in the lack of existing data indicating prevalence, the nil contribution from intersex persons in the legislative development process, and the challenges faced by health care professionals who have direct contact with these persons and their families in relation to confidentiality and data protection issues.

Moreover, this study revealed that a major challenge faced by intersex persons and their families is that of being in-between the two opposing and extreme poles of biological determinism. It put into light the social, practical and psychological struggles which may be experienced when an intersex child is born in a rigid two sexed culture, which may often render the concept of gender neutrality to become an idealistic notion. Findings also showed that two divergent perspectives -of whether intersex is a merely a normal variation to, or an abnormal deviation from, the standard biological norm- affect how arguments are positioned and as such, influence decision-making.

In addition, findings of this study put into light the urgent need for the appointment of the interdisciplinary team and working group, as required by the new legislation, so that this law is transferred from paper into practice. It also identified a gap between different bodies who are currently working in silos with no reciprocity.

CONCLUSION

In order to put this new law into motion, this study recommended a collective effort by all stakeholders so as to break down barriers – by moving away from their diverse standpoints and keeping the holistic needs of the growing child as the focal point at all times. Further recommendations for practice and research were put forward, which included measures to eradicate silence and increase visibility of intersex persons both in research and in society, as well as the importance of conveying optimistic messages in support provision.

Ultimately, it was concluded that legal change cannot occur in a vacuum. It requires a broader social and cultural shift. Hence, it was advocated that in order for intersex persons to fully embrace their fundamental rights, humankind must strive to eradicate heteronormative, divisive, conventional norms. This will only happen when society moves beyond the gender binary-becoming a society that truly accepts diversity of any kind.