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Reproductive justice for children and young people with gonadal variations:

Intersex, queer and crip perspectives

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ABSTRACT

INTRODUCTION: This article draws on understandings from reproductive justice, crip and queer theories to discuss gonadectomy for children and young people with gonadal variations. Gonadectomy is sometimes performed on people with gonadal variations without their free and informed consent. Some parents report experiencing pressure to consent to such surgery when their children are young. We understand this to be an issue of reproductive justice.

METHOD: Semi-structured interviews were conducted with parents of affected children and young people (n = 13). Thematic coding was used to identify data relating to gonads, ovaries, testes and gonadectomy. The data were analysed using discursive questions drawn from a reproductive justice framework.

ANALYSIS: Parents' talk about gonads suggests a process of sense-making that can be emotionally challenging. Our analysis situates their talk within broader societal discourses of ablebodiedness and the sex binary. Parents explained their choices and decisions by centring various understandings. Some explained how gonadectomy made sense for maintaining binary sex and following medical advice. Others emphasised the child's consent and bodily autonomy. Our analysis draws out how parents' decisions navigate reproductive justice *and* injustice.

CONCLUSIONS: Dominant beliefs about ablebodiedness and the sex binary appear to influence and frame decision-making about the gonads of children and young people with variations in sex characteristics. A crip, queer, and reproductive justice lens allows us to expand understandings of reproductive justice for all and potentially helps to destabilise and disrupt the sex binary.

Keywords: Intersex; reproductive justice; crip studies; queer studies; intersex, gonads; gonadectomy; qualitative; variations in sex characteristics; differences in sex development; healthcare

This article focuses on part of the reproductive anatomy: gonads. People with variations in sex characteristics, otherwise known as intersex variations, sometimes have gonads that do not develop typically. We understand this as gonadal variation. In the context of gonadal variation, it is not unusual for children or young people to undergo gonadectomy, and this issue is at the forefront of intersex activism and advocacy. Within intersex advocacy, as within other areas of reproductive justice, consent and bodily autonomy are central (Bird, 2005; Orr, 2022).

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Many children and young people with variations in sex characteristics undergo surgery that compromises their bodily autonomy, and that is done without their full, informed consent (Karkazis, 2008; Lampalzer et al., 2021). Some parents feel pressured to consent to surgery intended to make their child's body fit sexed norms (Lampalzer et al., 2021). Such surgery can include procedures at various ages to *normalise* genitals and remove gonads (Hughes et al., 2006; Lee et al., 2016). While gonadectomy is often explained as an attempt to mitigate gonadal cancer risk we understand *all* such procedures to *also* have a normative function and therefore be an issue of reproductive justice. We bring queer and crip theory to bear on questions about removing children's gonads in the context of a variation in sex characteristics.

Situating ourselves

As researchers, our work is always situated (Haraway, 1988). As people, we selectively express or obscure facets of our identity depending on context. Research is no different, and while we as authors are all familiar with our queer and feminist identities—rendering queer theory and issues of reproductive justice familiar—we wondered exactly *how* each of us is positioned with regard to crip theory. We (have) experience(d) a range of conditions (autoimmune diseases, chronic back pain and long Covid) and feel that we could have a (very) limited claim on disability. For example, Eileen's understanding of the social model of disability deepened when she realised that, during the Covid pandemic, the *lack* of societal mitigations and precautions taken by fellow citizens felt (and was) disabling as she has multiple autoimmune conditions. In this instance, despite never feeling disabled *as a person*, she often felt disabled by her *environment*. We all sit in a *disability-adjacent* space (albeit often with the privileges to mitigate the effects of any disability) and note, like others, that we feel a sense of "trepidation about laying false claim to histories of oppression, as well as a reluctance to simplify complex ways of thinking, feeling, and behaving" (McRuer & Mollow, 2012, p. 10). We approach the space where reproductive justice, crip and queer theory intersect with reflexivity and (limited) knowingness.

Eileen and Katrina are based in Aotearoa New Zealand, where some Māori people with intersex variations identify as ira tangata[1]. While the data we analyse are from Scandinavia and the United Kingdom, we see this issue as global and, therefore, as having relevance for practitioners in Aotearoa New Zealand. There are no clear statistics on how many people have a variation in sex characteristics (although the 2023 Census aims to capture this data (Stats NZ, 2021)). Currently, parents in Aotearoa New Zealand can consent to medical treatment on behalf of their children until the child is 16 years or over, with no requirement for court involvement in cases where the child is likely to be sterilised (McGeorge, 2018). Aotearoa New Zealand's limited legal framework for protecting disabled children and those with variations in sex characteristics from unnecessary surgery has been noted and condemned by the United Nations Committee on the Rights of the Child (Breen & Roen, 2023; UN Committee on the Rights of the Child (CRC), 2016).

Clinical context

Gonads is usually understood as the generic term for ovaries and testes. Some young people discover that, although they have been raised as a girl, they have internal testes. Some gonadal variations can not be simply described as ovaries or testes[2]. Some people are faced with the possibility of gonadectomy either in childhood or youth. In the case of complete androgen insensitivity syndrome (CAIS), for example, gonadectomy was standard practice soon after diagnosis (Deans et al., 2012). This changed in the early 21st century with research documenting the "negative impact of gonadectomy" in people's lives (Duranteau et al., 2020, p. 4) and some clinics "postponing prophylactic gonadectomy" (Cools & Looijenga, 2017, p. 176) in the context of CAIS.

For some diagnostic groups, gonadectomy in childhood can be lifesaving. For other diagnostic groups however, the risk of childhood gonadal cancer is much lower than previously thought. Gonadectomy impinges on fertility, hormone production and bone health (Weidler et al., 2019). Living without gonads necessitates hormone replacement therapy which can be hard to manage and potentially debilitating. Gonads are sometimes removed without parents being made aware of the choices open to them, such as retaining the gonads until at least after puberty. Intersex youth have spoken out about inadequate communication of choices about retaining gonads[3].

For variations where gonadectomy was once routine, attending to reproductive justice concerns means taking a gonad-sparing approach whenever possible. Some centres internationally now take such an approach, depending on diagnosis and data about malignancy rates (Steinmacher et al., 2021). The latest research suggests that decisions should be informed by shared decision-making (Döhnert et al., 2017; Steinmacher et al., 2021; Weidler et al., 2019).

Queering and cripping reproductive justice

Black feminists were the first to articulate notions of reproductive justice (thus expanding thinking beyond that of the pro-choice movement), with initial framings centred around three key principles: 1) the right to have a child; 2) the right to not have a child; and 3) the right to parent in a safe and healthy environment (Morison & Mavuso, 2022). Since these initial conceptualisations, queer scholarship has sought to broaden its framing beyond the boundaries of binary sex/gender and heterosexual reproduction to explicitly include and address advocacy for people outside these norms (George, 2020; Lane, 2019; Price, 2017). Some queer and reproductive justice advocacy groups work with an expanded definition of reproductive justice that prioritises bodily integrity and autonomy (Price, 2017).

George's (2020) work expands reproductive justice to include queer considerations, acknowledging: "Even within the reproductive justice movement's expanded conception of reproductive rights, advocates tend to ignore the queer community's specific reproductive issues" (2020, p. 672). Even within queered and expanded notions of reproductive justice, reproductive justice for people with variations in sex characteristics remains relatively unexplored (Morison & Mavuso, 2022). When reproductive justice for people with variations in sex characteristics is discussed, it is often conflated with the needs of transgender people and centres biogenetic parenting and access to assisted reproductive technology (ART) (Johnson et al., 2017; Rowlands & Amy, 2018; Stritzke & Scaramuzza, 2016). While we acknowledge this is important, and access to ART for people with variations in sex characteristics *is* an aspect of reproductive justice needing further exploration, it is not the only area of concern. The few who clearly bring intersex healthcare into reproductive justice understand that intersex surgery implicates "the fundamental questions of autonomy, equality, dignity, and liberty on which reproductive decision-making turns" (George, 2020, p. 702).

A queer, crip approach to intersex

Crip theory, which builds on critical disabilities studies, is sometimes considered analogous to queer theory (Kalender, 2010). Both crip theory and queer theory problematise naturalised norms, and avoid assimilationist strategies frequently found in other approaches to, respectively, disability and LGBTQIA issues (Kalender, 2010).

A dialogue between queer and crip theories has been under way for 20 years (Cohen, 2015; Kim, 2017; Martino & Schormans, 2020; McRuer, 2006) with Orr (2022) bringing intersex studies into the discussion. Orr draws on Kim's (2017) argument about "curative violence" perpetrated against disabled people to explain how medical interventions (including gonadectomy) on people with variations in sex characteristics seek to 'cure' the 'problem' of variations in sex characteristics. Orr noted that these procedures, akin to interventions on disabled people, are violent and aim to bring bodies with variations in sex characteristics in line with binary sex characteristics, ablebodiedness and heterosexuality—thereby exposing the compulsory nature of all three normative states. They note, ironically, that such interventions can be disabling. For example, removing gonads requires subsequent lifelong hormone replacement therapy, which can disrupt libido and increase the risk of side effects and other conditions, *including* cancer (Orr, 2022). Orr acknowledges that medical professionals "probably believe that the procedures they endorse and perform are benevolent … [and are] the best course of action" (2022, p. 61), but the concern remains that parents often do not have all the information before consenting to the procedure on behalf of their child. This speaks to the societal context for *all* decision-making involving bodies with variations in sex characteristics. Decisions about 'what to do' with the gonads of a child or young person with a variation in sex characteristics are about individual decision-makers *and* the discursive conditions permeating these decisions. We hope that by bringing notions of reproductive justice into the conversation, we can create space for counter-discourse that might destabilise the compulsory nature of all three normative regimes: heterosexuality, ablebodiedness, and binary sex characteristics.

Crip and queer theory as a lens for reproductive justice

Using understandings from crip and queer theory, we understand that *any* surgery on the reproductive anatomy falls within the remit of reproductive justice. Following Morison (2023), we take a postmodern approach to reproductive justice, focusing on intersecting power relations, centring marginalised groups and taking a social justice approach. We draw from theories that stand "for the dismantling of hierarchies and structural inequalities" and "for the recognition of differences, which elude categorisation" (Leibetseder, 2016, p. 142), keeping in mind the way pathologising categories have been used to define and constrain queer embodied subjects, disabled subjects and intersex subjects, among others.

In using crip and queer theory, we are not making claims about whether those with variations in sex characteristics are necessarily disabled and/or queer. Like others (Cohen, 2015; Cornwall, 2016; Martino & Schormans, 2020; McRuer & Mollow, 2012) we claim that bringing these theories together and considering variations in sex characteristics allows us to see what benefits emerge from cripping intersex studies (Orr, 2022, p. 8).

Four reproductive justice principles (drawn from the above literature) underpin the current research:

1. Consent: We have concerns about parents' and caregivers' (in)ability to meaningfully consent to gonadectomy. Research indicates that for parents, these decisions are challenging with (mis)understandings about the sex binary featuring in decision-making (Lundberg et al., 2019).

2. Bodily integrity: We believe that decisions about gonadectomy compromise the rights to bodily integrity of children and young people with variations in sex characteristics.

3. Reproductive status: We problematise instances where organs are primarily defined by their reproductive status rendering non-normative reproductive organs 'dysfunctional'. Gonads have

important physiological functions and psychosocial meanings beyond reproduction. We draw from crip theory to suggest that for some children and young people with variations in sex characteristics, gonadectomy is "curative violence" (Orr, 2022).

4. The right to a supportive parenting environment: We are troubled by instances where parents do not feel they had a genuine choice about medical intervention (Freda et al., 2015; Lundberg et al., 2017; Sanders et al., 2011) and may be pressured by child protection workers to consent to surgery (Rubin et al., 2022). Some parents experience a lack of support when making decisions about surgery, especially when choosing not to consent. Any such pressure violates a key reproductive justice principle: the right to a supportive parenting and birthing environment (Morison & Mavuso, 2022).

The current study focuses on parents of young people who have been involved in, or are subject to, decisions about gonadectomy. This study examines how they talk about gonads and their decisions around gonadectomy.

Method

This research was carried out in Scotland, England, Norway and Sweden as part of the SENS project (4). The analysis reported here draws from interview data with 13 parents recruited and interviewed in England, Scotland and Sweden. All participants were recruited on the basis that they had a child with a variation in sex characteristics. Parents were recruited via support groups.

The semi-structured interview guide prompted participants to talk about their experience of their child's diagnosis and medical intervention, and to talk more broadly about their life in general. Participants were given a gift card of approximately £15. Interviews were audio-recorded and transcribed word-for-word. Potentially identifying information has been deleted, and pseudonyms have been used to maintain anonymity.

This research was approved by the UK National Research Ethics Services (REC: 11/LL/0385 and 11/LO/0384); the Joint Research Office at University College London Hospitals (R&D Project ID: 11/0143), and the Ethics Committee at the University of Surrey (EC/2012/52/FAHS and EC/2011/68/FAHS).

Analysis

The data were coded thematically through line-by-line reading and rereading to identify excerpts relevant to the topic of gonads, ovaries, testes and gonadectomy. The analysis is structured by a series of questions that were used to interrogate the data (Corbin, 2021) and that enable us to investigate how research participants talk about gonads. The first questions we consider about gonads are: what to call them, how to understand them, how to feel about them, and then how to decide about them. Such questions helped us to explore meaning beyond the biological function of gonads to the discourses present. This could be understood as a first layer of questioning enabling us to organise and describe the data in detail. The second layer of questioning provides the framework for our more theoretically informed analysis and, thus, questions about reproductive (in)justice (Morison, 2023). This is guided by the questions: (1) What types of reasoning come into play when parents talk about deciding for or against gonadectomy on behalf of their children? And (2) what implications does this have for consent, bodily integrity, and reproductive justice?

Talk about gonads

Making sense of gonads and cancer risk

The language people use when talking about gonads and how they struggle with language gives us clues about how people think about this topic, what they associate with gonads, and what emotions come into play as they address it. Gonad-talk also tells us stories about how people articulate ideas and navigate discourses about the sex binary and ablebodiedness.

The terms used for these reproductive organs (ovaries/testes/gonads) are important in three key ways: first, the naming of these organs can seem at odds with a person's gender, and this can be very meaningful for the parents concerned (Lundberg et al., 2019); second, talk about these organs is often paired with talk about disease (Orr, 2022); third and relatedly, the language associated with this topic can be stigmatising (Bird, 2005; Orr, 2022).

Most participants who grappled with what to call ovaries/testes/gonads were parents of children whose variation in sex characteristics led to medical investigations and/or interventions. At the same time as learning to talk about their child's reproductive organs, they were grappling with biomedical understandings of those organs' potential for becoming cancerous.

Kezia explained that her daughter "hasn't got ovaries because they didn't develop; she had gonads, which is what you have when you start developing as an embryo […] and [the gonads] just didn't develop into anything, so they had to be taken out. It had to be taken out because she had a gonadoblastoma on one of them." Kezia moved from talking about "ovaries" and "gonads" to talking about an organ that "didn't develop into anything" and that "had a gonadoblastoma". Parents sometimes access literature to learn about their child's condition and talk with medical staff. It was most likely through this process that Kezia learnt about foetal development and concluded that her daughter's gonads "didn't develop into anything". The language used to refer to these reproductive organs may have a bearing on the decisions that can be made about them. The reproductive organs of Kezia's child are conceptually moved into a space of the undeveloped, the indeterminate, which is linked with the spectre of cancer.

Jasper's interview also suggested a process of developing an understanding of his daughter's reproductive organs that conflicts with normative expectations of gender and sex. Early on, he said, "we call them ovaries," and then, referring to the finding of cancerous development, he said, "they … found the … infected, um … ovary we call it". By this stage in the medical investigations, it was presumably clear that Jasper's daughter did not have ovaries. During the interview, the researcher offered the word "gonads", to which Jasper replied, "Yeah, gonads is a better word, yeah." Jasper explained, "it was quite some time before somebody actually said, 'It's actually testicular cancer'". Jasper's engagement with the language used by health professionals led him to various interpretations relating to his daughter's internal reproductive organs. In the interview, he returned to this question of terminology, saying, "it isn't even testicular cancer, it's gonads, isn't it?". He worked to move away from culturally discordant language by simultaneously grappling with new medical terminology, information that his daughter's reproductive organs are not "ovaries", confusion over what that means if his *daughter* has gonads that are not *ovaries* (then what are they?) and the concerning news that they may be cancerous. Even though several years had elapsed since the medical procedures, Jasper still grappled with these terms.

Miriam seemed to juggle similar issues. In referring to medical specialists, she explained, "they couldn't call them ovaries. They were calling them gonads by then. But … [another doctor] said testicular cancer". When asked if she talked with anyone about this topic, Miriam said, "only with my husband", explaining, "I didn't even tell her brothers and sisters in detail". The naming and potential stigma around these organs become interwoven as parents try to make sense of what clinicians tell them and as they try to develop narratives to share with family members. Miriam then explained what she felt able to say: "if anyone asked, I just said she had ovarian cancer".

Given that Miriam knew her daughter never had ovaries, this is an interesting narrative to develop for people who ask. Perhaps this reflects the stigma associated with gonads, especially gonads that defy sex/gender norms. Miriam's narrative reveals that it may be less stigmatising to say that her daughter had cancer than it is to say that her daughter did not have ovaries. In effect, Miriam smooths the discordance by aligning the terms for other people.

The topic of cancer and the associated discourses of risk and pathology weigh into how people feel about gonads and what decisions they might make. Next, we examine the language people used to refer to cancer, risk and pathology and then consider experiences people recount about cancer.

Parents used a wide variety of words to refer to their children's gonads as (potentially) pathological. Some said that the gonads "had gone to a gangrene" and were "infected" (Jasper), "hadn't developed properly" (Nia), "had a gonadoblastoma" (Kezia) "will be completely non-functional" (Matthew), "could become malignant later on" (Sara) or had "a slight risk of cancer" (Robert). Parents also described what they and their children had experienced while the issue with gonads was being investigated medically. They explained, "it was a whirlwind" (Enid), "we have had all these investigations done" (Kezia) and "It took … the medical establishment a little while to get to the bottom of it" (Jasper).

This assortment of pathology descriptions and the whirlwind of medical testing provided the context within which parents tried to make sense of their child's variation as well as new information about cancer and risk. To understand what is going on when parents are invited to make decisions about their children's gonads, we must keep in focus parents' new learning around gonads, as well as their response to cancer risk. These things will likely raise difficult emotions and weigh heavily in parents' decisions about their children's gonads and potential gonadectomy in a culture that privileges ablebodiedness and normative sex characteristics.

The emotions evoked in relation to bodies can tell us much about shared meanings (McDermott & Roen, 2016) and social norms (Ahmed, 2004). Parents spoke of their intense emotions when talking about gonads and gonadectomy. They referred to the situation as horrendous, their feelings of shock and desperation, and their experience of having wobbles and tears. Some parents described their worries and fears about what might happen. Tim, whose daughter was in preschool, described feeling "fearful" about how hormones from her gonads might "masculinise" her. He explained, "we were also worried that … somebody else would … see" the child's genital appearance that varied from 'typical' female appearance. He concluded, however, "nobody noticed anything". Nia also spoke about fears of what might happen, saying, "I thought she might feel more different if she looked different", and about her daughter's gonads, saying, "there is a fear of … them going cancerous". In relation to fears about what the child might feel and what other people might think, other researchers concerned with intersex healthcare have suggested that "parents should question their own fears … because their child might not share those fears" (Lampalzer et al., 2021, p. 478).

We understand emotion and affect as integral to the sense-making process, especially when that sense-making involves the body. This follows Wetherell's explanation of affect as "embodied meaning-making" (Wetherell, 2012, p. 4) and affective practice as drawing attention to the "relational negotiation of affect and emotion where people work together to make emotional sense"

(Martinussen & Wetherell, 2019, p. 109). Emotion and affect are important for what parents go through when told of their child's variation and how parents make sense of decisions about gonadectomy.

Explaining choices and decisions about gonads

Gonadectomy is the rational decision

In this part of the analysis, we examine how parents described decision-making about their children's gonads. This decision-making must be read in light of societal discourses framing sex/gender norms, ablebodiedness and the emotional context of gonads and cancer. Parents bear weighty responsibility to do the right thing on behalf of their children.

Nia explained that doctors recommended gonadectomy "cause they go cancerous". She said, "I felt quite happy with making that decision". She acknowledged things have changed in the 10 years since the gonadectomy: "there is *an argument* today that, that surgeons should not *advise* parents to do that and let the child make the choice for themselves later on" but still said, "we *felt* it was *right*" (italics our emphasis). Nia referred explicitly to argument, advice, and feelings of correctness, positioning parental decisions about bodily autonomy as subjective. Nia went on to note these are "big choices," but "even though I had wobbles about it and I was in tears, my husband [said] … 'we stick by what we agreed at the beginning.' And that paid off, it has hopefully." This could be interpreted as a strategy for managing uncertainty because abiding by the decision provides something to hold on to in the context of doubt and changing knowledge.

While willing to acknowledge this level of struggle and ambivalence, Nia repeatedly returned to a binary sex/gender rationalisation, explaining, "*we felt* it would mess [daughter] up more, um, being an in-between sex, that *we had to choose* one or the other. And *the evidence* that was given to us by the doctors … that she was being assigned as a female" (italics our emphasis). Here, Nia built an argument based explicitly on what "we felt" and on "the evidence". Her argument made sense so long as we understand sex as binary and the gonads as a threat to their daughter's binary sex.

On the one hand, Nia was open about her distress and ambivalence around the decision to go ahead with a gonadectomy in the first two years of her daughter's life. On the other, she repeatedly pointed to two underlying arguments for that decision: (1) the doctors recommended gonadectomy, based on the risk of gonadal cancer, and (2) retaining internal testes through her developing years might leave her daughter living "as an in-between sex". This is a familiar narrative in our data and is certainly not particular to Nia. It is, however, in contrast with some other parents we interviewed who gave clear rationales for not going ahead with gonadectomy.

Emphasising the child's consent and autonomy in decisions against surgery

Robert and Shirley centred consent and autonomy when discussing their decision-making. Robert said he did not want "to take decisions for my daughter", explaining, "that's a pretty important part of your body". He knew that "A lot of people decide, 'Well, it's part of me … I'm not losing it.'" Robert set limits on what *he* can decide *as a parent*. Shirley centred on the principle of gonad retention and letting the child decide later. She had read about adults who had experienced gonadectomy and could identify specific concerns: "despite hormone replacement therapy, it had negative effects. They felt less energy … less sex drive … there's negative things about it … there aren't any positives. I mean, the positives is that they [say] that it removes the risk of cancer … but I think with CAIS, the risk of cancer is very low … virtually 1 or 2%."

Shirley and Robert's accounts aligned with the reproductive justice principles of autonomy and bodily integrity (Morison & Mavuso, 2022). The way they spoke resonated with reproductive justice literature on parents reluctant to make fertility-related decisions on their child's behalf (Johnson et al., 2017, p. 404). They accepted that retention brought risk; however, the 'math' added up to the solution of centring their child's right to decide.

Juggling complex considerations of rights, "facts", and responsibilities

While Nia sat at one end of the decision-making continuum, and Shelley and Robert sat at the other, most parents seemed to negotiate a middle ground. Tim, for instance, described how the decision to remove their daughter's gonads was made "straight away", and they "pretty much tr[ied] to forget about it after that". He explained, "we can … live normally now until … ten, eleven" and then have "a serious discussion". Tim's explanation suggests that removing the gonads does not simply 'normalise' the child's sexed body. Instead, it seems to generate a little peace of mind. Tim explained that the pre-pubertal years would allow time to build an "open approach" to sexuality with their child to "broaden their mind".

Kezia's child had a gonadectomy early, and she found out later that this could lead to problems. Her explanation of the decision-making and later reflection is insightful:

> I am glad I didn't know [about potential problems] before [laughs] because I would have had issues with it, and that wouldn't be good if I had said no, don't do this, because I felt slightly pressurised into her having the laparoscopy, even though I said to them what is going to change in a year or two … shouldn't we wait for her to understand it better and give her own consent.

Kezia's experience reflects a common thread running through interview studies with parents whose children have gone through early surgery: parents do not always feel that they have given free and informed consent (Freda et al., 2015; Sanders et al., 2008), they sometimes feel pressured into 'agreeing' to medical procedures on behalf of their children, and they must live the rest of their lives with this knowledge. Such pressured decision-making violates not only the autonomy and integrity of the child but also the parent's right to parent in a safe and supportive environment.

Matthew explained the grounds for removing one gonad but said, "we're hoping we can keep one [gonad] to help … at least have a quasi-normal puberty". He explained the complexities of surgical decisions, saying they considered how it might be "even if [son] did wanna become a female". Matthew also explained that the decision was "fraught with … contentiousness. Between my wife and I" in relation to "the removal of the Müllerian structures"[5]. While Matthew "thought it was probably a good idea, [my wife] was not 100% sold … but … [the Müllerian structures are] underdeveloped, and … won't be of any use".

Matthew's account demonstrated the complexity of the decision-making required. Decisions about what surgery is deemed (un)necessary are layered and filtered through multiple discourses, including medical, parental responsibility, binary sex norms and bodily autonomy. He considered that leaving one gonad in place might allow the child to have "a quasi-normal puberty". Like Shirley and Robert, Matthew noted the reproductive justice principle of bodily integrity and autonomy—at least as far as the gonads are concerned. In making space for this, he also disrupted the sex binary by allowing for the possibility that his child may one day not want to be male. This is a complex juggling act; understandably, not all parents manage this.

Finally, Enid's description of the reasoning behind surgery for her child demonstrates a logic that is worth considering and contrasted with Matthew. She explained that, like Matthew's child, her child appeared to have one "functioning" gonad and one that is not. She said, "in his [the doctor's] eyes, if it's not really doing anything, it's worth removing because it's abnormal enough to potentially, in the future, be cancerous." Enid seemed concerned about receiving medical advice from someone who considers, "if you're already doing a surgery to remove one, if it's not useful, you might as well remove both." And, regarding the uterus, "if it doesn't have a purpose, and if it only can potentially cause infection, why not just remove it?"

Enid, like Matthew, juggled many complex considerations as she tried to contribute meaningfully to decisions about her child's health care. Both sought to retain one gonad and acknowledged that the child might want to make an independent decision about gender when they are old enough to do so. What was particularly interesting about Enid's account is her presentation of the surgeon's logic. The clear implication is that the surgical approach prioritises expediency: if doing surgery, we might as well take out everything at once; rather than prioritising the child's bodily integrity and the parent's and child's choice. This could be described as slippery-slope logic. This way of thinking may force parents into contentious discussions, and could lead to violation of principles of reproductive justice.

Reproductive (in)justice?

How adults make decisions about children's gonads raises questions about reproductive justice for people with variations in sex characteristics—especially children and young people. As we set out in the introduction, we have concerns about consent, bodily integrity, defining anyone through their reproductive status, and parental rights to a supportive parenting environment. These principles form the ground on which intersex human rights intersect with reproductive justice, and it is here that discourses of compulsory ablebodiedness and the enforced sex binary intersect.

Parents' decisions about their children's gonads occur in societal contexts that privilege specific ways of being a person, of inhabiting a body. Consideration of social context is critical to any reproductive justice analysis (Morison, 2023). Our data demonstrate that parents were conflicted over what was the *right* decision. Decisional 'rightness' involves present *and* future ramifications. This dilemma is common to all parents, considering the present *and* future child and potential ramifications (both from the child and wider society) (Ryan, 2020). Parents want to make the right decision, in part because (in Western culture) parents fear, not only judgement from their child (in the future), but social opprobrium if others perceive their decision to be wrong (Ramaekers & Suissa, 2011). Parents of children and young people with variations in sex characteristics must navigate these decisions in a culture that privileges those whose bodies align with the sex binary, ablebodiedness and heterosexuality. In this context, particular measures are needed to protect young people's consent and bodily integrity and to uphold parents' right to a supportive parenting environment.

Our analysis draws out distinct ways of thinking about childhood gonadectomy. These ways of thinking are embedded and located in the context of parents' bearing great responsibility. Some ways of thinking prioritise consent and bodily integrity, while others compromise these principles. These ways of thinking have broader implications for examining power, intersectional identities, and social justice, which are all foundational for reproductive justice. Table 1 sets out the reasoning that appears in our data and illustrates how that reasoning has implications for core principles in reproductive justice.

Table 1. Reproductive (In)Justice, Consent and Bodily Integrity

Promoting reproductive justice principles	• Wanting the child to be empowered to decide for themselves when they are old enough. • Striving to enable "quasi-normal puberty." • Exposing the child to respectful understandings about sexuality, gender and body diversity. • Wanting bodily integrity for the child.
Compromising consent and bodily integrity	• Utilitarian (able-bodied) approach: *If it's not working, take it out.* • Body-norm (able-bodied and dyadic) focused approach: *If it shouldn't be there, remove it.* • Queer fear: *We don't want our child to be in-between.* • No choice: *We went ahead with surgery without knowing about the options.* • Under pressure: *We felt under pressure to agree to surgery.*

The italicised phrases paraphrase data excerpts from this study.

The logic presented here is not novel—these arguments have long underpinned surgery on intersex children. Challenging this logic is central to seeking reproductive justice for children and young people living with variations in sex characteristics.

The current study raises questions about how we generally frame and respond to reproductive (in)justice issues. Understanding how gonads are positioned as dysfunctional for some people with variations has ramifications for how we think about other populations (for example, people with reproductive organ cancer, those experiencing menopause or infertility, and those who choose never to have children). Our analysis contributes to conversations about how to see people's bodies beyond their ability to procreate: gonads have meanings and functions beyond reproduction. Such discussions could destabilise the normative utilitarian able-bodied approaches we found in our data and disrupt the enforced sex binary (Orr, 2022). A reproductive justice approach to children and young people with variations in sex characteristics—such as that demonstrated by some of the parents we interviewed—would centre bodily integrity no matter the (dys)function and variation.

Our analysis demonstrates that issues of consent are bound up with complex and layered issues of power. Parents sometimes felt they had no choice and were pressured to consent to gonadectomy. Parents sometimes made hasty decisions about gonadectomy not just because of medicalised understandings about bodies but also a sense of queer fear. Parents need to be given space, conversational opportunities with co-explorations of understandings and time to move beyond these limiting framings *and* support their children so that they can make their own healthcare decisions when they are able to. Helping professionals such as social workers, and psychologists can assist parents to: 1) advocate for bodily integrity for their child; 2) question and potentially resist biomedicalised approaches; and 3) question their assumptions about their child's gender, fertility and variation. Such professionals can help define and demarcate a supportive environment for parenting—a fundamental principle of reproductive justice. (For guidance on this kind of psychosocial care, see[6].)

Conclusion: cripping and queering reproductive justice for all

Hegemonic sex binary and ableist discourses may support popular belief about the easy expendability of body parts that do not work as expected and dominate in medical settings—not only regarding variations in sex characteristics. The current study critically investigates the logic around childhood gonadectomy. We use crip and queer theory alongside a reproductive justice lens to show how young people's consent and bodily integrity are compromised in relation to gonadal variation.

Along with other authors (George, 2020; Orr, 2022; Price, 2017), we conclude that understanding of reproductive justice is enriched by crip and queer theory. In particular, we agree with George (2020) that "queer medical decision-making issues provide a clear opportunity from which the reproductive justice movement can build" (p. 702). Our analysis helps further understand coalitional opportunities between crip, queer and reproductive justice theories. We hope this analysis starts a conversation about centring reproductive justice for those with variations in sex characteristics that moves beyond the binary sex norms implied by discussions of pregnancy and ART *and* contributes more generally to conversations about reproductive justice.

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Notes

1. For an explanation of this term, see: https://www.intersexaotearoa.org/ira-tangata
2. For good resources describing variations more fully, see: https://ihra.org.au/18106/what-is-intersex/
3. Young people from North America https://www.facebook.com/watch/?v=10154742737199605, Europe https://interactadvocates.org/i-discovered-im-intersex-from-the-buzzfeed-video/ and Aotearoa New Zealand https://www.renews.co.nz/im-intersex-and-i-wish-doctors-had-left-my-body-alone/ have posted online about their concerns in order to raise awareness.
4. For more reporting of the SENS project, see:
    - **a.** Hegarty, P., Prandelli, M., Lundberg, T., Liao, L.-M., Creighton, S., & Roen, K. (2021). Drawing the line between essential and non-essential interventions on intersex characteristics with European healthcare professionals. *Review of General Psychology*, *25*(1), 101–114. https://doi.org/10.1177/1089268020963622
    - **b.** Joy, E., Lundberg, T., & Roen, K. (2023). Experiencing "the wrong kind of puberty": Navigating teenage years with a variation in sex characteristics. *Youth, 3*(1), 465–476. https://doi.org/10.3390/youth3010032
    - **c.** Liao, L.-M., Hegarty, P., Creighton, S., Lundberg, T., & Roen, K. (2019). Clitoral surgery on minors: An interview study with clinical experts of differences of sex development. *BMJ Open*, *9*(6), e025821. https://doi.org10.1136/bmjopen-2018-025821
    - **d.** Lundberg, T., Dønåsen, I., Hegarty, P., & Roen, K. (2019). Moving intersex/DSD rights and care forward: Lay understandings of common dilemmas. *Journal of Social and Political Psychology*, *7*(1), 354–377. https:/doi.org/10.5964/jspp.v7i1.1012
    - **e.** Lundberg, T., Roen, K., Kraft, C., & Hegarty, P. (2021). How young people talk about their variations in sex characteristics: Making the topic of intersex talkable via sex education. *Sex Education*, 1–16. https://doi.org/10.1080/14681811.2021.1911796
    - **f.** Roen, K., Lundberg, T., Hegarty, P., & Liao, L. M. (2023). Whose responsibility is it to talk with children and young people about intersex/differences in sex development? Young people's, caregivers' and health professionals' perspectives *Frontiers in Urology*. https://doi.org/10.3389/fruro.2023.1089198

5. Müllerian structures might otherwise be called fallopian tubes and uterus, however Müllerian ducts develop into the vas deferens and seminal vesicles in 'male' development.
6. Guidelines can be found online, tailored for clinicians (http://www.accordalliance.org/dsdguidelines/htdocs/clinical/index.html) and for caregivers (https://dsdguidelines.org/). Resources have also been developed by community-based organisations such as dsdfamilies in the UK (https://dsdfamilies.org/resources) and InterACT in the US (https://interactadvocates.org/resources/intersex-resource-topics/intersex-health-and-sex-education-in-schools/). Intersex Human Rights Australia provides information about health, wellbeing, and peer support for intersex people (https://ihra.org.au/health/). Intersex Aotearoa offer a range of resources for raising awareness about intersex (https://www.intersexaotearoa.org/resources).

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