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Ageing in obscurity: a critical literature review regarding older intersex people

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Abstract: *Intersex people experience a range of human rights abuses, including non-consensual, irreversible medical interventions on minors. These abuses have lifelong effects, yet little is known about older intersex people. People in this diverse group face multiple marginalisations and erasures across different policy and practice arenas. This article reviews literature about intersex issues, drawing out materials relevant to older intersex people using an historically grounded approach. It focuses on the key issues affecting older intersex people living in a range of countries in the global North, as harmful medical practices originated in this region. Based on existing evidence, we found a pressing need for medical reform including a cessation of harmful medical practices and the development of appropriate healthcare that centres the needs and wishes of each intersex person. As intersex issues are currently heavily erased in most countries, research, cross-sectoral policy and practice work, and awareness-raising are all needed.* DOI: [10.1080/26410397.2022.2136027](https://doi.org/10.1080/26410397.2022.2136027)

Keywords: ageing, intersex, healthcare, ethics, sex, gender, medicine, human rights, culture

Introduction and background

Intersex is an umbrella term used to describe a variety of sex characteristics that fall outside accepted binary notions of male and female bodies. Some traits are visible at birth while others are not apparent until puberty.¹ In the mid-1950s, Dr John Money theorised that children born with ambiguous genitalia could be successfully raised in whatever gender they were assigned.² Money's theory, embraced by medical professionals, led to procedures being performed to enforce sex binaries on intersex infants worldwide. This went largely unchallenged until the 1990s.³ As intersex conditions are generally associated with and considered only in relation to paediatric care, little is understood about the needs of the intersex person throughout the remainder of their life into old age.^{4,5} The paucity of literature relating to older intersex people³ illustrates how intersex variations are often relegated to paediatric urology and endocrinology and then seemingly forgotten about. Existing literature often includes only a handful of intersex participants.⁶⁻⁸ The oldest of the children operated on under the guidelines of Dr John Money are in their mid-sixties today.

Breaches of intersex peoples' human rights are well-documented.^{9,10} Violations include "... forced and coercive medical interventions... [lack of] legal recognition, and access to justice" (p.13).¹¹ Within most countries in the global North, irreversible and medically unnecessary procedures on children with variations of sex characteristics continue, with outcomes often reported as being poor and/or damaging.^{12,13} Bauer et al.¹⁴ argue that non-consensual, unnecessary, irreversible childhood intersex medical interventions form serious human rights abuses and are cultural practices comparable to female genital mutilation and torture. At an international level, a raft of human rights proclamations by UN Committees, the Council of Europe, and other bodies – driven by the work of intersex human rights defenders – increasingly argue against genital surgery on minors too young to give consent, and other ethically problematic procedures such as coercive sterilisation, experimental treatment, and traumatising medical examinations.¹¹ However, there is a dearth of analysis concerning the sexual, reproductive, and other human rights of older intersex people specifically, and a lack of

consideration of policy and practice issues. The sparse literature that exists indicates that levels of disability may be higher amongst older intersex people than amongst the general populace.⁵ Under the American Disabilities Act,¹⁵ “disability” refers to a physical or mental impairment that substantially limits one or more major life functions, including, but not limited to, reproductive functions. Intersex people who have been rendered infertile or left with sexual difficulties through medical interventions should therefore qualify as disabled.

The article aims to provide a critical review of existing literature from the global North, exploring concerns that older intersex people might face as they head into old age. The lead author is an older intersex scholar, and the second author is an older non-intersex person. It should be noted that intersex people are highly diverse and that not everyone uses the term “intersex”. The term “variations of sex characteristics” is an alternative, or Differences or Disorders of Sex Development (“DSD”) (which is widely rejected due to pathologising connotations) or indeed variation-specific terms. We use the term “intersex” in this article, and we define older people as those aged 50 and above. Readers need to be aware that whilst we focus on the impacts of historic violations of human rights, these breaches continue to take place in the majority of countries internationally.^{10,11}

Methods

A literature search was undertaken by the main author, using library databases and Google Scholar. The dates covered were 2000–2021 and the following keywords were used to identify potentially useful articles: *intersex*, *DSD*, *Differences of Sex Development*, *Disorders of Sex Development*, as well as *ageing*, *disability*, *community*, *health-care*, *housing*, and *discrimination*. Because of the paucity of literature relating to ageing and intersex people, the search was widened to include *LGBT* and *transgender*. Books, articles, or chapters in which the focus shed light on issues facing older intersex people or on issues potentially facing older intersex people published since 2000 were considered for inclusion. Only publications in English were chosen. Sixty-eight publications were included in this review. No unpublished works were included. A thematic approach was then taken to identifying the key issues. The first

author, who is an intersex person, led on writing whilst the second author, a non-intersex person, led on project design, and contributed to the literature analysis and writing.

Findings

This section is divided into four parts, beginning with a look at health and social care issues older intersex people may face. We found that while early surgery and hormonal interventions are performed with the intention of improving quality of life, the literature indicates that the opposite may be true, with intersex people left struggling with the effects of early procedures. There appears to be some connection between early medicalisation and disability, but research is needed. Additionally, older intersex people may have unique concerns regarding end-of-life care. The next section explores psychosocial wellbeing for older intersex people. Literature indicates that isolation and loneliness as well as rates of self-harming behaviour and attempted suicide might be higher for intersex people, but more research is needed. The section on socio-cultural issues examines how systems of purported care contribute to erasure, hiding evidence of intersex existence, which impacts intersex people in later life. The final section looks at structural dynamics, examining reasons that intersex people might find themselves particularly disadvantaged in later life, stemming from discrimination and a lack of legal protections.

Intersex people’s health and social care issues

The human rights of older intersex people have often been breached by early medical interventions. As intersex people who have undergone surgeries in childhood are rarely followed by medical professionals into adulthood,¹⁶ it is worth considering who gets to judge whether early surgery is successful and by what criteria. The intersex person struggling with sexual difficulties and discomfort in adulthood after having been subjected to irreversible surgeries in childhood, sometimes with their medical history hidden from them, may find little comfort in knowing that their surgeries were considered a success by those that performed them. There is little research on the later effects of these interventions,¹⁷ with the notable exception of a considerable amount of literature relating to failed hypospadias repairs.¹⁸ Hypospadias is an intersex variation manifesting in the

meatus, or urethral opening, being located on the underside of the phallus rather than on the tip. There is debate between medical professionals and intersex activists as to whether hypospadias by itself should be considered an intersex variation.¹⁹ Medical professionals are reluctant to view hypospadias itself as an indication of intersex without the presence of cryptorchidism, the absence of one or both testicles from the scrotum.²⁰ However, as hypospadias surgeries are performed on infants that are incapable of consent, for the purpose of preventing future imagined social emergencies,²¹ and are performed with the intention of surgically normalising a body to meet idealised, gendered notions of how a body should look and function,¹⁹ there is cause for hypospadias inclusion in intersex arguments for bodily autonomy and against unnecessary medicalisation. Individuals who have undergone surgical alterations for their hypospadias may require long-term medical care, and the risk of complications tends to increase with each subsequent surgery.¹⁸ Common complications with surgical hypospadias alterations include scarring, strictures, and recurrent fistulas.¹⁸ Individuals who have undergone multiple failed attempted hypospadias repairs are assigned the distressing label of “hypospadias cripple” with limited possibilities for reconstruction.²² Compared to controls, individuals with surgical alterations to hypospadias reported higher rates of avoiding relationships, lower numbers of lovers, erectile dysfunction, ejaculatory problems, sexual difficulties, and were significantly less satisfied with their sexual lives.²³ Skarin Nordenvall et al.²⁴ found that Swedish men subjected to hypospadias interventions were at higher risk of receiving disability pensions.

The wider literature shows that intersex babies were often assigned female because the associated surgeries were considered easier to perform.¹⁷ Feminising interventions involve the creation of genitalia that appear typically feminine to replace a seeming absence of genitalia, masculinised female genitalia, or masculine genitalia deemed inadequate by medical professionals.²⁵ Many interventions involve the removal of healthy testes, rendering the child infertile, followed by surgery to craft a functional vagina for future sexual penetration.²⁶ Vaginoplasties performed on infants often require repeated surgical revisions.²⁷ Clitoridectomies (the reduction or removal of the clitoris) have

been justified by beliefs that the clitoris served no purpose,² and that removal reduces the possibility of future homosexuality.²⁸ These practices diminish the possibility of future sexual pleasure, and often lead to long-term pain.¹⁷ Minto et al.²⁹ found that participants who had undergone clitoral reduction surgery experienced higher rates of non-sensuality and inability to orgasm than controls who had not had surgery. In another study, a contributor said:

“I have a very, very, very small amount of clitoral sensation. It’s not completely dead, but it doesn’t do anything for me. God help me if I should find the urologist who did this to me. I would call him a butcher”.^{30, p231}

Overall, many intersex adults who have undergone “normalising” interventions in childhood have reported dissatisfaction with appearance, scarring, pain, and sexual function that is diminished or absent.²⁵ Köhler et al.³¹ report high levels of sexual dissatisfaction and dysfunction compared to the general non-intersex population amongst intersex adults that had undergone medical interventions in childhood. Adults with Congenital Adrenal Hyperplasia (CAH)¹ who had undergone clitoral reduction surgery reported higher levels of sexual and relationship difficulties.¹⁷ This finding was reflected by Nermoen et al.³² who also found high levels of reduced fertility, and impaired subjective health in a study of Norwegian adults with CAH aged 18–80 years old, with significantly higher numbers receiving disability benefits than amongst the general population.

Higher levels of disability have been reported amongst older intersex people than amongst the general population.^{5,24} Disability is, for many intersex people, constructed at the point of medical intervention, leaving them with functional disabilities that profoundly impact the remainder of their lives; for example, those that have undergone gonadectomies in childhood are left with a higher risk of developing osteoporosis later on.³³ Mental health disorders that could render one as disabled, such as post traumatic stress disorder (PTSD), anxiety, and depression, could conceivably stem from early experiences

¹Congenital Adrenal Hyperplasia (CAH) refers to a group of genetic conditions that affect the adrenal gland which is responsible for regulating aldosterone, cortisol, and androgen.

of procedures described by intersex people as traumatic.^{30,34,35} It has been established that many intersex people are left to contend with disabilities related to reproductive abilities following early procedures.^{18,22,36,37} There is a need for research to examine connections between disability amongst older intersex people and early medical procedures.

Recent literature from paediatric endocrinologists and urologists underscores the difficulty in accurately assigning gender to an intersex infant.^{38,39} More than a quarter of intersex participants in one study were uncertain about their gender assignment or expressed a non-binary gender while 14% scored as transgender on a transgender identity questionnaire.⁴⁰ If an intersex person fails to develop in accordance with the gender assigned at birth, it could place them at risk for abuse and poor outcomes in adulthood.⁴¹ For example, they might suffer from gender dysphoria, a marked incongruence between one's experienced or expressed gender and the gender one has been assigned.⁴²

Rates of gender dysphoria have been found to be higher amongst intersex people than in the general population.³⁸ Gender dysphoria has been associated with significant levels of distress, anxiety, depressive disorders and impairment in school, work, and social settings.⁴² In extreme circumstances, gender dysphoria can lead to suicidal ideation, suicide attempts, and death. Much is risked for the intersex person accidentally allocated to a transgender existence, considering the disproportionately high rates of discrimination and violence faced by the transgender community.⁴³ There is little if any literature exploring the lives of older intersex people assigned an incorrect gender at birth.

Intersex people's healthcare issues and lack of rights impact on their capacities to access health and social care. Findings from a review of healthcare inequalities faced by ageing LGBTI people and barriers to providing care encountered by healthcare professionals⁴ show that needs are not being adequately met, as a result of insufficient specialised treatment and because LGBTI individuals often avoid medical treatment for fear of discrimination. One intersex woman explains:

"I will go to the doctor as a last resort. I don't like going to the doctor ... I think I have a little stronger phobia than the average Joe because the way I look

at it is, I have very vivid memories of being in [a children's hospital], laying on a table with my legs spread open, and all these doctors and these interns or student residents or whatever. I remember them marching in through my room, looking at me down there, poking me, you know, like I was a sideshow freak, you know?"^{35, p107}

In the first national study of intersex adults in the United States, Rosenwohl-Mack et al.⁵ found that over 43% of the 198 participants surveyed rated their physical health as fair or poor with significant differences by age. Almost one-third reported having difficulty with everyday tasks. Arthritis and hypertension were prevalent, with more than 20% reporting serious difficulty walking or climbing stairs. These findings suggest there is an urgent need to determine the health needs of older intersex people and improve outcomes for younger intersex people.

As there is little research on ageing intersex bodies, medical staff may fail to accurately predict the needs of older intersex people.⁴⁴ The bodies of intersex patients might not fit the expectations of carers.⁴⁵ Ageing intersex people entering retirement homes and retirement communities may harbour concerns about living amongst older non-intersex people who may already be less accepting and tolerant of anyone they perceive to deviate from societal or biological norms. Fear of reprisal, discrimination, and violence is to be expected, especially when much of the care provided is by organisations with religious affiliations.⁴⁶ Whilst home care may provide an alternative for those apprehensive about entering a care facility, older intersex people may also fear suffering abuse and humiliation from carers at home over variation-related, or surgery-related, bodily differences. Although ageing intersex people might fear being left to fend alone in their final years, they might also fear the loss of the intersex community they relied on for support. There is urgent need for research to help determine the specific needs of ageing intersex people.

Overall, older intersex people have frequently experienced violations of their sexual and reproductive rights and right to bodily integrity. They may have health issues that have been caused or exacerbated by medical interventions, in addition to facing barriers to appropriate health and social care. Little is known about how older intersex people have navigated medical

environments that have been instrumental in their erasure.

It is imperative that the needs of ageing intersex people are understood and addressed both for their benefit and to avoid contributing to overburdened future healthcare systems. More broadly, it is vital that adequate training be provided for medical and care professionals tasked with caring for older intersex people during one of the most vulnerable periods of their lives. Switzerland provides an exemplar with its plans to open its first intersex inclusive LGBTI elder care homes in 2025.⁴⁷

Older intersex people and psychosocial wellbeing

It is well documented that childhood trauma can have repercussions throughout the life of an individual.⁴⁸ Given that early trauma affects individuals later in life,⁴ the health of an older intersex person may differ significantly from that of an older non-intersex person. Many aspects of early medical interventions, such as surgeries, neo-vaginal dilation, and scrutiny by medical professionals can result in both physical and psychological trauma for the intersex person.⁴⁹ One intersex woman talked about feeling suicidal following a surgery she was falsely informed would be a hysterectomy. “I became depressed immediately after my orchiectomy. I struggled terribly with depression and attempted suicide ... I was really suffering terribly”.^{30, p 225} Indeed, research has shown that intersex people have considerably worse mental health than control groups.⁵ In a study that included 1040 intersex adolescents older than 16 years of age from six European countries, participants reported higher levels of anxiety and depression than the norm amongst the general population.⁵⁰ Rosenwohl-Mack et al.⁵ found that 53% of intersex participants reported their own mental health as fair or poor, with little variation according to age group. Depression and anxiety were common, with more than half reporting serious difficulties with cognitive tasks. Almost one-third of participants had previously attempted suicide⁵ compared to just over 1% of the general population.⁵¹ Schützmann et al.⁵² found that rates of self-harming behaviour and suicidal tendencies amongst intersex people were comparable to non-intersex groups of women that had suffered both physical and sexual abuse.

Torture has been shown to have profound effects on emotional brain functioning⁵³ in addition to psychological consequences such as post-traumatic stress disorder, anxiety, and depression.⁵⁴ Non-consensual medical interventions performed on intersex children have been acknowledged by the UN special rapporteur to be a form of torture.³⁶ It might be expected, then, that there are intersex people suffering far-reaching psychological repercussions from early medical interventions and their treatment by medical professionals. As a result of invisibility, it may prove difficult for older intersex people to find therapists capable of addressing their specific needs.

In addition to raising concerns about trauma and torture, the literature highlights issues with stigmatisation and related mental health issues that older intersex people may experience. Intersex people with co-morbidities may face additional difficulties in accessing healthcare due to negative experiences in therapeutic and medical settings not directly related to their variation. From the beginning of their lives, many intersex people are taught to keep fundamental aspects of their person hidden and secret, perhaps experiencing shame that is often so profound that the damage to their psychological health persists into the future.⁵ Hughes^{7,8} found LGBTI people face increased risk of certain health issues such as loneliness and psychological distress compared to the general population. One intersex person states, “I was really isolated, extremely lonely, and couldn’t talk to anyone about how I was different, my diagnosis or my body, or the surgeries. I was suicidal for most of my teenage years and a lot of my twenties”.^{30, p 224} Medical interventions can lead to the intersex individual experiencing stress, stigma, confusion, anger, resentment, and a sense of violation:²⁷ “I was forced to be surgically mutilated and medically raped at the age of 14. And that’s exactly what I consider it”.^{34, p 73} There has been insufficient research specifically measuring loneliness amongst ageing intersex people.

Whilst the trauma and discrimination that many older intersex people have experienced are major human rights concerns, some of the literature discussed coping strategies amongst intersex people that increase their agency, such as focusing on work or talents, accessing information, affirmative language, knowing oneself, accepting one’s body, personal growth work or

spiritual practice, and getting the right hormone therapy or other medical treatment.^{55,56} For some intersex people, activism to effect positive change, and seeing institutions such as the UN starting to address intersex people's human rights, are directly helpful to psychosocial wellbeing.⁵⁷ Overall, discrepancies in quality of reported mental health between older and younger intersex individuals may be attributed to building resilience and coping strategies in old age.⁵⁸ Although little appears to be written on the positive aspects of being intersex, it may be that there are older intersex people who reflect positively on some of the experiences and on the relationships that have grown from an intersex life and the perspectives this brings with it.

“... I do firmly believe that I'm different from most people in a way that is better, that gives a greater perspective. [Being intersex] has given me the ability to look at so many different people's perspectives, through so many different people's eyes. I feel sorry almost for people who haven't had this experience”^{34, p 134}

Socio-cultural issues

Intersex people face ageing in obscurity both in terms of their immediate social circles and at the level of cultural representation. This problem is particularly sharp with regard to biological family. Early medical interventions have led to infertility for many intersex people,^{36,37,59} decreasing the possibility that they will be surrounded by children and grandchildren in their later years. Older LGBTI people in Australia have been shown to have limited contact with biological family and are less likely to have children, and therefore grandchildren, relying instead on friends and intimate partners as they age.⁴⁴ Hughes^{7,8} found there was an increased risk of loneliness for older LGBTI people for reasons such as estrangement from family or reduced social networks. The risk of loneliness may be even greater for some older intersex people, however, due to stigmatisation and prejudice toward bodies and appearances that might be considered non-normative.⁶⁰ Stigma and discrimination early in the life of an intersex person can influence future interactions with people and their ability to form satisfying relationships.⁴ Early medical procedures are still justified as necessary to facilitate family acceptance;¹⁹ however, for some, these early procedures sow division between

parent and child. For example, “I was ‘going on vacation’, my parents said. It was done in the summertime. I remember a lot of pain, a lot of blood, a lot of confusion. My parents didn't talk to me about it”^{30, p 221} Destruction of the bond between a child and their family can contribute to social isolation and self-destructive behaviours in adulthood.^{61,62} For instance, a mother of one intersex person states:

“Part of what she's so upset about is that she feels raped, and in a way, she really was, and I couldn't help it. She can't see that I couldn't help it; all she can see is that I let it happen and ask, why didn't I protect her”^{30, p 210}

High levels of harassment towards intersex people in public spaces have been reported, for example, a European survey showed that 42% of intersex people are afraid to go out in public spaces due to the risk of attacks and abuse.⁶³ Such a high level of active discrimination may affect older intersex people, limiting opportunities for friendship and romance due to a lack of intersex awareness amongst the public.^{7,8} A study of women aged 20–54 with Androgen Insensitivity Syndrome (AIS)² have spoken about the damaging effects of silence and secrecy surrounding their variations and how some of them had difficulties forming friendships due to stigmatisation.⁶⁴ Older intersex people may also have experienced rejection and isolation from former places of worship, and ageism may contribute to discrimination in otherwise more welcoming LGBTQIA+ spaces. Importantly, contact with other intersex people through the internet⁹ or intersex support groups has been shown to promote feelings of normalcy and empowerment and to alleviate feelings of isolation.^{64,65} However, efforts by the medical establishment in 2005 to install DSD, or disorders of sex development, as universal umbrella terminology⁶⁶ may have contributed to furthering divisions amongst intersex people and people with variations of sex characteristics who do not identify as intersex. (see⁶⁷) Overall, these multiple marginalisations can form a challenging social environment for older intersex people.

²Androgen Insensitivity Syndrome (AIS) refers to a genetic variation where bodies with XY chromosomes are resistant to testosterone to varying degrees.

Social and cultural erasure can erase or impede older intersex people's rights and wellbeing. As readers may know, symbolic interactionist theorists suggest that the way we are excluded, included, and interact with a society combine to shape the self.⁶⁸ The media have been shown to have the power to shape how people see themselves, their relationships, and the world in which they exist.⁶⁹ Unless an intersex child knowingly has access to other intersex people, they may be forced to navigate through life without a map in a world where most of the evidence of their existence has been hidden or erased.⁶ To date, there has been little representation, positive or otherwise, of intersex people outside of ancient marble statues of hermaphrodites found in museums. More recently, positive cultural representations have emerged, such as MTV television show *Faking It*,⁷⁰ starring actress Bailey De Young as Lauren, a young intersex woman. Amanda Saenz and Bailey De Young appeared in a YouTube video entitled *9 things you need to know about being intersex* in 2014.⁷¹ The following year BuzzFeed released *what's it like to be intersex*, a viral video featuring young intersex activists Sean Saifa Wall, Pidgeon Pagonis, Alice Alvarez, and Emily Saenz, which was viewed 5,070,899 times.⁷² In 2021, the Schwulesmuseum in Berlin hosted its first-ever art exhibition dedicated to intersex stories past and present.⁷³ For many older intersex people this escalation of cultural representation may have come too late, however, with generations of intersex people growing up without role models. As intersex people are deprived of cultural representation, so is the wider non-intersex population left ignorant, including medical professionals, politicians, and policymakers, who appear to know little if anything about who intersex people are and what it is they need.

Structural dynamics

The last findings section of this article provides a snapshot of the structural underpinnings of the socio-economic marginalisation and erasure of older intersex people. We do not focus on the sex and gender binarism that plays such a key role in this, as it is widely discussed elsewhere.^{57,74} We note the literature about the marginalisation of older people more generally,⁷⁵ but space limitations preclude inclusion. Instead, we trace some key aspects of the legal and material forces and institutions that render older intersex people at

particular risk of hardship. In doing so, we take inspiration from intersectional approaches⁷⁶ and materialist sociology⁷⁷ in providing some indications firstly of the material inequalities that affect older intersex people, and secondly the legal erasures and barriers to intersex people's sexual, reproductive, and other rights.

Financial issues are linked inextricably to the ability to access quality care and housing.⁷⁸ Several factors potentially contribute to diminished later life solvency for intersex people. Coming out as intersex in later life in a society where intersex people are largely invisible may have the potential to jeopardise existing employment, relationships, and financial stability. Rosenwohl-Mack et al.⁵ found that 18.3% of intersex participants over 40 years of age were disabled or unable to work, while 77.6% reported worrying about meeting expenses with their current income. Employment discrimination against intersex people has been documented; for example, a large trans-European survey reported that 31% of intersex respondents felt discriminated against at work.⁶³ Because intersex is not included in the list of protected characteristics in terms of legal protections from discrimination in some countries, people with sex variations are vulnerable to discrimination.¹³ For intersex people in EU counties, protection from discrimination is enshrined in EU Treaties such as the Charter of Fundamental Rights of the European Union (Article 21) and Directive 2000/78/EC and related secondary legislation. Intersex people can be protected under the ground of "sex characteristics", but there is no case law yet to support this, and so discrimination could be taking place against older intersex people even where some legal provision is made to prevent this.

While not all intersex people are transgender, medical professionals increasingly confess that it is impossible to ascertain whether they are assigning the correct gender to an intersex child.³⁸ Irreversible surgery will already have been performed in many cases before the child is observed acting in a manner discordant with the gender they have been assigned at birth. In one recent study, only 23% of intersex individuals assigned male at birth felt they were assigned the correct gender.⁷⁹ For intersex people that find themselves at odds with societal gender expectations, this may begin a cruel cycle that could follow them throughout their life and into old age. Transgender people face high rates of underemployment

and inordinate levels of harassment in the workplace.⁸⁰ More research is needed to determine how intersex people fare in regard to financial security in later years in comparison with non-intersex people in the same age range.

An absence of legal recognition and protection forms a fundamental barrier to many older intersex people accessing basic human rights. For the most part, intersex people – along with transgender individuals or those situated outside the strict binary notions of gender – are denied explicit legal protections commonly afforded others.⁸¹ Legal recognition for intersex people is a recent development and is restricted at present to a few countries, such as Australia and Germany, so it is likely that there are older intersex people who have faced obstacles with marriage, adoption, surrogacy, and incarceration.⁸² It is common for LGBTQ+ and gender non-conforming people to face discrimination when dealing with inheritances, housing, and pensions in later life,⁸³ so it might be expected that some intersex people also encounter some discrimination in these areas. Spousal recognition may be denied in some locations, and legal difficulties may arise later in life from hostile families for couples where either or both parties are intersex and these could impact visitation, decision making, and inheritance.^{6,44} Whilst there is a body of literature addressing intersex people's human rights and their recognition at international levels, yawning gaps remain in the implementation of these rights at the level of the nation state.^{9,11,14} As there is little literature on how legal and human rights frameworks have failed to account for or protect intersex people, research is needed to determine how legal invisibility manifests in old age.

Conclusion

Our review of the literature about older intersex people paints a troubling picture across the key areas of health and social care, psychosocial aspects, socio-cultural issues, and structural dynamics. The review is limited due to the small amount of key literature currently in existence; we have drawn largely on the wider literature about intersex people to complete it. Overall, intersex adults report worse physical and mental health than controls,⁵ though older intersex people report better mental health, which may be due to resilience or because intersex people

with better mental health perhaps live longer lives. Because intersex people exist outside of protective legislative frameworks, they have not been afforded the rights and benefits commonly taken for granted by others. Research indicates that intersex people may be less financially secure in old age due to multiple factors, including incorrect gender assignment, discrimination, and diminished networking abilities. Secrecy surrounding intersex variations, though perhaps well-intentioned, has served to effectively erase intersex people, leaving them to grow up without role models or cultural representation. Stigma, invisibility, and medical sterilisation of intersex people, along with negative effects from early interventions, may combine to impair social support for intersex people in old age.

This review indicates several key areas for policy and practice reform to support the rights of older intersex people. Structural change, including legal reform and policies to tackle discrimination, is crucial. There is a pressing need for reform to support the rights of intersex minors (particularly, the cessation of irreversible non-consensual surgeries and unnecessary sterilisations). This is central to the realisation of the sexual and reproductive rights of intersex adults. Provision for appropriate health and social care that centres the needs of the intersex person is very important for ageing intersex populations. This needs to include measures to support intersex people who have experienced breaches of fundamental human rights, including traumatising medical interventions, whilst recognising that intersex people's lives and needs are very diverse. Training for care providers should include awareness as to the ways intersex lives and bodies might diverge from those of non-intersex people.

Suggested directions for future research

There is urgent need for research exploring connections between early medical interventions and disability, as well as what consequences, if any, exist for intersex adults assigned an incongruent sex at birth. There is need for research exploring social supports, loneliness, and legal invisibility amongst intersex adults and to determine the specific care needs of older intersex people. Overall, this review indicates a need for more research about older intersex people's lives, to inform positive policy and practice change.

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Résumé

Les personnes intersexuées subissent une série de violations de leurs droits humains, notamment des interventions médicales non consenties et irréversibles sur mineurs. Ces violations ont des effets permanents; pourtant, on sait peu de choses sur les personnes intersexuées plus âgées. Les personnes dans ce groupe divers font face à de multiples marginalisations et oblitérations dans différents environnements politiques et pratiques. Cet article examine les publications sur les problèmes relatifs à l'intersexuation, faisant ressortir les matériels pertinents pour les personnes intersexuées plus âgées à l'aide d'une démarche historique. Il se centre sur les principales difficultés touchant les personnes intersexuées plus âgées qui vivent dans différents pays du Nord, puisque les pratiques médicales pernicieuses ont leur origine dans cette partie du monde. Sur la base des données existantes, nous avons constaté un besoin pressant de réformes médicales, notamment l'arrêt des pratiques médicales néfastes et le développement de soins de santé appropriés qui se concentrent sur les besoins et les souhaits de chaque personne intersexuée. Étant donné que, dans la plupart des pays, les questions relatives à l'intersexuation sont actuellement dans une large mesure gommées, il faut mener un travail politique et pratique transversal et des activités de sensibilisation.

Resumen

Las personas intersexuales sufren una variedad de violaciones de los derechos humanos, tales como intervenciones médicas irreversibles no consensuales en menores. Estas violaciones tienen efectos de por vida; sin embargo, no se sabe mucho sobre las personas intersexuales mayores. Las personas en este grupo diverso son marginadas y borradas de múltiples formas en diferentes ámbitos de políticas y prácticas. Este artículo revisa la literatura sobre asuntos intersexuales y extrae materiales pertinentes a las personas intersexuales mayores utilizando un enfoque históricamente fundamentado. Se centra en los asuntos clave que afectan a las personas intersexuales mayores que viven en diversos países del norte global, dado que las prácticas médicas perjudiciales se originaron en esta región. Según la evidencia existente, encontramos una necesidad apremiante de realizar una reforma médica que incluya la cesación de prácticas médicas perjudiciales y la creación de servicios de salud indicados centrados en las necesidades y en los deseos de cada persona intersexual. Dado que los asuntos intersexuales actualmente son borrados marcadamente en la mayoría de los países, el trabajo en investigaciones, políticas intersectoriales y prácticas así como la sensibilización son todos necesarios.