

‘Does anyone else have this?’ The role of emotion in forum discussions about medical conditions affecting sex characteristics

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Abstract

When people experience rare medical conditions or variations, searching online may be the only way to find others with similar experiences. This study examines what happens when people do just that. The dataset for the research has been generated from online posts by people living with variations of sex characteristics, which some call intersex variations. Our analysis focuses on how emotion appears in online posts, how affect becomes embodied in digital contexts, and how norms are negotiated as people relate to one another about the variations that some of them experience. We offer an analysis grounded in digital affect theory to contribute to health research literature. We suggest how health researchers and healthcare providers might develop more nuanced understandings of the emotional realities of people living with variations of sex characteristics.

Keywords: intersex, variation of sex characteristics, diverse sex development, emotion, online

Introduction

Digital technologies provide opportunities for people to seek health-related support and information. This is particularly salient for people whose health concerns or bodily differences are rare or stigmatised, making it difficult to talk face-to-face with similar others. Health researchers have investigated what happens when people engage with one another online about specific health concerns and bodily differences (e.g. Faith, Thorburn and Sinky 2016; Hanna and Gough 2017; Wiggins, McQuade and Rasmussen 2016). Often, people seek others online to ask for or offer support and advice. Despite the importance of emotional support in these contexts, few health researchers have offered a theoretically grounded analysis of the emotional or affective aspects of these digital interactions (exceptions include Fullagar, Rich, and Francombe-Webb 2017; Fullagar et al. 2017).

How people engage with digital media is the focus of a rapidly growing field of social research. Recent years have seen significant development in understanding about how people form affective connections and a sense of community by using digital media (e.g. Andreassen 2017; Döveling, Harju and Sommer 2018; Prøitz 2018). Some scholars have used insights from digital media research to inform understandings of the emotional, relational and affective processes involved in healthcare (e.g. Fullagar et al. 2017). Some conceptualise a “sexuality-technology-health nexus” (Davis and Rasmussen 2015) and examine how digital technologies can “allow health subjects... to imagine new sexual health futures” (Crath, Gaubinger and Rangel 2019). Others argue that the ‘emotional alignment ... fostered by digital affect cultures becomes vital’ in the context of ‘permanently distorted and traumatizing situations’ (Döveling, Harju and Sommer 2018, 5) such as, we suggest, situations involving health and medical difficulties.

The current study works at the nexus of affect theory (Wetherell 2015, 2012; Ahmed 2004, 2010), health and wellbeing research (Bennecke et al. 2015; Garrett and Kirkman 2009; Carlquist et al. 2017) and digital media studies (Döveling, Harju and Sommer 2018; Prøitz, Carlquist and Roen 2018; Carlquist, Prøitz and Roen 2019). Our goal is to bring affect theory and insights from digital media studies into the arena of health research. We suggest that working at this nexus offers insights into how health professionals, researchers and healthcare decision-makers might better promote wellbeing by learning from how people engage affectively with one another via digital media. This study focuses on emotion and relationality in Web-based interactions among people with variations of sex characteristics, some of whom describe themselves as intersex.

Forging affective communities using digital media

The particularities of digital media use in relation to intersex are interesting because of the dynamics of medicalisation. In the latter half of the 20th century, dominant medical practice involved advising secrecy (Kessler 1998; Karkazis 2008). Even those who underwent medical interventions themselves were often not informed about their condition or treatment. For many, this has made it difficult to find similar others.

Since the 1990s, the Web has made it possible for intersex people to find one another. One of the groups that benefitted from this was ISNA (Intersex Society of North America) established by Cheryl Chase in 1993. Digitally mediated platforms have subsequently made it possible for numerous groups to emerge enabling people to form biosocial communities (Davis 2015) around the term ‘intersex.’ Despite this, many of those affected prefer not to

use the word intersex, or are not aware that it applies to them (Lundberg, Hegarty and Roen 2018), having only heard the medical diagnostic language in reference to their variation (Roen 2015).

Healthcare and (missing) emotional support

Although health professionals are expected to provide psychosocial input and signposting to peer support (Sandberg et al. 2017; Hughes et al. 2006), research shows that people with variations of sex characteristics, and their families, consider that their feelings are not adequately taken into account by health professionals (Chivers, Burns and Collado 2017; Lundberg et al. 2017; Ernst et al. 2016). Some studies show that health professionals are perceived as minimising patients' emotional concerns (Ernst et al. 2016; Lundberg et al. 2017; Sanders, Edwards and Keegan 2017).

It is popularly acknowledged that health professionals do not reliably help patients link with intersex/dsd¹ support groups, and some urge for improvement in this regard (Sandberg et al. 2017; Ernst et al. 2016; McCauley 2017). It is not clear that health professionals are well informed about the online support available. Seeking support in relation to a stigmatised variation can intensify one's vulnerabilities, leading to affective precarity.

Most research relating to intersex/dsd is medical research that does not tend to engage the topic of emotion. Psychologists have suggested that the lack of emotional engagement within healthcare can have serious consequences (Liao 2015). They explain that lack of psychological support and emotional engagement can contribute to a mistrust of healthcare, and to shame and stigma (Meyer-Bahlburg et al. 2017). It has repeatedly been documented that events taking place in healthcare settings are themselves a source of emotional distress (Boyse et al. 2014; Sanders and Carter 2015; Crissman et al. 2011). Some advocates suggest emotional support should be the only healthcare intervention except when a life-saving intervention is needed.

New developments in research on emotional wellbeing and intersex/dsd health care are now underway (Roen 2019). This research shows that people would like more support to work through emotional challenges of living with, or raising a child with, diverse sex development (Bennecke et al. 2015; Chivers, Burns and Collado 2017; Lundberg et al. 2017; Ernst et al. 2016).

There is little published research on online dialogue concerning intersex/dsd. There is a narrative analysis of posts to a support group website (Garrett and Kirkman 2009), and an unpublished analysis of XY women's forum posts (Stene 2015). These studies identify emotional challenges, but neither places emotion at the centre of the analysis. Frank (2018) examines posts about intersex experience and intimacy. Guntram and Zeiler's (2016) study of women who do not have a vagina or uterus focuses on emotion but not on digital media. Some intersex studies acknowledge the importance of emotion and online connections (e.g., Danon and Krämer 2017), but this is not their central focus. Finally, an experimental study offers useful insight into how viewers respond to online videos about social versus medical framings of intersex (Hegarty, Bogan-Carey and Smith 2019). This showed that student

¹ The term "dsd" can mean: disorders of sex development or differences of sex development. For discussion of the terminological debate, see: Delimata et al. 2018; Lundberg, Hegarty and Roen 2018; Davis 2015, 2014).

viewers preferred the video promoting the "social identity" intersex narrative over the medicalised narrative, and that the videos changed their beliefs about the harms and benefits of medicalisation. Only the medicalisation video led students to discuss fear and other negative emotions. While online videos with an "intersex identity" framing have garnered large online audiences, these do not necessarily communicate effectively about the more difficult emotions that become a focus in the present study.²

Our study addresses a gap in the research in that many studies about people with variations of sex characteristics come from clinicians' perspectives or rely on autobiographical analysis (Jones 2018). We take a relational approach to investigating emotion in order to understand what happens when people seek one another out online. We draw from theories of affect and research on digital connectivity to analyse online discussions among people with variations of sex characteristics. We examine how people respond to one another's emotional accounts and how digital affect is embodied. We also consider how digital affect is bound up in the production of 'normality.' Finally, we identify a number of healthcare implications.

Methods

This study examines Web-based communication involving individuals seeking others outside of established intersex or diagnosis-based groups. This dataset captures moments when people share their experience in contexts where there may not be others with similar experience. This sharing might involve affective precarity and set the scene for particular kinds of emotional investments.

Generating the dataset

The dataset consists of 39 pages of excerpts from 13 publicly available websites or fora identified through Google searches using diagnostic terms or the word 'intersex', paired with terms such as 'forum.' The dataset includes four sole posts and 9 threads, with each thread consisting of between 2 and 29 exchanges. We combined terms from each of the two columns in Table 1 and followed the method described by McDermott, Roen and Piela (2013).

The data were generated in May 2018. We prioritised websites set up to discuss health and body-related topics. That is, our focus is on discussions of variations of sex characteristics that take place in generic online settings. We aimed to sample a diverse range of sites, posts, and interactions, selecting threads where at least one person wrote about their own variation. In some instances, contributors wrote about their experience of having a child with a variation.

² We would like to acknowledge the contribution Peter Hegarty has made to our thinking here.

Table 1: Search terms used to generate data

Platform	Variation or diagnostic term
Blog	Intersex
Forum	CAH or Congenital Adrenal Hyperplasia
Network	AIS or Androgen Insensitivity Syndrome
Vlog	Hypospadias
	Klinefelter Syndrome
	Turners Syndrome
	MRKH or Mayer Rokitansky Küster Hauser Syndrome
	Swyer Syndrome

Research Ethics

Online research concerning those living with variations of sex characteristics raises ethical challenges regarding consent, privacy and anonymity. We take these challenges seriously and have reflected at length about how to most appropriately undertake this study. There has been long-standing mistrust between people with variations of sex characteristics and those working in healthcare. Sometimes, people with variations of sex characteristics have participated in lengthy health research processes that provide little or no personal benefit. We designed the present study so that it does not involve ‘participants’ and therefore does not ask anything of them. The healthcare relationships that contribute to mistrust typically fail to acknowledge the perspectives and emotions of people with variations of sex characteristics. A central focus of the present research is to respectfully address the emotions of people with variations of sex characteristics. The methodological decisions we have made here do come at a cost: this study is based on the public online posts of people who have not been consulted about the study. While this approach to online research is not unusual and can be understood in the context of online privacy being complex, relational and contextual (Marwick and Boyd 2014), our decision to take this approach must be carefully justified.

We are inspired by Highfield and Leaver’s (2016, 57) ethical reflections on ‘whether the act of researching surfaces material that would otherwise [have received] little attention’ and whether harm might be done by ‘amplifying that material through ... research reporting’. This concern must, however, be weighed against the detrimental effect of paying too little attention to the experiences of people engaging in healthcare contexts in relation to

variations of sex characteristics. We have therefore developed a way of working with the data while paying particular attention to privacy and anonymity. Rather than quoting any post in full, we have extracted minuscule pieces of the original post; or we have altered its wording with minimal loss of meaning, to ensure that it is not easily searchable. This makes it difficult to identify any particular individuals within the data, analysis or tables. The study was reviewed and ethically approved by the Norwegian Centre for Research Data.

Analytic approach

Our analysis was influenced by conceptual work at the intersection of cultural studies, gender studies and media studies (e.g. Butler 1993; Döveling, Harju and Sommer 2018; Ahmed 2010). The analytic process involved first, reading the data repeatedly, paying attention to the affective and relational nature of what is written; second, developing a detailed description of the data with particular attention to how contributors use emotion words; and finally, identifying an analytic focus on embodied affect, normality, intelligibility and relationality, and re-reading the data with this focus.

Analysis and discussion

This part of the paper is divided into three sections. The first section presents a content analysis of the emotion-related aspects of the data. The second section presents an analysis of how contributors engage with one another, focusing on the affective nature of that engagement. The third section focuses on the embodiment of affect, considering what this might mean for how one lives and whom one might become.

The affective content of online discussions

In order to address questions of affect, we identify the words contributors use when referring to emotion in their posts (see Table 2). Our descriptive analysis of these emotion-related terms suggests two main narrative themes: one of inner turmoil and relational disconnection, at worst ending in suicide; the other of recognising the sources of pain, explicitly initiating interpersonal connections, and expressing hopes for more powerful subjectivity. Contributors do not frame these hopes as romantic happy endings, but as possibilities for a future preferable to isolation and disconnected pain. These two narrative themes are both attempts to 'reach out'. In the paragraphs that follow, we provide a descriptive analysis of how emotion words appear within these themes.

Table 2: Emotion-related words and expressions in the dataset

Comment on occurrences	Words and expressions
These words occur very frequently across the dataset (more than 30 occurrences).	feel / feeling / feelings; help / helps / helped / helping / helpful
These clusters of words and expressions occur fairly frequently (between 10 and 29 occurrences).	worry / worries / worried; stress / stressed / stressful; love / loved; pain; inside / how I feel inside / who I am inside / empty inside; emotion; mental health / mentally ill / mental state / mental / mentally; depress / depressed / depression; fear / scared / afraid; crazy / berserk / insane
These clusters of words and expressions occur infrequently (between 1 and 9 occurrences).	fatigue / exhausted; bullied / mocked / harassment; hate / hated; luck / lucky; happy / unhappy; confidence; suicide / suicidal; cry; embarrassed / ashamed / shameful; moody / mood swings; insecure; struggle / struggling; freaks/ed me out; frustrated / frustrating; nightmare; sad; (feeling) strong(er); annoying / annoys; nervous; breaks my heart / good heart / heart pounding; alone; creepy; pissed off; don't care; uncomfortable / comfortable; unbearable; vent how you feel; emotionally fucked; fucked up thoughts; giddy with anticipation; never been OK; shocked; trust; selfish; relief

Contributors repeatedly refer to pain, sadness, suicidality, depression, or feeling crazy. The word 'pain' appears in various contexts throughout the data, but there are two contexts where it appears repeatedly. The first is in the context of describing the aftermath of hypospadias surgery. The second is in the context of emotional pain and suicidality.

Both of the people who use the word 'sad' are referring to the possibility of suicide in the context of describing how they feel about having hypospadias (a penile variation for which elective surgery is often undertaken). One explains that he feels sad with the knowledge that he will be living his life without a girlfriend, marriage or children. He explains that thinking of his family stops him from killing himself, although he has considered it 'thousands of times.' When he considers the life ahead of him, particularly without marriage and children, he describes the pain as 'unbearable.' In a different thread, a 14 years old contributor suggests that it would be 'sad and selfish' to kill himself, although he has thought of doing this in the context of ongoing experiences of hypospadias surgery. This same contributor states: 'I hate my life.'

Three contributors refer to depression repeatedly. One connects this condition with having hypospadias and being unable to work. The other two are women writing at length about depression in the context of long-standing difficulties with Congenital Adrenal Hyperplasia (CAH, an adrenal condition that requires medication and, for some, is life-threatening): trying to manage symptoms, get appropriate medication, and manage side effects. One of these contributors refers repeatedly to anxiety and depression in tandem. The

other describes her whole narrative as 'crazy' and 'emotional.'

People describe feeling suicidal in relation to medical interventions that seemed to exacerbate difficulties rather than resolving them. One graphic description comes from a woman with Congenital Adrenal Hyperplasia who describes being prescribed medication that made her feel 'twitchy,' 'moody,' 'agitated,' and suicidal, and like she might jump out of her skin. She describes this experience as a 'nightmare,' explaining she felt the 'emotion centre' of her brain 'went offline.' These are examples of the striking ways that contributors articulate emotional distress.

The articulation of emotional distress throughout the dataset appears to arise from intensely challenging, and sometimes life-long experiences. The turmoil and anguish are typically represented as emotions at breaking point, sometimes as result of the contributor not being recognised as being in crisis. The posts demonstrate how people strive to express what they are going through, seeking someone who might understand, even an anonymous stranger on a forum.

While the terms explored above point to an urgent sense of distress and disconnection, contributors also used terms that suggest connection and relationality. The terms we discuss below suggest emotion that is 'about' something (such as stress), or emotion that is explicitly relational (such as shame or love).

The word 'stress' occurs repeatedly in the dataset. Most references to stress are statements of contributors' own feelings in relation to their own bodily difference or medical issues. One contributor, within a hypospadias discussion thread, refers to his life as 'constantly stressful.' Another contributor, within a CAH discussion, describes not being able to cope with stress. Yet another, within a CAH discussion, links stress to metabolic issues, the body adjusting to medical treatment and the discovery that her opportunity to become pregnant might be severely curtailed. The two people writing about stress and CAH give accounts of their difficulties managing their condition and accessing medical support.

Among the relational terms, 'shame' and 'embarrassment' implicate others, directly or indirectly, via internalised norms or values that are deeply affecting. One contributor describes feeling it is shameful to be on a welfare benefit because of medical issues, 'mood swings and fatigue' relating to CAH. Another explains that their decision to share online information about their medical tests comes from an understanding that others in similar situations might 'be ashamed to ask.'

Relational terms referring to rejection involve being 'mocked', 'bullied', or 'harassed'. Contributors describe being mocked, bullied or harassed in relation to their sexed appearance or pubertal development. One, with Swyer syndrome (a variation that typically involves being raised as a girl but not going into puberty without medical intervention), talks about being different during adolescence, not going into puberty, and experiencing years of bullying. Even following medical intervention to induce puberty, she explains that it was difficult to begin perceiving herself differently following the bullying. Her body was developing but the emotional effects of bullying were still there. Another person, with Klinefelter (a variation characterised by XXY chromosomes and non-typical pubertal development), describes being raised as a girl but not going through female pubertal changes. This person describes school as an experience of being 'mocked constantly' and eventually changed schools, only to experience further bullying. Another describes their non-typical puberty as 'an invitation to harassment' in the school context.

Finally, one of the terms referring to relational wellbeing is 'love.' Although this word is used in many different ways, two recurring uses are to say that 'I love life' and to refer to

the possibility of being loved by someone else despite one's bodily difference. The suggestion is made that a partner 'should love you no matter what'— a theme that resonates through a discussion about the challenges and fears associated with penile difference.

Affective engagement

We now consider how contributors respond to one another's emotional accounts. Through three sequences, we reflect on how particular expressions of emotion and relationality might open the way for caring online relations. This part of our analysis is supported by psychological literature that informs our understanding of relationality.

In the first sequence, a contributor states that he has become 'crazily anxious and nervous' about his penis due to his condition of hypospadias, and that he had avoided undressing in the context of other men. A second contributor follows up by stating: 'You shouldn't feel insecure. It is nothing to worry about or feel ashamed of. At the end of the day what matters is that you love and accept yourself. Say to yourself; I am a good person. Everybody is different. You can only regulate how you feel about yourself'. Although this second contributor appears to be attempting to help, the advice suggests only partial perspective taking (Gillespie and Cornish 2010): Despite 'meaning well', the responding contributor literally instructs the initial contributor not to feel insecure, and states that hypospadias is nothing to feel worried about. Therefore, the response does not validate the emotions and worries of the initial contributor. Instead, it puts forth a neo-liberal solution to structurally imposed pain, suggesting that persons can only control how they *feel about themselves*. The response echoes a form of guidance offered in psychological self-help literature oriented towards individual mastery (Madsen 2015). This genre leaves little space for people to critically question or collectively resist prevailing dominant discourses of how the body should be understood and managed.

In another sequence, a contributor writes that they identify as intersex, were born with Klinefelter syndrome and brought up as a girl. The post includes a facial photograph and questions concerning other participants' thoughts about their physical appearance. The content of a following reply suggests an attempt to build a positive online relationship. This form of invitation is achieved by the use of phrases such as 'thanks for sharing', 'your story is interesting', 'did you find answers?', 'hope you are doing well despite troubles', and a smiley. The response thus signals curiosity and care while at the same time acknowledging the troubles. Furthermore, in contrast to a considerable minority of replies in our data set that immediately divert attention onto the responder's own problems or almost ignore previous posts, the temporal order of this response prioritises the other over the subject. The responding contributor relates to the initial contributor first, acknowledging that person's struggle, before proceeding to disclose their own story. In contrast to the previous example, the responding contributor shares their own gender identification, in this case, intersex. Nevertheless, at one point a normative gendered discourse surfaces: the looks of the initial contributor are described as 'nothing bad even though you look somewhat androgynous'. Here, the responder takes the position of judge, assessing the other person's androgyny and the extent to which it might be 'bad'. The response echoes a norm of dichotomous gender as the point of evaluative reference.

In a third example, a thread starter shares that they were born with ambiguous genitalia, and recently came across documentation revealing that while their parents wished for them to be a boy, the medical professionals wanted to 'make' a girl. The contributor

continues by describing their current upset in terms of 'crying so much like a girl', and not liking themselves. The first reply to this post is characterised by tentativeness and acceptance. It builds a potential relationship through expressing uncertainty ('I don't really know what to write, but I guess'), hesitation ('auuuhmmm...') and reassurance ('it's okay to be upset'). In our interpretation, the tentativeness and hesitation in this post constitute elements that function to acknowledge how the author ultimately cannot *know* the thread starter. The possibility of developing a considerate relationship begins with recognising that the Other is a mystery for the I (Simão 2007). However, there is a further issue at stake in this dialogue: Even in this open-ended and caring post, the responder does not fully take the potential perspectives of the other person. They assume a dichotomous construction of gender ('no difference whether you are a guy, or a girl') when referring to the crying. This phrasing precludes the possibility that the thread starter might identify neither as a guy nor girl, but it nevertheless effectively destabilises the norm that crying is undesirable and 'something girls do'.

The excerpts presented here illustrate some of the problems and possibilities involved in acknowledging emotional experience. Taken together they demonstrate complexities of perspective taking and exemplify how widespread and taken-for-granted normative discourses might limit the development of caring online relations. From this analysis, we suggest that productive relational strategies involve acknowledgement of the other's experience, validation of the other's emotion, and an expression of caring and openness to others.

Embodied affect

In this final section of the analysis, we seek to understand what kind of affect is located around what kinds of bodies within the data (see Table 3). According to Ahmed, emotion can be understood as both relational and embodied. She explains how 'it is through emotions ... that ... the "I" and "we" are shaped' (Ahmed 2004, 10) and how 'emotions operate to ... "shape" bodies as forms of action' (Ahmed 2004, 4). We consider the implications of this for those who are subject to such shaping through the workings of emotion, as evidenced in our own data. This part of the analysis is informed by discourse analytic thinking about how particular ways of being can be opened up through the discursive framing of one's situation.

Our analysis of how bodies appear in the data suggests the body is intensely affective in its unruliness and its refusal to do what is expected of it (Butler 1993). The body is affective in its visible and experiential variations - hormonal variations that are associated with severe emotional effects, and anatomical variations that are presumed to have social and relational effects. Affect works its way through the body's interior with unseen biochemical processes playing a part in feelings of exhaustion, frustration, and craziness. Affect works on the body's surface by inscribing feelings of anxiety and unlovability on particular anatomical features.

Table 3: Examples of embodied affect

Terms used	Narrative context
Worry	Contributors describe feeling worried in relation to their genitalia that are different and might not be accepted by a partner; Contributors describe feeling worried in relation to long-term medical issues that are exhausting and seem irresolvable;
Afraid	Contributors write of being afraid in the context of being unsure about going ahead with further penile surgery;
Bullied	Contributors write of being bullied because the body is not going through typical pubertal changes and the sexed appearance is not typical
Feeling crazy	Contributors describe feeling crazy in the context of problems following penile surgery; Contributors describe feeling crazy in the context of complex hormonal / medical issues.
Pissed off	Contributors describe feeling pissed off in the context of wishing that parents had had the hypospadias 'fixed' during early childhood;
Hate	Contributors describe feeling hate in the context of unintended consequences of CAH medication; Contributors describe hating to look at their body
Love	Contributors refer to love in the context of writing that a partner should love you regardless of whether your penis looks different; Contributors write of being intersex and loving their life

The embodied affect flowing through contributors' posts doubtless has significant implications for contributors in terms of how they live their lives and whom they become. We consider that various kinds of subjects are produced through the embodiment of affect. Nervous, anxious, insecure and worried subjects who might never be able to enjoy sexual intimacy - never be able to experience loving partnership - are repeatedly produced through the data. Crazy, exhausted, annoyed and worried subjects who spend years of their lives trying to manage complex medical conditions, find health professionals who understand, and manage the unintended consequences of medication are produced through this writing. Bullied subjects, whose sexed appearance is not like that of their peers and becomes a source of ridicule, are produced through this writing. Loving and loved subjects, who deserve to be loved by others and who do love their own bodies, are also produced through this writing.

One specifically writes that they 'love' their 'body and ... life as intersex'. What people write online, when they write about their bodies and how they feel, tells a powerful story of who they are and what they consider to be *possible*.

Understanding through what regulatory norms a body (a life, a human) becomes possible, we have explored alliances and attachment to certain desirable or, to use Ahmed's notion, 'happy' objects. The child or having children is a recurrent issue, which many contributors engage with. Some mention that they gave birth to children despite their variations of sex characteristics, for some infertility has been ascertained, whereas others ask the forum whether someone with their diagnosis can have children. One contributor wrote that her partner left her because she could not have children. Others are worried that they will have to live the rest of their lives without having children, a pain some express as 'unbearable.' Some ask readers 'What can I do to have a child?' One wrote that they 'think about it 24/7' and explained that the wish to have a child is 'always in my head.' In order to live meaningful, intelligible, and coherent lives, one has to comply with certain 'life schedules' (Halberstam 2005), with humanly 'thinkable bodies' (Butler 1993, 8). In this manner, customs, habits, rituals, repetitions, and praxis constitute bodies and lives that are discursively understood as 'normal' and 'good.' Ambjörnsson et al. (2010, 9) argue that the metaphoric strength in the idea of reproduction lies in the idea of a child being woven together with promises of hope and future. The child, in our examples, represents the 'happy object': it is attached to certain scripts of normality which one becomes a part of and aligned with. In our understanding, these scripts and ideas function as *promises*. The desire to be close to these promises of happiness and normality - or indeed their fulfillment - is, however, not necessarily a good thing (Bissenbakker and Myong 2015). Following Berlant (2011), optimistic attachments to a given object (e.g. a child) is not necessarily good or bad in itself, but the attachment can become 'cruel' if what one desires impedes one having a life ('I think about it 24/7'). In this manner, the child holds an affective value signifying a good and normal life (Ahmed 2010). Profound worries about not being able to experience pleasure from proximity to 'happy objects' run through the data. Explicit implications are that some contributors imagine a life without having children, shared sexual pleasure and intimacy, a life of being ridiculed and bullied because of bodily difference, a life of feeling endlessly exhausted, frustrated, and crazy because one's body does not work as expected.

The personal sharing that takes place in the posts suggests that these forums are 'relational spaces in the digital environment' characterised by 'affective flows' and 'emotional resonance and alignment' (Döveling, Harju and Sommer 2018, 1). Here, sex characteristics have become part of digital affect culture. This analysis demonstrates how embodiment and affect can be woven together even when the medium is as (potentially) disembodied as Web-based fora. Crucially, the embodiment of affect that we see here is part of relational processes (people sharing experiences), and processes of re-negotiating norms (articulating how it feels to live with a body that does not conform to expectations).

Interaction across geographical, cultural and social contexts, as well as time-zones, is part of contemporary life. Digital media have increasingly reconfigured interactions between people, affording new forms of embodied, sensory, and affective experience. This means that users can respond to anonymous forum posts (e.g. about variations of sex characteristics) and then switch rapidly to mundane conversations on messaging apps with friends – navigating seamlessly between plural and quite different contexts online. Although the digital media do not fully liquefy space-time boundaries, they bring disparate spaces and times into close proximity. Digital media practices therefore play a pivotal role in aligning affect and emotions

with new and plural forms of rhythm and temporal structure (Mainsah and Prøitz 2019). This development can be understood as entailing new forms of simultaneity, involving both stretching and contracting of experiences of time, space and intimacy in ways that shape affective relations and practices (see Prøitz, Hjorth and Lasen 2018).

Conclusion

In our analysis of online posts about living with variations of sex characteristics, we begin by identifying the emotions that contributors write about. We note that some aspects of the writing suggest inner turmoil and a sense of disconnection, while other aspects of the writing suggest a more relational and sometimes optimistic or empowered perspective. Importantly, we also note that the relational opportunities offered by this kind of reaching-out online are very uncertain, and that the very practice of reaching out in this way – not knowing whether others will respond sensitively – involves affective precarity. We offer examples of online interactions that highlight the challenges of perspective-taking and navigating normative discourses. These challenges must be negotiated successfully if caring online relations are to be established, even momentarily.

In addressing embodied affect, we consider the kinds of subjecthood that become possible based on how affect appears to work on the body. The particular subjects produced through the data include anxious, insecure subjects who consider they might never be able to enjoy intimacy. Medically unwell subjects whose on-going attempts (over a lifetime) to manage symptoms, side-effects, and health services are produced through the data as feeling crazy and exhausted. Subjects with variations of sex characteristics are also produced through the data as relationally positioned, e.g., as bullied and ridiculed, or loving and loveable. These various discursive productions can be powerfully affecting and delineate what kinds of lives can be lived.

This research shows how embodiment and affect are woven together in digital space. For many contributors, it is either the figure of the child or the idea of sexual intimacy that is embraced as a happy object and that becomes the focus for feelings of hope or loss. For some, the digital space becomes a forum for embodying difference with confidence and self-love. In both instances, relational processes and the (re-)negotiation of norms are central.

Health research and health services relating to intersex/dsd have been criticised for paying too little attention to the emotional aspects of living with variations of sex characteristics and undergoing associated medical interventions. Some have called for a concerted effort to take emotional and psycho-social aspects into account more fully. The present study uses digital affect theory to offer a way of understanding the emotional aspects of people's online engagements with one another around the experience of variations of sex characteristics. We encourage other researchers working in this field to develop theoretically-grounded understandings of emotion, with a view to providing a base for healthcare practices that take emotion into account in non-pathologising ways.

Our hope is that health researchers and healthcare providers might develop more nuanced ways of engaging respectfully with the emotional realities of people with variations of sex characteristics. Based on the present study, we highlight three opportunities for change on the part of health professionals. First, it is important to acknowledge emotion without pathologising emotional responses. Second, it is valuable to engage professionals who have the expertise to foreground this aspect of healthcare rather than foregrounding the medical aspects. Third, there is a need to be proactive in signposting people to sources of support

(online and offline), acknowledging that living with variations of sex characteristics is a lifelong relational and emotional process. Further indications of how health professionals might take a more emotionally nuanced approach can be found within the psychosocial research literature (for example Roen 2019; McCauley 2017; Liao et al. 2011; Liao 2003, 2015; Ernst et al. 2016).

In conclusion, it is particularly urgent for healthcare to shift its emphasis from stigmatising and medicalising approaches that can lead to severe distress. The shift we suggest, towards appropriate acknowledgement of emotion, and addressing emotional distress, offers possibilities of meaningful connection and respectful understanding.

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Data availability statement

The dataset is not available due to confidentiality requirements.

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