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A relational approach to youth healthcare: examining young people's, parents' and clinicians' experiences in the context of variations in sex characteristics

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Abstract

According to popular understandings, children grow from a state of dependence to eventually become independent adults. Interdependence helps to disrupt the in/dependence binary and is a useful concept for making sense of the experiences young people with variations in sex characteristics in relation to healthcare. This study used semi-structured interviews with 32 health professionals, 33 caregivers and 12 young people recruited in the UK and Sweden. The analysis is guided by the questions: (1) how do young people, carers and health professionals position themselves in the adult/young person relationship in the context of healthcare? (2) how is the (in/ter)dependence of young people imagined when young people, carers and health professionals talk about healthcare? Our analysis shows how carers and health professionals might support dominant understandings about young people growing towards independence while providing little opportunity for young people's agency and voice. Interviews with young people gave clear examples of their negotiating relational ways of being, seeking agency in the context of healthcare and not simply becoming independent of adults. This analysis also draws attention to the ways young people might be silenced within healthcare contexts. The present paper is based on secondary analysis of data from the SENS project. It works with concepts of relationality and interdependence to draw out the possibilities of voice and agency for young people with variations in sex characteristics in healthcare contexts.

Keywords

Intersex, variations of sex characteristics, young people, healthcare, relationality, interdependence, parents, agency, qualitative

There has been a change over decades towards rethinking healthcare so that children and young people's voices can play a meaningful role (Gabe et al., 2004; Krockow et al., 2019). The current paper examines how this works for young people with variations in sex characteristics, also known as intersex variations or differences in sex development (Delimata et al., 2018). This focus on young people's voice and agency in the context of intersex healthcare is timely as recent years have seen the publication of human rights statements that clinicians have not adequately taken into account intersex children and young people's rights (United Nations Human Rights Council, 2013; United Nations Human Rights Office of the High Commissioner, 2023). Simultaneously, there has been a growth in youth-led intersex advocacy and activism. Youth-focused intersex research continues to highlight the importance of youth agency in regard to healthcare (De Clercq, 2021; Lundberg et al., 2016; Lundberg et al., 2021; Steers & Andrews, 2021; Steers et al., 2020), but this research does not tend to foreground a relational perspective. Youth agency is important in the context of any health issue a young person might face. It is a particular issue in relation to the medicalisation of variations in sex characteristics because of the lifelong harm that can be caused by medical interventions on sexual and reproductive organs early in life (Crouch et al., 2005; Roen, 2023; Schützmann et al., 2009). Over some decades, intersex advocates and researchers have been documenting the harms caused by the medicalisation of intersex children (e.g., Carpenter, 2020; Chase, 2000; Holmes, 2009).

The present research is located within dialogues about interdependence and relationality. It is increasingly understood that the notion of "youth as a transition from dependence to independence is problematic" (Thomson & Holland, 2015, p. 2). Within youth studies, commentators underscore the importance of a "critically informed relational focus" (O'Dell et al., 2017, p. 153) and write about "parental care relationships, where ideas of

dependence/independence are replaced by those of interdependence" (Whittle, 2022, p. 674). Through understandings of relationality and interdependence, it is possible to rethink concepts of care, vulnerability and agency. We draw on these concepts as we lay the foundation for taking a relational approach to the healthcare of children and young people with variations in sex characteristics.

Childhood studies researchers argue that "agency and vulnerability must be understood from a relational perspective" (Roest et al., 2023, p. 383) if we are to better understand human interactions in context. From this point of view, agency and vulnerability are not located within young people in clinical settings but are located within the network of relationships that make up healthcare processes. The role of those responsible for healthcare is not simply to protect young people because they are "vulnerable" or to give young people voice but, instead, to consider how the network of relationships can be configured to promote interdependence and agency.

Relational approaches can be traced back to Indigenous thinking and feminist research that challenges Western, individualist and masculinist assumptions about human life. Indigenous scholars have long problematised Western preoccupations with independence, suggesting a different onto-epistemological approach to understanding how humans are in relation with one another and the world (Wildcat & Voth, 2023). For Māori (Indigenous people of Aotearoa New Zealand), a state of total independence is akin to being *unhealthy*, since "to be human means understanding ourselves through our relational entanglements" (Hamley et al., 2021, p. 8) and can be expressed by the term whanaungatanga (Durie, 1998). The African concept of ubuntu contributes to understandings of relational ethics and interdependence and has been widely drawn on, including among health professionals (Ewuoso & Hall, 2019). In a North American context, relational epistemologies of Cowichan tribes provide a way of understanding how everything and everyone is connected (Elliott-Groves, 2019). Concepts of

connectedness are theorised in Pacific contexts, including Tongan and Samoan cultures, through the idea of vā. “Vā is the space between … not space that separates but space that relates, that holds separate entities and things together … giving meaning to things” (Wendt, 1996). It is worth reflecting on how relationships are conceptualised in Western healthcare contexts, and health sciences, and contrasting that with frameworks of understanding that centre relationships, enabling concepts such as whanaungatanga, ubuntu and vā to make sense.

Working in parallel with Indigenous understandings of interdependence and relationality, a thread of feminist literature problematises the over-valuing of independence (Harding, 1986). Miller and Stiver’s (1977) work in psychology highlights how individual-focused psychology seemed unhelpful from the point of view of trying to understand women's relationships and emotional connections. They also questioned the idea that children are supposed to become independent from their parents, instead suggesting that relational connections between people, fostering growth, is needed for psychological development.

Miller and Stiver (1977) point to the many books that urge women to become independent, telling them that they 'love too much.' Strong connections are deemed immature in both popular and academic psychological understandings, and women who maintain strong connections are blamed for doing something wrong. Young people’s close connections with one another are also undermined, as though one should strive to grow away from those youthful connections and achieve an individualist goal of independence (Lesko, 2001). The overvaluing of individualism and independence and the “repudiation of capacities for… emotionality and dependence” (Layton, 2010) might best be understood as aspects of “the psychic life of neoliberalism” (Gill & Orgad, 2018; Scharff, 2016).

Thinking relationally helps us to take a critical approach to the power/knowledge dynamic and to strive for ethical ways of working in institutions. Some scholars urge “those who hold

privilege ... [to] incorporate relational thinking into their ... institutional practices, and to reflect on power relations that mark some knowledge and bodies as universal, and others as marginal" (Kinkaid et al., 2022, p. 1567). Agency is hindered by relational inequality (Litalien, 2021) and promoted by ethical ways of working. Agency is important because it is linked with one's subjective existence (Krause, 2015) and one's personhood (Litalien, 2021). It is worth considering how these understandings about agency, power and marginalisation could be used in the context of reworking the healthcare relationships within which young people with variations in sex characteristics find themselves entangled.

Some researchers have brought relational thinking into healthcare contexts. Jämterud, for example, highlights the necessarily relational nature of healthcare, explaining how relationality and autonomy can work together with "the patient exercising their autonomy within a framework of relations" (Jämterud, 2022, p. 952). Autonomy has particular valence in intersex studies as it is conceived as bodily autonomy – the chance for an intersex person to make their own medical choices – and understood alongside bodily integrity as a human right (Carpenter, 2016; Crocetti et al., 2021). Jämterud, writing about healthcare generally, explains that fostering relational autonomy requires "a trusting interpersonal environment, and continuous and personal discussions both within the team as well as with family and patients" (Jämterud, 2022, p. 958). It is worth considering how relational autonomy and bodily autonomy might play out when young people with variations in sex characteristics engage with health services.

A relational approach to healthcare can sit in tension with objectivist approaches that are often regarded highly within health sciences. This point is translated to the specific context of healthcare for people with variations in sex characteristics by Lih-Mei Liao (2022). Some commentators who examine power relations between different ways of knowing have pointed out that Western scientific knowledge has been established as a singular, dominant,

"objective" way of knowing that promotes hermeneutical ignorance (Pohlhaus Jr, 2012) and epistemic injustice (Fricker, 2007). Arguably, we all have an ethical responsibility to attend to ways of knowing that have been developed from positions that we ourselves do not experience (Pohlhaus Jr, 2012). This is understood as "ethics built on the foundations of relationality" (Birhane, 2021, p. 5).

Within the Western cultural context of the present research it is often assumed that, during teenage years, parental relationships are renegotiated with young people beginning to play a bigger role in making decisions about things like healthcare. In this paper we examine how young people with variations in sex characteristics talk about their relationships with carers and health professionals and the extent to which they experience autonomy. Their talk troubles any assumption of a linear progression from (child) dependence to (adult) independence. Rather, young people negotiate how they want to be in relationship with others, including parents/carers, other family members, health professionals, and friends.

Research process

The present analysis draws from semi-structured interviews with 32 health professionals, 33 carers and 12 young people recruited in the UK and Sweden. Health professionals were recruited based on their involvement with a multidisciplinary team working with people who have diagnoses relating to sex development. Carers were recruited based on their experience of raising a child with a diagnosis relating to sex development. Young people were recruited based on their lived experience of having a diagnosis relating to sex development. Participants were primarily recruited via clinical networks.

The data set as a whole was organised thematically. Excerpts addressing questions of control, (in)dependence and children/young people's development were identified. This material was

then considered in dialogue with literature from youth studies and addressing relationality and interdependence. The analysis is guided by the questions: (1) how do young people, carers and health professionals position themselves in the adult/young person relationship in the context of healthcare? (2) how is the (in/ter)dependence of young people imagined when young people, carers and health professionals talk about healthcare?

The current paper presents a secondary analysis of the SENS dataset that has been introduced elsewhere (Hegarty et al., 2021; Roen et al., 2023). The SENS project invited participants to talk about their experience and understandings – their sense making – around diagnoses and treatment practices relating to sex development. The primary analysis focused on individual participant groups and dilemmas they faced (Liao et al., 2019; Lundberg et al., 2017; Lundberg et al., 2016). The present analysis is novel in bringing data from three different participant groups into dialogue for the purpose of building understanding about relational aspects of the sense making process to which all participant groups contribute.

The young people, carers and health professionals quoted in this paper do not necessarily know one another and they refer to a wide range of variations and medical conditions. The point of this paper is not to focus on specific variations or diagnoses but to develop broad understandings about relational ways of engaging in the context of healthcare.

This research was reviewed by the following research ethics committees: (i) health professional interviews: NHS National Research Ethics Service (reference: 11/LO/0384); University of Surrey Ethics Committee (reference: EC/2011/68/FAHS); (ii) young people and carer interviews: National Research Ethics Services: NRES Committee London/West London (REC: 11/LL/0385); Joint Research Office at University College London Hospitals (R&D Project ID: 11/0143); Ethics Committee at the University of Surrey (EC/2012/52/FAHS); (iii) carer interviews: The Norwegian Social Science Data Services (32055/3/MAS).

The data analysis is reported under the following two headings: (1) growing towards independence? And (2) negotiating interdependence and thinking relationally. These headings provide a way of structuring the analysis and bringing the data into dialogue with understandings of interdependence and relationality.

Growing towards independence?

The parents and health professionals we interviewed made it clear they regarded increasing independence as a natural and inevitable part of a young person's journey into early adulthood. We present examples of how parents and health professionals spoke about who is in control of the treatment process, and the potential of a young person taking more responsibility for their healthcare over time. The point of presenting data from parents and health professionals here is to think broadly about the relational context within which young people might strive to have some autonomy and attain some control over their bodies and healthcare. Parents we interviewed often drew from popular understandings of growing towards independence and some spoke in ways that suggested they anticipated having ongoing oversight or concerns as their children grew to adulthood.

Parents of younger children talked of an imagined future where their child becomes more independent and some shared their mixed feelings about this. Lily pictured "the early stages of independence" and said "I'm terrified about her going to college and out in the world. But I don't want to stop her". Kezia spoke of a future where her daughter is "a grown-up" and expressed worry, saying "oh my God who is going to marry her like this".

Participants whose children were already young people spoke somewhat more confidently of independence. Linda said: "you can't not encourage your children to become independent". She continued: "you don't want to raise them so they depend on, on you for the rest of their

lives." Similarly, Alicia said "I think in the end … you have to step back because … they've got to live their own life." Despite this acknowledgement, the movement away from childhood dependence is not something that happens without effort.

Some parents tempered their endorsement of independence, citing the medical condition as a reason. Anna, for example, said: "I'm happy for them to be independent, but I still need to be aware of everything". She admitted that she has "always wrapped them up in cotton wool and made sure that wherever they go I'm there". Melissa reflected on the bumpy transition period as her daughter started having to take responsibility for her own health. Melissa said "I think when … she turned 16 it started being more her thing to deal with … and less of mine. … I still worry but, now she owns some of it." Melissa continued: "I would say she's been absolutely terrible… understanding her own condition is just (laughter) a nightmare."

Given the weight of parents' concerns, what space is there to imagine a young person experiencing bodily autonomy and taking responsibility for their own healthcare? In the text above, we see the idea that young people must become independent as well as marked concerns about whether this would go well for them. This could leave limited space for young people's bodily autonomy and decision-making. It clearly also leaves parents worrying.

The health professionals we interviewed drew from popular understandings of young people growing towards independence as they described clinical interactions. The data we examine here address questions of control, agency and autonomy.

At some point, it might become desirable or necessary for a young person to attend medical appointments without a parent present. Health professionals explained that young people reach a point where they leave their parents in the waiting room. When asked what they observe when a person is going through puberty, Alex, a paediatric endocrinologist said

“when I go out in the waiting room I always just say the child’s name … and then the child and the parent will come but then at some point they leave the parent in the waiting room”. Alex took this as a sign of the young person's development. Both health professionals and young people described examples where they had made space for healthcare conversations to take place without a parent present. This sometimes involved directly asking the parent to stay in the waiting room. One mother, Anna, reflected: “now they’re getting older and I get asked to leave the room sometimes. (laughter)” acknowledging that this is in tension with her “need to be 100% … aware of what’s going on”.

On the topic of who makes decisions about the medical treatment of young people, we were curious to understand what level of input carers and young people might have. For some young people with variations in sex characteristics, hormonal intervention is needed to enable pubertal development. With regard to such puberty induction, we asked health professionals “… between you and the parents then, what are the points of negotiation, or what are the things that they [want]?” Sam, a paediatric endocrinologist explained: “… some parents will want to start [puberty induction] a little bit early and you just then explain the pros and cons of that … Others want to delay it because they feel that their children aren’t quite ready for it … they wanna try and control it and leave it as late as possible … the majority will go by your advice”. This suggests that, when parents try to “control” their child’s puberty induction, they may be advised otherwise by endocrinologists.

One paediatric endocrinologist explained that “we wish to induce puberty at … the appropriate tempo” and over “an appropriate period of time” and that “we are guided by the physical changes” (George). This suggests that it is the young person’s body and its response to medication that guides treatment. We were interested to find out how much leeway there might be for a young person’s wishes to be taken into account so we asked “what about the young person’s own reports of how they perceive their development”? George replied: “it

tends to be more an issue with the girls … Who say that, ' … [I] have been taking oestrogen but my boobs aren't big enough.' And you think, 'Well actually … all boobs come in different shapes and sizes ...' So again it's managing their expectations here … as long as there are progresses within the normal range then I think one should be satisfied". It seems that puberty induction is determined by the bodily response to medication and by endocrinologists who respond to parents' and young people's wishes by "managing their expectations". It is not clear from our data that young people's voices are prioritised in relation to decisions about puberty induction.

While puberty induction is one intervention that would hopefully engage young people in dialogue with carers and clinicians, another type of clinical intervention where young people's bodily autonomy is most pertinent is vaginal construction. Some clinicians stressed the importance of letting young people initiate this conversation. Lee, a paediatric surgeon said "we counsel parents right from the beginning that vaginal surgery would be when their daughter requests it". Ali, a gynaecologist working in a transition clinic explained that, when girls with CAH come into the clinic they are "often not at an age or stage where they actually want to engage with how the vagina works" and "they might be well into their 20s before they are ready to engage about 'how am I going to make my vagina work?'" So the role of the clinician is to be available when needed, perhaps starting by saying "this is something that … you might want to be interested in the future, and I'll help you with it if you want me to" (Ali). Here, the gynaecologist positions themselves as offering "help" with making the "vagina work" if a person with CAH wants that. This explicitly assigns agency to the young person, allowing them to set the pace and decide if and when they "want" "help". It also presumes a heteronormative frame of reference where the vagina is expected to "work" in a particular way (Alderson et al., 2018; Roen et al., 2018). Young people in this clinical setting might have the agency to ask for "help" with their vagina, but what opportunities are there for

young people who prefer to think outside of body-normative and heteronormative assumptions about what the vagina is for and how it is expected to "work"?

Although a number of clinicians stressed the importance of the young person's choices with regard to vaginal construction, it was a parent who spoke of involving different sources of knowledge by talking with people with lived experience. Tim said in relation to dilation or surgery "I think it … does help … to talk to people … that are like you" and not just medical professionals. Tim was clear about the importance of relational connections and diverse ways of knowing contributing to his daughter's decision about vaginal interventions. By highlighting lived experience and diverse forms of knowledge, Tim could be interpreted as bringing epistemic credibility to those with lived experience. Conceptualising bodily autonomy involves thinking about diverse relationships (including peer support relationships) that might contribute to one's bodily choices rather than imagining an independent (disconnected, isolated) individual making "free" choices. Important work has been done by intersex advocates and allies to foster peer support relationships and some research foregrounds peer support relations more than the current paper (De Clercq, 2021; Steers & Andrews, 2021).

The data presented in the present paper offer insight into how parents and health professionals think about the bodily autonomy and independence of the young person who is growing up with a variation in sex characteristics. The data reflect popular understandings of development as a linear trajectory from dependence to independence. We also see, embedded in the data, assumptions that are unlikely to hold true for young people with disabilities or chronic illnesses where the need for (inter)dependence might be more obvious. The data illustrate how, in drawing from dominant understandings about development and (in)dependence, carers and health professionals might, intentionally or not, push back against

a young person's attempts to take control of their own situation, make decisions about their own healthcare and have some say about their own body. The data show examples of parents who, while stating that young people must grow towards independence, make more or less pronounced efforts to maintain control or oversight. The data also show examples of clinicians who, while acknowledging that pubertal and adolescent changes involve increased independence, seem quite clear that the puberty-related treatment plan they set out is the "best" plan and should not be altered by the wishes of young people or parents. Our analysis suggests that any attempt a young person might make to assert bodily autonomy or try to be in control of their situation may be met with contradictory responses. On one hand, adults tend to agree with the popular notion that young people become more independent over time. On the other hand, adults might find it difficult to foster such independence and this is exacerbated by medical contexts where there might be little opportunity for bodily autonomy. One possible way to address the tension presented here is by engaging the concept of *interdependence*.

Negotiating *inter*dependence and thinking relationally

In the following analysis of data from young people, we consider (1) young people negotiating parental presence in the clinic, (2) what kinds of relationships young people want with health professionals, and (3) young people managing adult-to-adult relationships with parents.

Ella was clear from very early on that she wanted to attend medical appointments without her parents, but recognised that not all young people want that. Like other participants, Ella considered that the young person should be included and at the forefront in all their healthcare decision-making. Ella captured this best when she said: "people are different … I think the only blanket rule would be like, ask the child, teenager, what they want". She noted

that some people would like "parents to act as intermediaries". Ella was convinced that her parents were not qualified to discuss medical matters and this stemmed from how they communicated her condition to her during her teen years which left her feeling angry:

> My parents had this idea that it would be better for them to communicate the diagnosis … they had this kind of vision in their head [that] … I was … [a] desperately naive little person who wouldn't be able to like cope with the idea of a disorder of sex development. Um, so I'm annoyed with them for thinking that and I'm annoyed with the doctors for letting them.

Relationality is centred even when absent. From Ella's perspective, her parents' failure to understand her damaged the relationships with her *and* the medical professionals.

While Ella's views were firm, it is important to allow for the possibility of change over time. This was highlighted by Maggie who reflected that while she felt "really embarrassed that my mum and dad were there" when the health professional told her about her condition, she was later "glad they were there because I wouldn't have been able to tell them" and talking with them about it "would have been really awkward". Young people need space to reflect and change their mind about what they need from relationships with the adults around them. This does not mean that young people do not know what they want and that adults know best. Rather, it means that young people *just like adults* can shift in their views. It is worth allowing space for regular check-ins by carers and health professionals where decisions made previously are reviewed.

While some young people proactively excluded parents from visits with health professionals, many found this hard. Ashley found it difficult to ask parents to leave even when health professionals said "the parents can go out" she felt "it's just a bit awkward". When we asked

"would it be good that the clinician said like well now the parent has to go out for a while?" Ashley replied "Yeah … Like it's not a question, it's just like ten minutes and then you don't have to say anything, but you can if you want." The point is for Ashley to have an opportunity to speak alone with a health professional, whether or not she has something particular she wants to say during that time. Ashley articulates the need for health professional help in creating a *regular* space *away* from parents so that young people do not have to ask for it. Through this proposed workaround Ashley hints at possible relational risks in expecting young people to *explicitly* advocate for themselves and constructs a relationally-centred solution. The proposal allows space for whatever the young person wants — independence, dependence or interdependence — something emphasised later by Ashley when she explained:

> I can go by myself [to appointments], but it's just easier with [Mum]. But [Mum's] like, I don't know if she was saying like basically come by yourself, but if she does I'll just probably bring my friend or something.

Here we see that Ashley's mother creates space, perhaps even pushing Ashley towards independence, however Ashley pushes back and renegotiates, centring relationality and interdependence. At this point in time, Ashley prefers having someone with her, either her mother or a friend. This negotiation that Ashley describes resonates with Jämterud's comment that relational autonomy "reconciles the patient's situation of being dependent on care, receiving help while at the same time having one's autonomy respected. Furthermore, it recognises that autonomy is played out in relations." (2022, p. 957).

Both Maggie and Ashley engage relationality and interdependence. Through their talk, we see how vulnerability and agency can work together. This is a version of agency where people are interdependent. Maggie and Ashley acknowledge life's emotional challenges and the feeling of vulnerability and they find ways to seek support from others, sometimes

parents.

Like Ella and Ashley, Cheryl wanted health professionals to think more carefully about the relational aspects of the healthcare context. Cheryl explained that health professionals "kept getting my Mum involved, and I kind of thought … if I was old enough to be told all of that, I should've just been told, and without my Mum being there." Cheryl wanted space to explore emotions with health professionals. She felt that health professionals focused on "specifics" and "weren't really worried about my feelings". Cheryl wanted more opportunity to talk with health professionals about things that mattered to her, such as societal expectations of having children and raising a family. She implied that health professionals need to understand that for young women, learning that they may never conceive children in a 'natural' way can disrupt powerful societal norms in ways that need to be talked about. What matters is a relational approach that allows space to talk about social and emotional topics. The point is to take a "critically informed relational focus" (O'Dell et al., 2017, p. 153) addressing *interdependencies* rather than simply assuming that children are dependent and become independent.

Taking a relational approach means understanding interdependency as well as acknowledging the possibility of change over time. Josephine looked back over her younger years and reflected on this change. She experienced the shift from paediatric to adult services as an important catalyst. Josephine acknowledged that, although she needs someone to "look after me medically" in fact, "if I … had a choice I probably wouldn't share any … information" and when clinicians tried to engage her it was "like [they were] invading my bubble". She spoke of feeling "more comfortable" with her current specialist than she had with doctors who had known her from "when I was a child".

Josephine did not want to share things with the clinicians who had known her throughout her childhood. The different kinds of relationships within the adult healthcare context allowed

her to feel more comfortable talking with clinicians. Effectively, Josephine was situated within the child services in a way that led to her self-silencing. In adult services, however, Josephine began to feel comfortable to build healthcare relationships where she was no longer silent. We might understand this as a relational dynamic that is not simply about paediatric or adolescent services; any health service involves relational dynamics that could produce self-silencing. We suggest this distinction is worth exploring. Being curious about why a child or young person is silent, and thinking relationally about that, might open the way for relational dynamics that better enable children and young people to play an active role in conversations about their bodies and healthcare. We suggest that it does not help to attribute a child or young person's silence to non-understanding, disinterest, or immaturity. Rather, silence can be understood as part of a wider relational dynamic that needs to be addressed in order for ethical healthcare to be possible.

Josephine went on to say "I guess in … looking after children you don't so much give them an option … they don't really know what's best for them or the way forward medically I guess. So you just do what you think is best". She described how after she left paediatric services, health professionals asked her what she wanted "whereas I don't think they were (laughter) so bothered previously". Josephine described how engaging with paediatric services felt like "me trying to keep things from them, and them trying to take things from me". Here, Josephine characterises the relationship between paediatric specialists and her "adolescent" self as a power struggle that involves "keep[ing] things" or "tak[ing] things" from one another. Josephine used self-silencing (her "bubble") in an attempt to retain some control in a relational dynamic where she was not comfortable.

Throughout our research, clinicians often commented that young people do not necessarily say much in clinic. Sadowski and colleagues distill ideas from relational research that offers an interpretation of silence and could be applied in this context. The key points they put

forward relate, first, to the way young people in "socially subordinate groups" (Sadowski et al., 2009, p. 178) tend to silence "themselves in order to be with other people" (Gilligan, 1996, p. 245). And, second, the "relational paradox" (Miller & Stiver, 1977, p. 81) where girls "dissociate from their thoughts, feelings, and knowledge – in a sense losing relationship with themselves – in order to maintain relationships with others, especially those who are part of dominant social groups (e.g., boys and adults)" (Sadowski et al., 2009, p. 178, drawing from Taylor, Gilligan and Sullivan, 1995). What might this theorising about silencing mean for young people like Josephine? It is possible that some young people with variations in sex characteristics are silenced by the context and/or they silence themselves in order to remain in healthcare relationships. This might involve a degree of dissociating from what they think, feel and know. Our analysis suggests that participating in healthcare relationships under these circumstances might force them out of relationship with themselves and this resonates with the research findings of Georgiann Davis (2015). What might the implications of this be for the well-being of the young people concerned? How might it affect their ability to participate in decision-making about their own bodies and healthcare?

It is important to think critically about the meaning of silence – remembering that silence is not assent – especially in the context of youth healthcare. For families where there is a variation in sex characteristics, silence must be read in the context of long-standing patterns of shame and secrecy around this very topic (Roen et al., 2023). Silencing should also be understood in the context of clinical practices that centre looking at, and intervening on, a person's body rather than engaging that person in dialogue (Roen, 2019). This includes the practice of (unwanted) genital examination that can be experienced as intrusive and aversive, leaving the person feeling different or like a "freak" (Meyer-Bahlburg et al., 2017). When Sanders and Carter asked young women with variations in sex characteristics to talk about their healthcare experiences, some young women described switching off and withdrawing

from dialogue rather than engaging with health professionals (Sanders & Carter, 2015). We think it is important to read this kind of self-silencing and disengagement in the context of clinical practices that involve looking at the genitalia of people with genital variations, seeking to undertake genital examination in a context where some will experience such examination as obligatory (Engberg et al., 2016) and some will leave the clinic feeling angry and horrified at having been asked to undergo such examination (Sanders et al., 2017). Some write about this clinical dynamic and its long-term emotional effects, comparing intersex genital interventions with sexual abuse (Schützmann et al., 2009; Tosh, 2020). It is also worth noticing the extent to which testimonial silencing (Dotson, 2011) is a feature of contemporary responses to people with intersex variations (Baratz & Karkazis, 2015). That is, the accounts of intersex people are often discredited and not regarded as valid accounts that could inform clinical practice.

Eventually, as a young adult, Josephine talked about deciding to undergo surgery and choosing not to tell her parents until the last minute. She explained that she had been reluctant to tell her parents but "I had to tell them … it's again almost like that ownership thing, so it's my stuff… I don't want to have to tell you". When young people have spent years of their lives with limited agency over their bodies, it is not surprising that they might choose to withdraw emotionally or withhold information. When she became old enough to make decisions about surgery, Josephine understood that it was a matter of "ownership" in relation to her body and her healthcare that made her reluctant to tell her parents that she had decided to go ahead with surgery. We see this not as a sign that she has reached "independence" but, rather, that she is negotiating a new kind of relationship with her parents where she is *doing* agency in the context of healthcare decisions and information sharing. Negotiating agency and building relationships of interdependence takes time. This is part of

the "relational ebb-and-flow of family life" (Mila-Schaaf, 2006, p. 11) occurring across a lifetime.

Some young adults we interviewed reflected on their current parental relationships. Chloe spoke in a way that suggests an adult-to-adult mother-daughter relationship. In relation to a peer support group she joined around the age of 19 years, she said "I told my mum that I was in the group … and she was like, 'Oh that's great.'" Chloe noted that some girls' mothers also participated in the support group but she considered that she did not have to invite her mother. Chloe said "if she wanted to find [a support group] I'm sure she could." Chloe was not aware of her mother being involved in a support group and considered that is "obviously because she feels like she is fine and I'm sure she is". Chloe said "now I'm an adult … I'm less involved with what she does in terms of talking to people." This is an example of relationality and interdependence: here, the adult daughter is reflecting on how her mother might feel and acknowledging that it is her mother's choice to seek support or not. There is an interplay of emotional connection (Chloe thinking about how her mother feels) and autonomy (Chloe seeking support as needed).

In conclusion, Chloe said "I don't think she feels like she needs, um, particular support with it, because I think she knows that I'm going to be fine." It is important to Chloe that her mother has whatever support she needs and that her mother knows that Chloe is "going to be fine". This is interdependence. We read this as a picture of relationality between an adult daughter and her mother. There is a level of care and vulnerability as well as agency and autonomy.

Discussion

According to popular understandings, children grow from a state of dependence to eventually become independent adults (Thomson & Holland, 2015). Neoliberal and developmental discourse is popularly taken up by adults who recognise the importance of "being there" for their children as well as acknowledging that those children will, one day, "live their own life" (Alicia). The concept of interdependence helps to disrupt the in/dependence binary and trouble neoliberal assumptions that infuse the idea that we all ideally grow to be independent individuals (Whittle, 2022). Indigenous and feminist scholars have articulated the problems inherent in any such ideal (Gilligan, 1996; Hamley et al., 2021; Mila-Schaaf, 2006; Miller & Stiver, 1977). Interdependence is a useful concept for making sense of the healthcare experiences of young people with variations in sex characteristics.

Social science and qualitative research attends to the experiences of people whose knowledges and positions are often regarded as marginal or otherwise invalidated. Knowledge developed from marginalised positions provides understanding of parts of the world that cannot be known and may not be recognised from the perspective of dominant positions (Pohlhaus Jr, 2012). Health sciences that purport to produce knowledge about the health, well-being and healthcare of diverse populations cannot effectively do this while privileging Western scientific knowledge over ways of knowing that have been developed from diverse and marginalised positions. As Birhane explains, in an effort to "establish timeless and absolute knowledge, abstract and contextless reasoning is prioritised over concrete lived experience submersed in co-relations, interdependence, fluidity, and connectedness" (Birhane, 2021, p. 3). In relation to knowledge based on lived experience, intersex researchers and advocates have published an impressive range of narratives (e.g., Davis, 2016), though the challenge remains for those ways of knowing to impact substantively on healthcare interactions.

Despite a privileging of individualist understandings, everyday life and caring relations rely on interdependence (Raw & McKie, 2020). Pohlhaus Jr explains the importance of positionality (the social positions from which epistemic resources are produced) and interdependence (the social connectedness that is necessary for developing, communicating and using epistemic resources). Pohlhaus Jr invites us to examine our situatedness and our interdependence as knowers. She argues that "there is a dialectical relationship between the knower's situatedness and her and interdependence" (Pohlhaus Jr, 2012, p. 716). In practice, health professionals work in relationship with one another and with those who present to health services. This opens up the possibility of relational ways of knowing.

To bring this thinking to bear on the current research, it might help to picture a young person with a lifetime of experience with a variation in sex characteristics, in relation with carers who have a their own lived experience, in relation with a health professional who has career-long experience of medico-scientific research literature and medical practice. Each of these parties draws from knowledge bases (lived experience and/or academic learning) that reflect their situatedness (as a young person, a carer, and a health professional). Neither knowledge-base provides a complete understanding of the situation; all knowledge-bases are relevant; there is an opportunity to understand this situation in a way that centres relationality and interdependence. Pohlhaus refers to these knowledge-bases as "epistemic resources" in writing that "knowers are interdependent insofar as the epistemic resources or tools with which we know operate collectively not individually" (Pohlhaus Jr, 2012, p. 718) and that "[good] epistemic resources put us in particular relation to our experiences" (Pohlhaus Jr, 2012, p. 718) .

Understanding the healthcare process relationally can disrupt the evidence-based knowledge hierarchy, instead making way for all parties to be heard and for knowledge based on lived experience to be valued. This includes the knowledge based on the lived experience of people

with variations in sex characteristics generally (e.g., Davis, 2015; Hart & Shakespeare-Finch, 2022) and children and young people specifically (e.g., De Clercq, 2021; Steers & Andrews, 2021).

The present paper works with concepts of relationality and interdependence to draw attention to the possibilities of voice and agency for young people with variations in sex characteristics in healthcare contexts, as advocated for by intersex authors. We urge health professionals to consider relational ways of knowing as important for the healthcare of young people with variations in sex characteristics and that means rethinking relational dynamics that leave young people silenced in clinical contexts. It also means questioning the kinds of clinical knowledge that speak over the knowledge gleaned from lived experience. An ethical and relational healthcare approach supports young people as agentic beings in a network of relationships.

Practical implications

Taking a more relational approach could mean practical changes in the way adults (including parents and health professionals) engage with children and young people who have variations in sex characteristics. New protocols for engaging with children and young people could be based on frameworks that are trauma-informed, inclusive, anti-oppressive and attentive to human rights. With an inclusive and sensitive framework in place, it will hopefully be more possible for in-the-moment ethical and relational connections between young people, health professionals and parents to unfold. Some of the key practice points emerging through this paper are drawn out in Table 1.

Table 1. Promoting relational ways of engaging with children and young people in the context of a variation in sex characteristics

General principle	Practice point
Reflect	• Reflect on the relational aspects of what happens in clinical settings
Make space	• Provide young people regular space for talking with a health professional when a parent is not present • Allow space for decisions to be reviewed • Provide young people space to talk with health professionals about the things that matter to them, including personal and emotional topics
Notice	• Be curious about why a child or young person is silent in the clinic • Understand silence as part of a relational dynamic that must be addressed for ethical healthcare to be possible
Prioritise	• Prioritise building trusting interpersonal relations through ongoing communication • Prioritise knowledge based on lived experience and value what can be offered through peer support

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