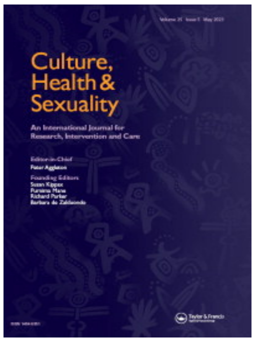

Culture, Health & Sexuality

An International Journal for Research, Intervention and Care

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/tchs20

Navigating the complexities of adult healthcare for individuals with variations of sex characteristics: from paediatric emergencies to a sense of abandonment

Daniela Crocetti, Adeline Berry & Surya Monro

To cite this article: Daniela Crocetti, Adeline Berry & Surya Monro (2023): Navigating the complexities of adult healthcare for individuals with variations of sex characteristics: from paediatric emergencies to a sense of abandonment, Culture, Health & Sexuality, DOI: 10.1080/13691058.2023.2208194

To link to this article: https://doi.org/10.1080/13691058.2023.2208194

CULTURE, HEALTH & SEXUALITY
https://doi.org/10.1080/13691058.2023.2208194

Taylor & Francis
Taylor & Francis Group

Navigating the complexities of adult healthcare for individuals with variations of sex characteristics: from paediatric emergencies to a sense of abandonment

Daniela Crocetti[a,b], Adeline Berry[a] and Surya Monro[a]

[a]School of Human & Health Sciences, University of Huddersfield, Huddersfield, UK; [b]subsequently Independent Researcher, Intersexesiste NGO, Bologna, Italy

ABSTRACT
Intersex people and those with variations of sex characteristics face significant health and social issues. This paper analyses the complexities of adult healthcare for this diverse population, including the root causes of deficiencies in care provision. Many minors with variations of sex characteristics are subjected to irreversible, non-consensual medical interventions, which can have negative effects on their health and wellbeing as adults. This 'emergency' approach to intersex paediatric healthcare has been challenged since the 1990s, but there is still a lack of understanding about how the paradigm affects adult care. This paper aims to raise awareness of the health challenges faced by adults with variations of sex characteristics. It identifies themes related to the challenges associated with accessing appropriate adult care, including the repercussions of childhood treatment, the lack of transitional services and psychological support, the limited general medical knowledge about variations of sex characteristics, and the reluctance to access services due to fear of stigma or past medical trauma. The paper indicates the need for more attention to intersex people's health needs as adults, moving away from attempts to 'fix' them as minors towards approaches which consider and provide for their diverse healthcare needs in a broader temporal context.

ARTICLE HISTORY
Received 3 October 2022
Accepted 25 April 2023

KEYWORDS
Variations of sex characteristics; disorders or differences of sex development (DSD); intersex; adult health care; sexual health medicine

Introduction

Since the first public protests in the USA in the 1990s, the medical treatment of children with variations of sex characteristics (VSC) has been a source of ethical debate. The Intersex Society of North America (ISNA) and variation-specific support groups emerged during this period to advocate for the rights of intersex individuals (Chase 1998). One of the main criticisms of medical treatment has focused on the irreversible bodily modifications, such as genital surgery, performed on children who

CONTACT Daniela Crocetti d.crocetti.ac@gmail.com

cannot provide direct consent. In response, human rights lobbying has reframed these issues as violations of universal rights, such as autonomy and bodily integrity (Carpenter 2016; Ghattas 2019; Crocetti et al. 2020a). Despite the fact that healthcare professionals treating minors may consider the needs of the future adult, this is not always evident, and there is significantly less medical literature about *adult* care for people with variation of sex characteristics.

This paper explores the connection between deficits in adult healthcare for individuals with variations of sex characteristics and the 'emergency paradigm' in which the birth of intersex infants is treated as a medical emergency, even when there is no risk to life (Davis and Murphy 2013). The erasure of intersex traits in childhood is compounded by a lack of appropriate adult services. The US activist Kimberly Zieselman has written: 'just because we want doctors to delay unnecessary surgery on children doesn't mean we don't want more specialised intersex care. On the contrary, we're desperate for it' (2017; n.p.). Intersex activist calls to demedicalise variations of sex characteristics involve *reducing* the medical attention given to socially constructed categories of genital form and gender presentation, but also *increasing* data-driven attention to health issues (see Eve et al. 2017, 5), such as endocrinological, cardiac, skeletal or mental health issues (see Monro et al. 2017).

Adults with variations of sex characteristics may face numerous challenges as they navigate adulthood, including the long-term effects of paediatric medical interventions and lack of specialised adult care. There is a significant body of literature that documents the potential negative impact of childhood genital surgery (Minto et al. 2003; Diamond and Jameson 2014; Davis 2015; Carpenter 2016; Ferrara and Casper 2018), as well as other aspects of childhood medical treatment such as unrequested hormone therapies, stigmatising and invasive genital examinations, lack of full disclosure, and exclusion from decision-making processes during childhood (Creighton et al. 2009; Davis 2015). Recent large-scale studies conducted in the USA (Rosenwohl-Mack et al. 2020), Europe (Nordenström et al. 2018) and Australia (Jones et al. 2016) have found high levels of mental distress in adulthood and difficulty accessing healthcare.

The transition from paediatric to adult care can be challenging for individuals with chronic diseases, as noted by Colver et al. (2020). However, this process can be even more complex in cases where the paediatric care provided was unnecessary, non-consensual, non-informed, stigmatising or traumatic. It is important to acknowledge that the categorisation of intersex and variations of sex characteristics as 'diseases' is a contested issue, as pointed out by Reis (2007) and Carpenter (2018a). While variations of sex characteristics are congenital and some may be associated with health concerns (such as salt-wasting in some individuals with Congenital Adrenal Hyperplasia) many intersex bodies are healthy and represent natural variations of physical form. As Kimberly Zieselman implies earlier, all bodies require medical attention and care as they age, and it is essential that the planning and delivery of such care reflects variations in biological attributes that may be relevant to that care.

Variations of sex characteristics encompass a broad range of physical differences, and healthcare options for adults with these variations are unevenly distributed. Currently, little is known about the health concerns that most adults with variations of sex characteristics face, which is a persistent issue for variation-specific health activists (see Crocetti, Monro, and Yeadon-Lee 2021). Furthermore, the need for adult care, including endocrinological and psychological support, can be a direct consequence of earlier paediatric medical interventions, such as genital surgery and gonadectomy. As a result, some scholars argue that the majority of medical attention to variations of sex characteristics represents a temporal solution (Danon 2018; Griffiths 2021), and ignores the emergent body (Garland and Travis 2020). By focusing primarily on the child, healthcare professionals may overlook the healthcare needs of adults. The lack of adequate or appropriate adult care is a recurring theme in the literature and interviews analysed in this paper.

This paper begins by providing an overview of variations of sex characteristics and how medical attention tends to focus on childhood. Next, we present a secondary analysis of qualitative data, building on themes identified in the adult health literature (Berry and Monro 2022). We develop two main themes, focusing first on the long-term impact of childhood medical treatment and then on the challenges associated with accessing appropriate adult care. Our analysis highlights the perspectives of activists, health advocates and medical allies, identifying several sub-themes. We conclude by offering some insights into future patient-driven adult care.

Background

The term Variations of Sex Characteristics is employed strategically in human rights advocacy to establish 'sex characteristics' as a potentially legally protected category that can only be modified with the individual's consent, rather than that of their legal guardians. Carpenter (2021, 522) observes that the use of 'sex characteristics' can be advantageous in framing rights for non-normative *bodies* rather than non-normative *identities*. This approach allows for the protection of individuals with diverse sex characteristics, regardless of their gender identity or sexual orientation, and emphasises the importance of informed consent and bodily autonomy.

It is important to note that there is ongoing debate in the field regarding terminology and the boundaries of the umbrella terms used by different stakeholders. Griffiths (2018) highlights the fluid boundaries of what is encompassed under the medical umbrella of Intersex, DSD (Disorders of Sex Development), and dsd (differences of sex development). Some variation-focused associations and medical professionals dispute the inclusion of variations such as Hypospadias, Klinefelter Syndrome (KS), Turner's Syndrome (TS), and Congenital Adrenal Hyperplasia (CAH) as part of the intersex umbrella, while they may be included under DSD/dsd. Nevertheless, minors with these variations often face contested childhood treatment decisions regarding bodily autonomy, and foetuses with these variations may be subject to eugenic abortion. Moreover, adults with these and other variations may have health concerns that require attention.

The medical practice of altering the bodies of children with variations of sex characteristics was consolidated in the 1950s, when John Money's Optimal Gender of Rearing (OGR) model was established (Karkazis 2008). Critics argue that this model is based on the flawed assumption that healthy psychosexual development depends on the appearance of the genitals, leading to medically unnecessary and harmful interventions on minors (Diamond and Sigmundson 1997). Despite revisions to protocols in 2006 that intended to shifted the focus to ‘patient centred care’ (Lee et al. 2006), there is still a lack of non-surgical paediatric protocols (Liao, Wood, and Creighton 2015), psychological support for families (Ernst et al. 2018), transitional services (Liao et al. 2010; Crouch and Creighton 2014), and adult health research (Cools et al. 2018). Definitions of what is considered a ‘necessary’ intervention in childhood remain contested, and there is little medical consensus about it (Hegarty et al. 2021). Doctors may still confuse physical sex with social gender and sexuality (Prandelli and Testoni 2021), or confuse the request for a third legal gender with requests for bodily autonomy (Crocetti, Monro and Yeadon-Lee 2021, 167, 178–9). However, there are some paediatric teams committed to postponing irreversible treatment until the intersex individual can be involved (Knight 2020; Crocetti, Monro, and Yeadon-Lee 2021).

According to Iain Morland (2009), medical bodily modifications in childhood persist in the psyche and body of adults with variations of sex characteristics. Although surgery on minors may seem future-oriented (Griffiths 2021, 514), it limits future choices in consequence can negatively impact adult care. Recent publications have shed light on issues such as deficits in adult care (Reis and McCarthy 2016; Zieselman 2017; Carpenter 2018b; Hiort et al. 2019; Zeeman and Aranda 2020), older people’s sexual rights (Latham and Holmes 2017), and how to strengthen health systems to care for people with variations of sex characteristics across services (Grimstad et al. 2021). Medical care for individuals with variations of sex characteristics still appears to require a temporal shift from current treatment norms that focus primarily on the child. Advocates and medical allies suggest a non-surgical, proactive paediatric model that supports families and ensures the overall body health of *future* adults (Magritte et al. 2022).

Methods

The discussion presented in this paper is based on a secondary thematic analysis (Braun and Clarke 2014) of multi-method research conducted in 2016-2019 during the EU funded European Intersex Citizenship (EUICIT) project and an in-depth literature review focused on adult health (see Berry and Monro 2022) conducted between 2021 and 2022 as part of the ESR1 research project, Intersex: New Interdisciplinary Approaches (INIA; 2020-2024), EU funded international training network. The paper is the result of a collaborative discussion between the three authors, an intersex scholar (AB) and two endosex scholars (DC and SM. AB’s perspective is particularly valuable, as they bring insights based on their positionality as an older intersex person. In addition, Authors DC and SM have significant experience in social scholarship and advocacy related to intersex issues.

The INIA research project led by AB, ESR1 - Older Intersex People, employed a multi-method approach to address the challenges faced by intersex individuals aged 50 and above. Adopting a pan-European perspective, the project examined the unique issues faced by this often-overlooked group. This paper draws on the literature review from this ongoing project.

The EUICIT project involved qualitative and participant action research in Italy, Switzerland, and the UK by authors DC and SM These countries were chosen due to differences in healthcare structures, types of activism, and national debates regarding gender. The research team collected empirical data through 40 interviews in 2017 with intersex activists, patient association members, policy makers, and medical professionals (15 in Italy, 19 in the UK, and 6 in Switzerland). All participants were informed about the project's aim of investigating perspectives on intersex rights and the data was anonymised unless participants specifically requested to be named. Both research projects adhered to strict ethical guidelines that met both EU and national legal and ethics requirements and were approved by the University of Huddersfield Ethics Board.

Findings

From a sense of abandonment to a nightmare. Accessing healthcare as an adult with a variations of sex characteristics

> 'One reaches adulthood and there's a bit of a feeling of abandonment.' (Alice AISIA-Italy 2017)

The healthcare experiences of adults with variations of sex characteristics are shaped by various factors. Individuals may experience health problems that are related to their variation, or that are caused by childhood medical treatments themselves. They may also receive inadequate care due to ignorance or stigmatising approaches. In this section of the paper, we focus on the sub-themes developed from our research related to the consequences of childhood treatment, the lack of transitional services and psychological support, the limited understanding of variation of sex characteristics among healthcare providers, challenges with accessing healthcare services, intersectional issues, and difficulties related to stigmatisation.

Childhood medical interventions can have a range of long-term impacts, with potential health problems arising from the treatments received during infancy. According to research participant Jay Hayes-Light, Director of the UK Intersex Association, many intersex individuals have no health problems besides the health issues they inherited from paediatric interventions (2017 interview). As noted by Italian activist Sabina Zagari OII-IT in 2017: 'In my case, having my gonads removed created a series of problems for me.' Early gonadectomy is a controversial practice due to historical misrepresentation of cancer risks, necessitating lifelong hormone therapy (Bertelloni et al. 2013).

Genital surgery performed during childhood may also require repeat interventions or result in chronic infections and complications (Griffiths 2021). Our research findings emphasise the importance of considering the emergent body (Garland and Travis 2020). For instance, one contributor to the EUICIT project stated that 'ultimately that little bundle isn't going to be little very long', highlighting the importance of fostering future independence and health (Ellie Founder member of dsdfamilies speaking in private capacity, UK 2017). A research paper from dsd-LIFE[1] found that adults who had undergone early genital surgery reported poor levels of satisfaction and recommended that constructive genital surgery should be minimised and performed mainly in adolescence or adulthood with the patient's consent (Köhler et al. 2012, 577). Studies clearly indicate the associated trauma and need for dedicated adult psychological support (Rosenwohl-Mack et al. 2020; Nordenström et al. 2018; Jones et al. 2016). The human rights model also suggests that surgical timing and consent should not be determined solely by outcome data, but by ethical principles such as concern for bodily integrity and autonomy.

The transition of teenagers with chronic health conditions into adulthood is increasingly being addressed by healthcare providers across all fields (Colver et al. 2020). However, issues arising from situations where aspects of paediatric healthcare were concealed from the individual, were unnecessary, and/or perceived as traumatic, are often overlooked. These issues are particularly pertinent to young adults with variations of sex characteristics, who additionally face a lack of transitional services (Crouch and Creighton 2014; Sanders et al. 2022). A recent scoping review of literature related to intersex multidisciplinary teams (Gramc et al. 2021) found a dearth of focus on adolescents, with none of the papers referring to adult care or transitioning care from adolescence to adulthood. According to authors, Gleeson and Wisniewski (2014, 136), 'there is evidence that we are failing to transition young people with DSD safely, resulting in them getting lost to follow-up and not receiving appropriate care in adulthood'.

During the EUICIT study, participants reported a lack of mental health support for families, transitioning teenagers, and adults. As mentioned earlier, large-scale studies have indicated high levels of mental stress among people with variations of sex characteristics (Nordenström et al. 2018; Rosenwohl-Mack et al. 2020), including trauma related to childhood interventions (Jones et al. 2016). According to an Italian activist, 'the national health service is by no means ready to repair the damage it has caused' (Sabina Zagari OII-IT 2017), and does not offer informed psychological support services for people with variations of sex characteristics. One UK participant emphasised the need for peer-support as well, stating that 'no child is going to…sit in a clinical room with an esteemed regarded medical practitioner…and tell them that everything that they did was wrong' (Holly Greenberry Intersex UK 2017).

A lack of specialised services and research can make individuals who require care feel abandoned as adults. A recurring theme for the Italian AIS group, AISIA, has been the scarcity of knowledgeable endocrinologists, with some people remaining in paediatric care even in adulthood. As noted by one AISIA member regarding adult services, there is a 'feeling of emptiness […] Unfortunately, most of the professionals we come into contact with are predominantly paediatric endocrinologists' (Alice AISIA Italy 2017). Another AISIA member shared her experience of seeking advice about changing hormone therapy as she got older, where a team of adult endocrinologists had told her that she knew more about what to do for her hormone therapy than they did (Claudia AISIA Italy 2017).

Our data highlights an issue whereby healthcare practitioners' lack of understanding about variations of sex characteristics, including confusion with sexuality or gender identity, can also result in difficulties accessing general healthcare. This is also supported by existing literature, such as a study in which 28% of participants faced challenges while trying to access specialist care (Thyen et al. 2018). A study by Prandelli and Testoni (2021) revealed that Italian healthcare professionals showed significant ignorance and confusion about intersex, often mistaking bodily variations for sexual orientation or gender identity. Specialised medical practitioners also reported instances where parents refused to delay surgery, fearing their children would become homosexual or trans (Crocetti et al. 2020b). Paul D from KSA-UK emphasised 'there is still a huge amount of ignorance, amongst GPs in particular' (2017 interview).

Another issue is that, as previous studies indicate (Crocetti 2013; McPhail and Fulop 2016), individuals with variations of sex characteristics may avoid seeking medical care. A recent study in the Republic of Ireland found that many participants were reluctant to engage with medical practitioners, even for routine check-ups (Ní Mhuirthile et al. 2022). The EUICIT study and the literature review indicated that this reluctance may stem from childhood medical trauma as well as stigmatising experiences where people's sex character variations were inappropriately addressed. For example, the independent UK intersex activist Valentino Vecchietti stated 'I hate hospitals, its uncomfortable, its nasty, it's not nice being examined' (2017 interview), citing the complication of explaining their physiology and medical needs to healthcare providers who may not understand intersex variations. Our research and other studies have identified a recurring theme of fear among individuals with variations of sex characteristics of being stigmatised or receiving inappropriate care. This fear is exemplified by an Italian activist who avoided seeking general medical care due to negative past experiences. According to Alessandro Comeni OII-Italy, 'accessing the health system is a nightmare for intersex people […] When it is not about my shoulder for example, but about my genital system […] I often decide not to go' (2017 interview).

A further issue concerns intersectional dynamics, as seen in Ní Mhuirthile and colleagues study where one participant reported being denied care when they were suicidal because they were intersex and trans (2022, 157). Medical specialists have suggested that intersex individuals may be more likely to request legal gender change as adults than endosex individuals (Callens et al. 2016; Cools et al. 2018). However, intersex individuals who seek legal gender change may face complex challenges when accessing medical care as adults. These challenges include negotiating irreversible medical interventions they may have undergone, and the common barriers experienced by transgender individuals in accessing healthcare (Warner and Mehta 2021).

Finally, appropriate medical services become less available as people age, as discussed by the Italian activist Claudia of AISIA (2017 interview). This problem is also documented in the literature, for example, a participant in an Australian narrative project expressed worry about potential discrimination in assisted living facilities as an ageing intersex person, stating: 'As an ageing intersex person, if I end up in a position where I'm showered by somebody else and my body is in its naked state, a visibly different body, I think how is that going to play out?' (Latham and Barrett 2015, 21).

Inadequate or inappropriate adult care issues are further exacerbated by the fact that care and research remain primarily focused on paediatric services, which we will discuss further in the next section.

A lack of attention to temporality: data and dedicated services

> 'So, we need a health service that sees us in a temporal sense and sees us with variation and allows for that.' (Valentino Vecchietti independent intersex rights activist and academic UK 2017)

The lack of long-term health data on variations of sex characteristics is a recurring concern among activists, variation-specific health advocates, and medical practitioners alike. This leads to inadequate dedicated adult services and insufficient medical education on intersex health matters (Liang et al. 2017; DeVita, Bishop, and Plankey 2018). While there has been a significant professionalisation of paediatric care in this field, including the mandate to create multidisciplinary teams in the 2006 guidelines (Lee et al. 2006), there has been a notable lack of similar attention to adult services (Gramc et al. 2021). The updated international best practice statement highlights a significant lack of data concerning surgical timing and consent, gender assignment, and fertility (Lee et al. 2016). Medical experts have consistently called for the collection of further data regarding paediatric surgical outcomes (Lee et al. 2012), yet some argue that 'repeated systematic reviews of evidence have found no quality data confirming their safety and benefits for each affected child' (Zillén, Garland, and Slokenberga 2017, 40). The uncertainties in the field only partially explain why few non-surgical options are available to parents, as noted by Liao, Wood, and Creighton (2015). One recent preliminary study on surgical deferment, conducted by Bougnères et al. (2017), reported positive results, while another study (Fisher et al. 2022) found that over one third of caregivers regretted giving permission for surgery.

According to a recent clinical consensus statement on DSDs (Cools et al. 2018), adults with variations of sex characteristics often have unanswered health-related questions and there is a lack of evidence about how these variations evolve in later life. This highlights the need for more data on the health problems that may be associated with variations of sex characteristics. Older activists with chromosomal variations have reported being told that they would not live past 40 (Crocetti 2013), which underscores the need for further research on the health outcomes. Members of AISIA have participated in research projects aimed at providing information on bone density and cardiac health at a paediatric centre, but these projects have not yielded health recommendations (2017 interviews).

Uncertainties are common for adults with variation of sex characteristics. For example, the dsd-LIFE study, which included a large-scale European cohort, found that while 80% of participants were satisfied with their hormone therapies, many were also concerned about, or experienced, side effects (Nordenström et al. 2018). The EUICIT data also highlights these issues, for example, one activist reported feeling pressured to make important therapeutic decisions alone, weighing the risks and benefits of oestrogen therapy, including bone density, depression, energy levels and libido (Claudia AISIA Italy 2017). The participants who identified as female in the EUICIT study also raised concerns about the insufficient focus on energy levels and libido. Additionally, XXY activists have criticised the disproportionate medical attention given to enhancing masculine traits like libido, which has resulted in neglect for other health concerns (Crocetti 2013). Discrepancies in medical consideration of what sexual activity and satisfaction looks like for people classified as either male or female have also been documented in this area (Karkazis 2008; Crocetti 2013). Furthermore, reproductive options are under-researched, even for individuals who have not been sterilised by paediatric treatment.

The issue of uncertainty is especially significant for older individuals with variations of sex characteristics. For instance, a participant in Latham and Barrett's Australian narrative research stated, 'I have no idea, and health professionals have no idea, what the long-term effects of hormone replacement are. They seem to have no interest in finding out' (Latham and Barrett 2015, 19). Our own research findings also suggest that uncertainties and anxieties are prevalent among individuals with variation of sex characteristics. For instance, Valentino Vecchietti (independent UK intersex rights activist and academic, 2017) expressed concerns about the long-term health effects of pharmacological treatment, stating: 'I know that some of the medications have long term health effect problems […] bone integrity and things'. They also noted that the lack of clarity and guidance for their healthcare was scary and unsettling.

Given the insufficient data and healthcare provision in the field of variations of sex characteristics, findings from EUICIT reveal that patient groups and informal networks often rely on community-based or 'crowd-sourced' care information. Within these networks, individuals with variations of sex characteristics share information about various healthcare concerns, either privately or online, in order to address the gaps they encounter in adult services and health data. As one member of AISIA explained, many members ask each other for information about hormone therapy side effects, types and dosages, but 'these are not structured research projects […] they consist of comparisons between individual experiences' (Alice AISIA Italy 2017). This experience is also reflected in the UK, where activists report that variation-specific groups create unofficial databases of endocrinological experiences, often referring to one another after not receiving sufficient information from healthcare providers. Despite years of activism and advocacy by both activists and patient groups, this valuable input has not been fully integrated into medical practice. However, the recent large-scale studies mentioned in the introduction did include advocates and activists in research design and implementation (USA, Rosenwohl-Mack et al. 2020), variation specific health-advocates in initial recruitment (dsd-life, Europe, Nordenström et al. 2018), and advocates and activists in research design and implementation (Australia, Jones et al. 2016). The collaboration between medical allies, activists, and health advocates in the US study is particularly encouraging as it yields data that is considered valid by the medical community while being 'led by community input' as indicated in the Darlington Statement (Eve et al. 2017, 5).

Conclusion

This paper has analysed the ways in which the over-medicalised paediatric care of intersex people contrasts with a lack of appropriate healthcare for adults with variations of sex characteristics. This dynamic has its roots in the emergency paradigm that characterised the protocol developed in the 1950s, which sought to eliminate evidence of variations of sex characteristics in infants, due to cultural fears about gender and sex diversity, and related practices of secrecy.

Importantly, however, excessive physical interventions in childhood can lead to a range of physical and mental health problems that can last a lifetime (Morland 2009; Griffiths 2021). This pattern of long-term negative health impacts stands in stark contrast to the efforts of clinicians to 'fix' variations of sex characteristics at an early point in childhood. Current lack of provision in specialised adult care implies the assumption that this 'fix' will eliminate the need for further care for people with variations of sex characteristics, whereas in reality, care needs can be complex and multifaceted.

The lack of adequate or appropriate adult care is a recurring theme in the literature and interviews analysed in this paper. We explore the connection between deficits in adult healthcare for individuals with variations of sex characteristics and the view that the birth of intersex infants should be treated as a medical emergency, even when there is no risk to life. The erasure of intersex traits in childhood is compounded by a lack of appropriate adult services. This paper highlights the perspectives of activists, health advocates and medical allies, identifying several sub-themes related to the long-term impact of childhood medical treatment and the challenges associated with accessing appropriate adult care.

The authors acknowledge the limitations in terms of the paper's small dataset (40 interviews drawn from three European countries) and its focus, which is primarily on the Global North. It does not aim to be representative of all healthcare situations for minors and adults with variations of sex characteristics. Rather, we hope to provoke discussion about the complexities of adult intersex people's healthcare, to draw attention to the current severe deficits in care, and to point out a core problem regarding the temporally situated 'fixing' and 'emergency' paradigms of intersex healthcare that remain dominant in many countries today.

We build on existing literature regarding the temporal disparity concerning medical interventions, notably Danon's (2018) emphasis on the significance of temporality in understanding the healthcare needs of intersex individuals, as well as Garland and Travis (2020) exploration of emergent body rights issues. Addressing temporality allowed us to delve further into the consequences of the emergency approach. These include practical difficulties with the lack of transitional care for individuals reaching adulthood, feelings of anxiety and uncertainty, inadequate specialised and general healthcare services for adults with variations of sex characteristics, and lack of data about adult intersex people's healthcare, especially the long-term effects of interventions on minors. Research participants also highlighted the effects of stigmatisation, which is also linked to the fallout from the emergency model, fostering cultures of secrecy. As a result, some individuals avoid healthcare altogether due to discriminatory experiences, or resort to do it yourself approaches. The emergency paradigm in childhood may also lead to some intersex people being assigned to a gender that they subsequently need to change, adding a temporal dimension to their lives in which they are forced to confront both transgender and intersex discrimination in healthcare settings (Ní Mhuirthile et al. 2022).

Our paper is situated in the context of activist demands to halt unnecessary medical interventions on minors who are too young to consent (Chase 1998). Despite these demands, parents continue to be offered insufficient non-surgical alternatives and support services (see Liao, Wood, and Creighton 2015). Our research highlights the detrimental impact of concentrating care and research in the field of paediatrics, including not just the continued perpetration of interventions that are often harmful, but also neglect of transitional and adult care. More broadly, there is a pressing need to shift away from a focus on early interventions and instead adopt an approach that takes into account intersex people's lives over time. As one aspect of medical reform, better use can be made of the resources and knowledge that intersex activists and advocates have developed. A possible solution is to prioritise the health needs and requests of individuals by involving intersex people directly in health research design and implementation (in a manner that is properly acknowledged and renumerated) as part of a broader cultural shift towards the democratisation of healthcare.

Note

1. dsd-LIFE was a EU funded medical research project conducted in 14 European medical centres across France, Germany, the Netherlands, Poland, Sweden and the UK between 2012-2017 "with the purpose to improve clinical care in individuals with differences of sex development (intersex conditions)" https://www.dsd-life.eu/about-dsd-life/index.html

Acknowledgements

We thank the research contributors. We would also like to thank the reviewers and Clare Desplats for their editorial assistance. This paper reflects the authors' views only, and the funding agencies are not responsible for any use that may be made of the information it contains.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by a European Commission Marie Skłodowska Curie Grant (number 703352). Part of the work was undertaken as part of the INIA, Intersex – New Interdisciplinary Approaches Innovative Training Network supported by a grant from the European Commission's Marie Skłodowska-Curie Actions programme under grant number 859869 .

ORCID

Daniela Crocetti http://orcid.org/0000-0002-5144-8804

References

Berry, A. W., and S. Monro. 2022. "Ageing in Obscurity: A Critical Literature Review Regarding Older Intersex People." *Sexual and Reproductive Health Matters* 30 (1): 2136027.

Bertelloni, S., E. Dati, P. Ghirri, F. D'Alberton, F. Baldinotti, and G. I. Baroncelli. 2013. "Gestione Clinica Dei Disturbi Della Differenziazione Sessuale Con Cariotipo 46, XY: Aspetti Emergent." *Prospettive in Pediatria* 41 (170): 110–120.

Bougnères, P., C. Bouvattier, M. Cartigny, and L. Michala. 2017. "Deferring Surgical Treatment of Ambiguous Genitalia into Adolescence in Girls With 21-Hydroxylase Deficiency: A Feasibility Study." *International Journal of Pediatric Endocrinology* 2017 (1): 5.

Braun, V., and V. Clarke. 2014. "What Can 'Thematic Analysis' Offer Health and Wellbeing Researchers?" *International Journal of Qualitative Studies on Health and Well-Being* 9 (1): 26152.

Callens, N., M. Van Kuyk, J. H. van Kuppenveld, S. L. Drop, P. T. Cohen-Kettenis, and A. B. Dessens; Dutch Study Group on DSD. 2016. "Recalled and Current Gender Role Behavior, Gender Identity and Sexual Orientation in Adults with Disorders/Differences of Sex Development." *Hormones and Behavior* 86: 8–20. doi:10.1016/j.yhbeh.2016.08.008

Carpenter, M. 2016. "The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change." *Reproductive Health Matters* 24 (47): 74–84.

Carpenter, M. 2018a. “Intersex Variations, Human Rights, and the International Classification of Diseases.” *Health and Human Rights* 20 (2): 205.

Carpenter, M. 2018b. “What Do Intersex People Need from Doctors?” ‘ *LGBTQIA Magazine* 20 (4): 32–33.

Carpenter, M. 2021. “Intersex Human Rights, Sexual Orientation, Gender Identity, Sex Characteristics and The Yogyakarta Principles Plus 10.” *Culture, Health & Sexuality* 23 (4): 516–532.

Chase, C. 1998. “Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism.” *GLQ: A Journal of Lesbian and Gay Studies* 4 (2): 189–211.

Colver, A., T. Rapley, J. R. Parr, H. McConachie, G. Dovey-Pearce, A. L. Couteur, J. E. McDonagh, C. Bennett, G. Maniatopoulos, M. S. Pearce, et al. 2020. “Facilitating Transition of Young People with Long-Term Health Conditions from Children’s to Adults’ Healthcare Services–Implications of A 5-Year Research Programme.” *Clinical Medicine* 20 (1): 74–80.

Cools, M., A. Nordenström, R. Robeva, J. Hall, P. Westerveld, C. Flück, B. Köhler, M. Berra, A. Springer, K. Schweizer, et al. 2018. “Caring For Individuals with a Difference of Sex Development (DSD): A Consensus Statement.” *Nature Reviews. Endocrinology* 14 (7): 415–429.

Creighton, S. M., J. A. Greenberg, K. Roen, and D. L. Volcano. 2009. “Intersex Practice, Theory, and Activism: A Roundtable Discussion.” *GLQ: A Journal of Lesbian and Gay Studies* 15 (2): 249–260.

Crocetti, D. 2013. *L’invisibile Intersex. Storie Di Corpi Medicalizzati*. Pisa: ETS.

Crocetti, D., E. A. Arfini, S. Monro, and T. Yeadon-Lee. 2020a. “You’re Basically Calling Doctors Torturers’: Stakeholder Framing Issues Around Naming Intersex Rights Claims as Human Rights Abuses.” *Sociology of Health & Illness* 42 (4): 943–958.

Crocetti, D., V. Vecchietti, S. Monro, and T. Yeadon-Lee. 2020b. “Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health.” *Culture, Health & Sexuality* 23 (4): 500–515.

Crocetti, D., S. Monro, and T. Yeadon-Lee. 2021. “Rhetoric of Change: Intersex Rights Claims, Rhetoric and Medical Practice in Italy.” *Illuminazioni* 5: 146–194.

Crouch, N. S., and S. M. Creighton. 2014. “Transition of Care for Adolescents with Disorders of Sex Development.” *Nature Reviews. Endocrinology* 10 (7): 436–442.

Danon, L. M. 2018. “Time matters for Intersex Bodies: Between Socio-medical Time and Somatic Time.” *Social Science & Medicine* 208: 89–97.

Davis, G. 2015. *Contesting Intersex: The Dubious Diagnosis*. New York: New York University Press.

Davis, G., and E. L. Murphy. 2013. “Intersex Bodies as States of Exception: An Empirical Explanation for Unnecessary Surgical Modification.” *Feminist Formations* 25 (2): 129–152.

DeVita, T., C. Bishop, and M. Plankey. 2018. “Queering Medical Education: Systematically Assessing LGBTQI Health Competency and Implementing Reform.” *Medical Education Online* 23 (1): 1510703.

Diamond, M., and J. Garland. 2014. “Evidence Regarding Cosmetic and Medically Unnecessary Surgery on Infants.” *Journal of Pediatric Urology* 10 (1): 2–6.

Diamond, M., and H. K. Sigmundson. 1997. “Sex Reassignment at Birth: Long-Term Review and Clinical Implications.” *Archives of Pediatrics & Adolescent Medicine* 151 (3): 298–304.

Eve, B., K. Bond, T. Briffa, M. Carpenter, C. Cody, A. David, AIS Support Group Australia, et al. 2017. *Darlington Statement: Joint Consensus Statement from the Intersex Community Retreat in Darlington, March 2017*, Sydney, NSW. https://eprints.qut.edu.au/104412/1/Darlington-Statement.pdf

Ernst, M. M., L.-M. Liao, A. B. Baratz, and D. E. Sandberg. 2018. “Disorders of Sex Development/Intersex: Gaps in Psychosocial Care for Children.” *Pediatrics* 142 (2): e20174045.

Ferrara, M., and M. J. Casper. 2018. “Genital Alteration and Intersex: A Critical Analysis.” *Current Sexual Health Reports* 10 (1): 1–6.

Fisher, R. S., H. C. Espeleta, L. S. Baskin, C. L. Buchanan, Y.-M. Chan, E. Y. Cheng, D. E. Coplen, D. A. Diamond, N. J. Nokoff, B. W. Palmer, et al. 2022. “Decisional Regret About Surgical and Non-Surgical Issues After Genitoplasty Among Caregivers of Female Infants With CAH.” *Journal of Pediatric Urology* 18 (1): 27–33.

Garland, F., and M. Travis. 2020. “Temporal Bodies: Emergencies, Emergence, and Intersex Embodiment.” In *A Jurisprudence of the Body*, edited by C. Dietz, M. Travis, and M. Thomson, 119–147. Cham: Palgrave Macmillan.

Ghattas, D. C. 2019. “Protecting Intersex People in Europe: A Toolkit for Law and Policy Makers.” *OII Europe* May 13, 1–25. https://www.oiieurope.org/wp-content/uploads/2019/05/Protecting_intersex_in_Europe_toolkit.pdf.

Gleeson, H., and A. B. Wisniewski. 2014. “Working with Adolescents and Young Adults to Support Transition.” In *Understanding Differences and Disorders of Sex Development (DSD). Endocrine Development 27*, edited by O. Hiortand S. F. Ahmed, 128–137. Basel: Karger.

Gramc, M., J. Streuli, and E. De Clercq. 2021. “Multidisciplinary Teams Caring for People with Variations of Sex Characteristics: A Scoping Review.” *BMJ Paediatrics Open* 5 (1): e001257.

Griffiths, D. A. 2018. “Shifting Syndromes: Sex Chromosome Variations and Intersex Classifications.” *Social Studies of Science* 48 (1): 125–148.

Griffiths, D. A. 2021. “Queering the Moment of Hypospadias ‘Repair.” *GLQ: A Journal of Lesbian and Gay Studies* 27 (4): 499–523.

Grimstad, F., J. Kremen, C. G. Streed, Jr, and K. B. Dalke. 2021. “The Health Care of Adults with Differences in Sex Development or Intersex Traits is Changing: Time to Prepare Clinicians and Health Systems.” *LGBT Health* 8 (7): 439–443.

Hegarty, P., M. Prandelli, T. Lundberg, L.-M. Liao, S. Creighton, and K. Roen. 2021. “Drawing the Line Between Essential and Nonessential Interventions on Intersex Characteristics with European Health Care Professionals.” *Review of General Psychology* 25 (1): 101–114.

Hiort, O., M. Cools, A. Springer, K. McElreavey, A. Greenfield, S. A. Wudy, A. Kulle, S. F. Ahmed, A. Dessens, A. Balsamo, et al. 2019. “Addressing Gaps in Care of People with Conditions Affecting Sex Development and Maturation.” *Nature Reviews. Endocrinology* 15 (10): 615–622.

Jones, T., B. Hart, M. Carpenter, G. Ansara, W. Leonard, and J. Lucke. 2016. *Intersex: Stories and Statistics from Australia*. Cambridge: Open Book Publishers.

Karkazis, K. 2008. *Fixing Sex*. Durham: Duke University Press.

Knight, K. 2020. ‘First US Hospital Pledges to End Intersex Surgeries’ *HRW*. https://www.hrw.org/news/2020/07/30/first-us-hospital-pledges-end-intersex-surgeries

Köhler, B., E. Kleinemeier, A. Lux, O. Hiort, A. Grüters, and U. Thyen. 2012. “Satisfaction with Genital Surgery and Sexual Life of Adults with XY Disorders of Sex Development: Results from the German Clinical Evaluation Study.” *The Journal of Clinical Endocrinology and Metabolism* 97 (2): 577–588.

Latham, J. R., and C. Barrett. 2015. “Appropriate Bodies and Other Damn Lies: Intersex Ageing and Aged Care.” *Australasian Journal on Ageing* 34: 19–20. doi:10.1111/ajag.12275

Latham, J. R., and M. Holmes. 2017. “Intersex Ageing and (Sexual) Rights.” In *Addressing the Sexual Rights of Older People: Theory, Policy, and Practice*, edited by S. Hinchliff and C. Barrett, 84–96. London: Routledge.

Lee, P. A., C. P. Houk, F. Ahmed, I. A. Hughes, J. Achermann, L. Baskin, S. Berenbaum, et al. 2006. “Consensus Statement on Management of Intersex Disorders.” *Pediatrics* 118 (2): e488–e500.

Lee, P. A., J. Schober, A. Nordenström, P. Hoebeke, C. Houk, L. Looijenga, G. Manzoni, W. Reiner, and C. Woodhouse. 2012. “Review of Recent Outcome Data of Disorders of Sex Development (DSD): Emphasis on Surgical and Sexual Outcomes.” *Journal of Pediatric Urology* 8 (6): 611–615.

Lee, P. A., A. Nordenström, C. P. Houk, S. F. Ahmed, R. Auchus, A. Baratz, K. Baratz Dalke, L.-M. Liao, K. Lin-Su, L. H. J. Looijenga, et al. 2016. “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.” *Hormone Research in Paediatrics* 85 (3): 158–180.

Liang, J. J., I. H. Gardner, J. A. Walker, and J. D. Safer. 2017. “Observed Deficiencies in Medical Student Knowledge of Transgender and Intersex Health.” *Endocrine Practice* 23 (8): 897–906.

Liao, L.-M., E. Tacconelli, D. Wood, G. Conway, and S. M. Creighton. 2010. “Adolescent Girls with Disorders of Sex Development: A Needs Analysis of Transitional Care.” *Journal of Pediatric Urology* 6 (6): 609–613.

Liao, L.-M., D. Wood, and S. M. Creighton. 2015. “Parental Choice on Normalising Cosmetic Genital Surgery.” *BMJ (Clinical Research ed.)* 351: h 5124. doi:10.1136/bmj.h5124

Magritte, E., J. Williams, E. Amyot, M. Usipuik, and C. Sanders. 2022. “Listening to Individuals with Differences in Sex Development or Intersex and their Families: ‘Not Doing Surgery Does Not Mean Doing Nothing.” *Hormone Research in Paediatrics*. Advance online publication. doi:10.1159/000525452

McPhail, R., and L. Fulop. 2016. “Champions’ Perspectives on Implementing the National Lesbian, Gay, Bisexual, Transgender and Intersex Ageing and Aged Care Strategy in Queensland.” *Australian Health Review* 40 (6): 633–640.

Minto, C. L., L.-M. Liao, C. R. Woodhouse, P. G. Ransley, and S. M. Creighton. 2003. “The Effect of Clitoral Surgery on Sexual Outcome in Individuals Who Have Intersex Conditions with Ambiguous Genitalia: A Cross-Sectional Study.” *Lancet* 361 (9365): 1252–1257.

Monro, S., D. Crocetti, T. Yeadon-Lee, F. Garland, and M. Travis. 2017. *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change*. Huddersfield: Huddersfield University Press.

Morland, I. 2009. “What Can Queer Theory Do for Intersex?” *GLQ: A Journal of Lesbian and Gay Studies* 15 (2): 285–312.

Ní Mhuirthile, T., M. Feeney, M. Duffy, and A. Staines. 2022. ‘Mapping the Lived Experiences of Intersex/Variations of Sex Characteristics in Ireland: Contextualising Lay and Professional Knowledge to Enable Development of Appropriate Law and Policy.’ Project Report. Dublin City University. 1–242. https://doras.dcu.ie/26873/

Nordenström, A., R. Röhle, U. Thyen, C. Bouvattier, J. Slowikowska-Hilczer, N. Reisch, H. Claahsen van der Grinten, A. Brac de la Perriere, P. T. Cohen-Kettenis, and B. Köhler 2018. “Hormone Therapy and Patient Satisfaction with Treatment, in A Large Cohort of Diverse Disorders of Sex Development.” *Clinical Endocrinology* 88 (3): 397–408.

Prandelli, M., and I. Testoni. 2021. “Inside the Doctor’s Office. Talking About Intersex with Italian Health Professionals.” *Culture, Health & Sexuality* 23 (4): 484–499.

Reis, E. 2007. “Divergence or Disorder?: The Politics of Naming Intersex.” *Perspectives in Biology and Medicine* 50 (4): 535–543.

Reis, E., and M. W. McCarthy. 2016. “What Hospitalists Should Know About Intersex Adults.” *Perspectives in Biology and Medicine* 59 (3): 391–398.

Rosenwohl-Mack, A., S. Tamar-Mattis, A. B. Baratz, K. B. Dalke, A. Ittelson, K. Zieselman, and J. D. Flatt. 2020. “A National Study on the Physical and Mental Health of Intersex Adults in the US.” *PloS One* 15 (10): e0240088.

Sanders, C., E. Amyot, M. Usipuik, L. Crawford, N. Callens, J.-P. Chanoine, and T. Jones. 2022. “Lifespan Healthcare Transitions Among Individuals with Intersex Traits in Canada: A Mixed-Methods and Qualitative Study.” *BMJ Open* 12 (4): e055759.

Thyen, U., T. Ittermann, S. Flessa, H. Muehlan, W. Birnbaum, M. Rapp, L. Marshall, M. Szarras-Capnik, C. Bouvattier, B. P. C. Kreukels, on behalf of the dsd-LIFE group, et al. 2018. “Quality Of Health Care in Adolescents and Adults with Disorders/Differences of Sex Development (DSD) in Six European Countries (dsd-LIFE).” *BMC Health Services Research* 18 (1): 1–12.

Warner, D. M., and A. H. Mehta. 2021. “Identifying and Addressing Barriers to Transgender Healthcare: Where We Are and What We Need to Do About It.” *Journal of General Internal Medicine* 36 (11): 3559–3561.

Zeeman, L., and K. Aranda. 2020. “A Systematic Review of the Health and Healthcare Inequalities for People with Intersex Variance.” *International Journal of Environmental Research and Public Health* 17 (18): 6533.

Zieselman, K. 2017. “In the Intersex Community, We’re Desperate for Quality Care.” *Doctors Aren’t Listening*. Stat+Oct 26. https://www.statnews.com/2017/10/26/intersex-medical-care/.

Zillén, K., J. Garland, and S. Slokenberga. 2017. “The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties.” Committee on Bioethics of the Council of Europe Report. https://rm.coe.int/16806d8e2f