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WORKING PAPER: INTERSEX MOVEMENTS AS EMBODIED HEALTH MOVEMENTS: RETHINKING A THEORETICAL PERSPECTIVE

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Abstract

The emergence of intersex activism is a relatively recent phenomenon. The main demand for many intersex activists is to end non-consented and medically unnecessary surgeries and medical treatments that are carried out for psycho-social or cosmetic purposes on intersex children aimed at altering their sex characteristics to reflect 'typical' standards of sex assigned at birth. For my research, I conducted 30 semi-structured interviews with people engaged in activist efforts to protect the rights of intersex persons. The findings suggest that embodied experience influences their decision to become involved in intersex activism as well as the political identity of many intersex activists. Embodied experience also facilitates coalition building with other groups, in particular, movements for body diversity or against harms such as sexual violence. Embodied experience is also an essential aspect when rejecting pathologizing medical categories or diagnoses such as 'disorders of sex development' (DSD). I primarily use P. Brown et al.'s (2004) framework of analysis on embodied health movements to reflect on intersex activists' relationship to their embodiment. As such, this paper aims to provide a contribution to the literature on intersex studies, embodiment theory, and social movements.

Keywords: Intersex activism, social movements, embodied health movements.

Introduction

Embodiment theory is a theoretical framework used often in cognitive science, philosophy, and other fields (Varela & Shear, 1999; Wacquant, 2015) to highlight the importance of the body in shaping and influencing knowledge, perception, emotion, and thought (Pitts-Taylor, 2015). This theoretical framework challenges traditional views that focus primarily on the brain as the central processing unit for cognition (Pitts-Taylor, 2015; Wacquant, 2015; Wainwright & Turner, 2003).

Pitts-Taylor (2015) points out that feminist writers and sociologists "articulate the body as the primary ground of knowledge" and have critiqued "the overly intellectualist, mentalist, disembodied approach to mind, knowledge, subjectivity and agency" (p. 20). Using theories such as phenomenology, pragmatism, and naturalism, feminist scholars have shed light on how embodied experience is a powerful tool for perceiving and understanding different realities.

Feminist scholars have noted that embodiment theory is also relevant to the study of power dynamics and social inequalities related to the body or 'body politics' and matters linked to gender, gender identity, race, and plenty of other axes of oppression (N. Brown & Gershon, 2017; Richardson, 2022; Sharrow, 2017).

In this paper, I explore how the embodied experience of a number of intersex activists has been an essential factor in their activism. By applying embodiment theory to the study of intersex social movements, I aim to gain a deeper understanding of how the physical and sensory aspects of intersex activists' experiences are related to their social and political goals. I mainly use P. Brown et al.'s (2004) theoretical framework as it resonates with many of the political strategies and themes explored during the interviews given the close relationship between intersex activism and medicine as an institution.

In the following sections, I expand on existing literature about intersex embodiment and P. Brown et al.'s (2004) theoretical framework on health social movements and embodied social movements. After explaining the methodology for this research, I look deeper at how embodiment has shaped the experiences of a number of intersex rights activists when it comes to identity formation, alliances with other social movements, contestations to the disorder diagnosis, intersex person's relationship to medicine, and knowledge production. This paper aims to contribute to intersex studies by reflecting on the actions and dynamics of political activism expressed by research participants, by combining embodiment theory and theory applied to social movement studies.

Intersex embodied experience

Research on intersex embodiment is ever-growing in the field of intersex studies, as the body is central to the experience of intersex persons. From an early age, intersex persons are subjected to medical treatments, including genital surgery. These treatments aim to modify their bodies to align with what society and medicine deem as 'typical' male or female bodies (Greenberg, 2017; Horowicz, 2017; Thyen et al., 2005).

The main demand of intersex persons (and allies) involved in activism is to end these medically unnecessary interventions and to protect the rights to bodily autonomy and self-determination of intersex children (Australian and Aotearoa/New Zealand intersex organisations and independent advocates, 2017; Chase, 2013, 2018; The Third International Intersex Forum, 2013). The pathologization of intersex bodies is deemed by many as one of the main causes that lead to such interventions and the ultimate reaffirmation of medical authority over the lived experience of intersex persons (Davis, 2014; Feder & Karkazis, 2008; Garland et al., 2022).

Embodied experience has been a critical lens used in research to explore the personal meanings of the intersex body. An embodiment perspective is an important tool for analyzing how medical interventions affect intersex individuals' experiences and sense of self. For instance, recent research has explored the experiences of loneliness of intersex persons following unconsented treatments (C. Jones, 2022) and the experiences of older intersex persons navigating the intersex experience (Berry & Monro, 2022).

Embodiment can also be applied to understand the relationship of intersex bodies to social aspects. Orr (2022) has explored, for instance, how ableist medical views understand and construct intersex bodies as disordered, diseased, or disabled. In turn, intersex bodies must be "fixed" or "exorcised" to comply with what Orr (2022) calls "compulsory dyadism," the idea that people (and bodies) should find a place in the sex dyad (p. 23-28).

Malatino (2019), using the figure of the monstrous body, has shed light on the failures that medicine has had concerning intersex persons and how changing the pathologizing perspective can open new doors for the recognition of intersex persons' human rights.

Griffiths (2018a, 2018b) has explored the construction of the intersex body through medicine across the ages, particularly in the UK. This medical gaze has resulted in the normalization of medical treatments to 'change' or 'normalize' intersex bodies, a practice that activist groups heavily reject.

Similarly, Reis (2018) has explored extensively the medical 'construction' of the intersex body in the United States. She argues that cultural meanings influence medicine, this means that medicine as an institution has constantly othered intersex bodies for not being able to classify them within the binary male/female system.

Roen (2004) has written about the ethical aspects of 'normalizing' intersex bodies and whether or not "inaction (not offering treatments) is ethically sound" (p. 127). Furthermore, Roen (2008) has noted that in order to deal with the 'problem' behind the ethics of 'normalizing' genital surgery, the intersex subject is broken into three parts.

> What is interesting about the ways in which clinicians currently engage with the problems inherent in intersex surgery is the way that notions of self – of the intersex subject – are broken down into manageable components: the body (that can be operated on); the psyche (that needs to be better understood); and the political voice (that is not often acknowledged as offering anything substantive to thinking about the treatment of intersex children). (Roen, 2008, p. 52)

Embodiment is also a powerful tool for analyzing the relation of the intersex body to social institutions such as law and medicine (Garland & Travis, 2022; Rubin, 2017). In their recent works, Garland and Travis (2022) have extensively written about intersex embodiment; for them, embodiment "encompass the material experience of the body and its relationships with both discourse and institutions" (p. 11).

Garland and Travis (2022) note that the medical construction of intersex bodies as disordered has mostly gone unchallenged and unchanged by most legal systems; this is because of the deferral of jurisdiction to the medical authority. According to their analysis, when the law has addressed intersex issues, it has done so via the establishment of anti-discrimination laws or by limiting actions to the recognition of third-sex gender markers, which have limited impact on the lives of intersex persons (Garland and Travis, 2022). While these two aspects might benefit some intersex persons, they fail to address the main demand of activists, which is ending unnecessary treatments and surgeries that are based on the pathologization of their bodies. The authors have also explored how the perception of intersex bodies as "temporal bodies" promotes the idea that their bodies ought to be promptly changed or 'fixed' to suit the medical and social standards of binary sexes (Garland & Travis, 2020, p. 119).

Health social movements and embodied social movements

Within social movement studies, there is a growing discussion about the role of patients as active stakeholders in matters that affect their own health and medical treatments (Aegerter, 2022; Epstein, 2016; Petersen et al., 2019). In a way, these collective patients' social movements aim to change the paradigm of patients from a passive role in their healthcare treatment to a more active one with meaningful participation and agency (P. Brown et al., 2004; Zavestoski et al., 2004).

Embodiment theory perspective can be applied to social movements to understand how people's experiences, perspectives, and perceptions are related to their participation in activism. For example, how and why people decide to use their bodies during protests or demonstrations (Goldberg, 2020; Richardson, 2022; Veneracion-Rallonza, 2014). It can also serve to trace a relationship between self-identity and the body (Kwan, 2009; Price, 2007).

Indeed, embodied identity is central to many social movements, for example, black movements, feminists, disability, fat and intersex movements (Breu, 2016; Groch, 1994; Kwan, 2009; Pitts-Taylor, 2015; Richardson, 2022). Therefore, embodiment can be a good theoretical tool to shed light on people's experiences and their involvement in social movements, from personal to communal experiences (G. Brown & Pickerill, 2009; Goodwin et al., 2007).

P. Brown et al. (2004) have written about the particularities of social movements with a close relationship to medicine. The authors define health social movements (HSMs) as "collective challenges to medical policy and politics, belief systems, research and practice that include an array of formal and informal organizations, supporters, networks of co-operation, and media" (P. Brown et al., 2004, p. 52).

P. Brown et al. (2004) argue that HSMs usually organize around mainly three goals: a) access to health care, b) inequalities in the provision of and access to health care, especially those based on race, gender, class, and disability, among others, and c) the lived experience of 'disease', 'illness' or 'disability'. The authors also speak about different subcategories of HSMs with different priorities; these are *"health access social movements", "constituency-based health movements,"* and *"embodied health movements* (EHMs)" (P. Brown et al., 2004, p. 50).

In this paper, I mainly use P. Brown et al.'s (2004) framework to explore the dynamics of people participating in intersex activism. I argue that these groups groups can be understood as health movements because of their close relationship to medicine as an institution and matters related to access to health care.

Methodology

This paper draws on data from 30 semi-structured interviews with people engaged in activist efforts to protect the rights of intersex persons. During the interviews, participants were asked about their experience with intersex activism, including their motivation to become involved, alliances and collaborations with other social movements, relations and engagement with medical practitioners and institutions, strategies, forms or organizing, and political goals.

Participants were contacted between May and November 2022 using snowball sampling (Browne, 2005) and by sending emails to organizations working on intersex human rights to receive the views of people involved in intersex activism, whether they identify as intersex or not. Interviews were conducted online with activists from different countries in Europe, North America, Latin America, Africa, Asia, and Oceania. Most interviews were conducted in English; however, two were carried out with a French interpreter's support and two with an

Italian interpreter's support. One interview was done in Spanish and then translated into English. Two of the interviews were paired interviews.

One of the main attributes when seeking participants was that they viewed themselves as engaged in intersex activism as this study aimed to study social movements' dynamics. Because of this decision, I did not actively reach out to groups that primarily see themselves as patient or family ‘support groups’ for people with differences in their sex characteristics. Nonetheless, the literature concerning these groups is analyzed below.

After the interviews were conducted, data was transcribed and coded using NVivo. I used thematic analysis (Braun & Clarke, 2006) to identify and analyze themes related to activism first and then about how the body and intersex embodiment are made relevant in activists’ identity, actions, organizing, and framings.

Regarding ethical aspects, all participants were informed of the project's aims, provided and signed informed consent forms, and were given the option to have their data pseudonymized or have their names public. This is reflected in the use of quotes, where those who wished for names to be provided are named, and those wishing for pseudonymization are numbered.

Participants received their final transcripts for review and had the option to withdraw their data from the research project. The 30 interviews used in the analysis belong to those who decided not to withdraw their information.

The research project received approval from the Research Ethics Committee of the University of Granada, Spain. Participants received an information sheet about the way their data will be stored, which is in line with European standards for data protection.

Findings and discussion

The analysis of the interviews using P. Brown et al.’s (2004) framework of EHMs revealed that embodiment is essential in producing and reproducing knowledge and conducting political activism. The main topics of this section refer to the themes that emerged in my analysis, namely, how embodiment becomes relevant in terms of a) embodied identities, b) embodied experience and coalition building, c) embodied experience and the contestation of ‘illness/disorder’ diagnosis, d) intersex activists’ relationship with medicine and practitioners, and e) embodied knowledge and epistemic (in)justice.

Embodied identities and embracing activism

For many of the interviewed participants, their embodied experience with medicine and the experience of violence upon their bodies carried out by medical practitioners, the secrecy surrounding their bodily variations, and the necessity (or not) of interventions was a critical factor in starting their journey into activism. Many participants recounted how the process of realizing they had an intersex variation and how the medical procedures they had experienced growing up led them to become engaged in intersex activism. As a participant stated:

> I think the starting point was shortly after I found out that I'm intersex because then, you know, you kind of do a personal search, but then I ended up meeting my first other intersex person, who was an activist, and they helped me to understand the scope of this

> issue and I think this was the initial thing that happened to turn me into an activist. (Ins, Germany)

Other participants recounted how the process of realizing that they had an intersex variation, recognizing the regulation of medicine of intersex bodies or their experiences with medical treatments while growing up led them to become engaged in intersex activism.

P. Brown et al. (2004) speak about how the embodied experience of those persons going through similar processes of experiencing 'illness' shapes their identity, particularly when they decide to engage in activism. From their perspective, EHMs have a closer relation to the body and medical practice as they have often experienced different processes related to health and illness (P. Brown et al. 2004).

In the case of intersex participants in my research, many spoke about their experience with medicalization and pathologization as being key defining aspects of why they decided to become activists. This is reflected in the quote below.

> I was born intersex and submitted to several surgeries as an infant and as a child, genital mutilation, and yes, when I was 35 I found out that what really happened to me and that there are other intersex persons in the world and it's been 15 years now that I started to do intersex activism. (Daniela, Switzerland)

While the majority of participants did not speak of being intersex as an 'illness', some did talk about health care needs related to their bodily variations or that emerged because of early childhood treatments such as gonadectomies. Many also talked about shared experiences of medicalization processes and medical treatments (despite being in different geographical locations), such as being kept in the dark about their variations, not being heard by doctors, or having difficulties accessing various forms of health care, for example as one participant stated:

> [S]he tried really hard to find the endocrinologist who would actually take care of her (…). No one did care after they gave her the different hormone treatments. No one, you know, thinks about the particular situation of a woman with XY chromosomes and 62. (Claudia, Italy - Interpretation)

Another form in which embodied experiences shaped an informant's identity was observed in the case of a participant from Croatia who spoke of feeling like she did not belong to the intersex community. She recounted initially having doubts about calling herself intersex and joining intersex activist spaces because, while having an intersex variation, she does not share the experience of the trauma of having had surgery done on her body.

> And after that, I went, I visited an OII event where I talked to a lot of the intersex people, and then I was included in this exclusive chat for intersex people, and I met a lot of people. The reason why I was very insecure at first is because I don't come from a place of having operations done to me, like surgeries done to me (…), so I felt like an imposter. But like all the people I talked about reassured me of me being a person with intersex traits. (Aleks, Croatia)

Aleks' words describe how sharing embodied experience is important for community building. However, the embodied experience of trauma was not what most intersex activists that I spoke with cared for when identifying peers or building community. Most people did not seem to require ‘proof’ of an intersex variation. The findings of the interviews suggest that most participants looked for personal and social circumstances in which they could recognize each other. A participant reflected:

> My motivation, I think, to be honest, was less, like definitely always about making change, but also just about connection. Like that sense of isolation and like a lack of family or a lack of like peers that at least kind of understood my experiences and could help me make sense of the world was really missing. (Participant 13, Aotearoa New Zealand)

These shared experiences, having more to do with social aspects including with medicalization rather than with their intersex variations, have motivated a shared identity in many participants.

Intersex activist documents often remind us that intersex variations should not be considered a gender identity (Ghattas, 2019). However, during the interviews, a number of participants framed being intersex not as a ‘gendered’ identity but as a political one, a process of self-identifying oneself through a political lens of embodied experience. A participant from Switzerland spoke of the idea – common in French-speaking intersex activism – of making the distinction between being intersex and being intersexed [*intersexué*] (Bastien Charlebois, 2017).

Like the notion of being a gendered or racialized subject, being intersexed recalls the idea of being subjected to a political process where one person is ‘othered’ by another(s), in this case, due to the sex characteristics observed in their bodies. The action of naming a person as 'intersexed' is carried out by an outsider, or external agent, whether the medics, the parents, the family, or society. In contrast, calling oneself ‘intersex’ is the own recognition of a political identity based on the body or embodied experience.

> So, any person who has a variation in sex characteristics is a person who is intersexué [intersexed]. Actually, in English, there was the same distinction at the time, but it never stayed. It's a person who is intersexed. But it's not because you're intersexed or intersexué that you are necessarily intersex, in the sense that to be intersex, it's also part of your identity. It's something that you use as a way to describe yourself or to describe a political movement. (Participant 18, Switzerland)

On a similar note, Morgan Holmes (2022) speaks of “intersexualization” of subjects and has written about how acknowledging “the process of intersexualization” without labeling a person as intersex “avoids essentializing the person but leaves open the possibility for any individual subjected to intersexualization to (re)claim ‘intersex’ as an identity” (p. 7).

The experiences of participants reflect what P. Brown et al. (2004) call the “personal experience” and the “social construction” of illness (p. 55). This is when the medical condition happening in the body develops a particular identity that represents “the intersection of social constructions of illness and the personal illness experience of a biological disease process” (P. Brown et al., 2004, p. 55).

For the participants the shared experience of medicalization and the experience of loneliness and longing for community seems to be essential factors in their decision to engage in political activism but also a big part of their political identity.

Embodied experience and coalition building

Embodied experience is also connected to building alliances and collaborations between intersex activists and other social movements. A number of participants emphasized creating alliances and building bridges with movements and groups closely related to bodily harm, including sexual violence. Whether because of the discrimination and stigmatization of certain body types or matters related to bodily injuries or abuse, this was perceived as a starting point, a connection to build alliances.

> We work with different organizations where we had the opportunity to talk there, we worked like with rape survivors, and this is also like something that, yeah, I think usually these groups understand so much better because also they see what it means to be violated. But I would love to do more allies, allyships with, like, body acceptance movements, like, for example, the fat acceptance movements, or I don't know. I think the question is accepting different bodies. (Participant 18, Switzerland)

Participants also spoke about alliances with LGBTQ groups. In particular, they noted how helpful it has been for many of them the work and connections already done by LGBTQ organizations.

> So, you know, in Asia, at least, one good thing is that organizations have been great allies of the intersex movement and in whichever country. We've been able to connect with local activists, and it is more or less always has been through the major LGBT organizations of the country. So, in this sense, both regional level organizations as well as national level LGBT organizers they've been very helpful. (Prashant, India)

Intersex movements have historically found alliances with LGBTQ movements, particularly with trans movements (Chase, 2003, 2013). A point of intersecting interests is the medical pathologization that trans and intersex persons continue to face from medical institutions (Davy, 2015; Suess-Schwend, 2020, 2024).

Laurent[1] wrote extensively about the connections between the early emergence of the intersex-led organization, the 'Intersex Society of North America' (ISNA), and trans movements (Chase, 2013), marking as crucial for intersex activism, the path walked by trans activists in the USA.

Other authors like Grabham (2007), Thoreson (2013), and Davis et al. (2016) also wrote about the similarities and connections between both movements. Meoded Danon (2018) highlights that there is a particular similarities but also differences between intersex and trans activism in which they challenge medical control but for opposing reasons:

> (…) both transgender and intersex people are in conflict with the biomedical experts, who control the treatment tools, rushing medical intervention for intersex babies, but delaying it for transgender people (Meoded Danon, 2018, p. 90).

Concerning EHMs, P. Brown et al. (2004) also suggest that EHMs have a natural connection with movements that came before "EHMs also represent boundary movements to the extent that they are the outcome of social movement spillover (…) the influence of previous movement outcomes on strategies, goals, and framings." (p. 54)

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[1] Before changing name, the author published under the name of Cheryl Chase.

Despite the benefits of working with previous movements, as stated before, there are important differences between LGBTQ and intersex demands. Garland and Travis (2022) have indicated that the use of an LGBT embodiment for framing intersex persons demands risks prioritizing anti-discrimination legal and political reforms over addressing concerns about bodily integrity, medical authority, and pathologization.

Some participants also noted the differences with LGBT organizations, particularly in priorities, regarding discrimination *vis a vis* challenging the current medical paradigm when it comes to controling intersex bodies.

> Allies is good, good for support of course, other people or matters of discrimination or bias, of course. But sometimes, it is hard to maintain because the main point, for me, is to stop the medical interventions. So, if you use a flag, 'we are all people, LGBT people, we are all friends, we are all…' if you just use it, it's hard to make physicians, families, people to understand that the point is the trauma, violence, mutilation. (Manuela, Italy)

My analysis of the data suggests that many intersex participants and their groups have built alliances, particularly with LGBTQ and bodily integrity groups, and this has helped move their advocacy efforts forward. In the case of trans movements and bodily diversity social movements embodied experience is a point of resonance.

The alliances with LGBTQ groups have also helped open doors, networks, and opportunities to discuss intersex bodies concerning cultural notions of sexuality, sex, and gender. While there are positive aspects to the alliance with LGBTQ movements, many participants noted that the majority of their group's constituency was not LGBT. Participants also highlighted differences regarding framings and priorities, for instance, anti-discrimination legislation or third gender ID documents. Participants who spoke of alliances with LGBTQ groups underscored the importance of keeping bodily integrity as a priority issue that should not get lost in the mix of anti-discrimination demands.

Embodied experience and the contestation of the 'disorder diagnosis'

Rejecting the pathologization of their bodies and medical categories or diagnoses such as 'disorders of sex development' (DSD) is a key point in most intersex activist groups (Davis, 2011, 2014), as discussed by the participant's statement below.

> [W]e are still considered diseased, we're still considered unhealthy, and we don't know anything about ourselves and our one variation, so it's still just the medical profession who has the right to tell us what we are. (Claudia, Italy - Interpretation)

P. Brown et al. (2004) consider that individuals with a shared experience of medicalization or what they call 'illness' tend to "develop a 'cognitive, moral, and emotional connection' with other illness sufferers, a collective illness identity emerges" (p. 60). A politicized identity emerges when this collective identity is critical of medical knowledge and the construction of illness or disability (P. Brown et al. 2004).

P. Brown et al. (2004) also have observed that groups that develop a collective medicalized political identity can show an "oppositional consciousness" (p. 62). This is when groups challenge medical paradigms that are viewed as the source of structural problems. When this happens, social movements tend to prioritize not just access to medical treatments or health care but also require structural changes in the perception of their medical condition.

In the case of many participants, their experience with medical institutions governing their bodies and taking away their agency has led them to challenge dominant medical paradigms that aim to 'control' and 'normalize' their bodies. Consequently, they challenge discourses, practices, and institutions that contribute to perceiving their bodies as disordered, and depathologization has become a primary political goal (Davis et al., 2016). This is, however, in opposition to other groups that take on their identity or role as 'patients,' complicating dynamics between groups (Crocetti et al., 2020; Davis, 2014).

Intersex groups have recognized a difference between medicalization and pathologization. In 2023, the intersex-led organization Organisation Intersex International Europe (OII Europe) launched the online campaign "Depath intersex" (OII Europe, 2023, n.p.). The Campaign acknowledges that "[t]he terms *pathologization* and *medicalization* are often used interchangeably, but they do have some subtle differences" (OII Europe, 2023, n.p.). According to OII Europe (2023) "pathologization is the act of *framing* and *generalising* a given physical or behavioural reality as 'sick', 'abnormal', 'disordered', non-functional, in need of 'fixing', while medicalization is the process of expanding the scope of medicine to include physical or behavioural realities which were not treated as a medical problem before, through diagnoses, medical practices, and research." (n.p.).

Research participants also discussed how their embodied experience and perspectives concerning their 'diagnosis' influenced internal and inter group dynamics. For some, despite initially participating in support groups, those groups did not satisfy their needs for organizing or being politically visible; therefore, they decided to seek other spaces, eventually getting involved in human rights activism.

> In Argentina, I knew other people with the same diagnosis, which I had told you as if it was like the first group that approached me, but I didn't consider what I was doing activism, let's say. Because it was just like a more support group, like on WhatsApp, let's say, where we talked, but at no point did we think about it, just like a political demand. (Macarena, Argentina – Own translation)

Participants also acknowledged the division between intersex groups and what I will call here 'patient support groups' or 'DSD-support groups'. An important aspect of this division is the challenges to medical authority and rejection or not of the medicalization and pathologization of their variations. As one participant stated:

> Since the beginning I am in contact with some patients' associations, and then there is a very old and strong community from the Klinefelter syndrome, who are all either patients' organizations or associations who do not question their medicalization. (…) I have a lot more friends who are intersex people who do not accept their intersex condition than within intersex activists. I am also friends with individual people who are members of patients' associations that are questioning things and do not have the answers about what they are expecting from the association. (Sarita, France - Interpretation)

Literature suggests that in some places, DSD-support groups are disengaged with political strategies or organizing for contesting the 'disorder' label of diagnosis set by medicine about their bodies (Crocetti et al., 2020; Davis, 2011). In many contexts, the primary goal of these support groups is to secure access to health care for people with DSDs (Davis, 2011) but they do not contest medical authority. In some more polarized contexts, DSD groups and patient support groups, including those led by family members, are more politically active, often confronting intersex groups, for example, for embracing the intersex identity – a term many consider offensive-, challenging the medicalization of DSDs, challenging gendered regarding people's bodies and using oppositional strategies against doctors, amongst other things (Crocetti et al., 2020; Davis, 2011; Lundberg et al., 2018).

Burke (2011) has explored the inter-group dynamics around diagnosis and medicalization in trans movements. She notes that while medicalization has been traditionally studied as a form of control, for some trans persons, it could also represent 'easier' access to health care and is not always rejected.

My research suggests a complex relationship with the contestation of medical authority in many intersex participants. While most of them explicitly spoke about rejecting pathologization, a number of them talked about how not every person with an intersex variation shares this view, and it becomes a complicated process to try to include such groups within their activism or to feel included within patient support groups. For some it is also strategic to do code switching or accepting a diagnosis for the purposes of accessing health care, while for others this is unacceptable and has become an obstacle for attending to their health care needs.

Embodied trauma and the relations with health professionals

A central topic raised in the interviews was how the embodied experience of participants had shaped their relationship with medicine and doctors. For many, the secrecy about their intersex variations, the clinical view regarding the medical necessity of interventions, and the lost of agency and ability to consent to medical interventions creates a relationship of mistrust not only to their physicians but to medicine as an institution in general. This was evident in several of the interviews.

> Generally, in Italy if someone, an intersex person is born, they need to be quiet. That means that they are then tied to the original doctor who treated them and that they don't have access to other medical care. The end result is that they can never make decisions for themselves. It's always the medical professionals who are deciding for them. (Claudia, Italy - Interpretation)

> I don't want my name to be linked to any medical professional, never. I've been asked to be on the advisory board of a medical project or to be working on the research team with like five other doctors, and I'm like, 'No, I'm not working with five other doctors as the only intersex person. I'm not doing that.' I don't like you. Even though you're maybe a nice doctor or a better doctor, you are still a doctor, and I don't like you. (Participant 18, Switzerland)

The last quote shows the reluctance of an activist participant to 'collaborate' (which was defined in broad terms) with doctors. This reluctance was marked by her personal experience, given that in her youth, she had actively collaborated with her doctors and was considered a 'star patient' until she started asking questions about the necessity of the surgeries she had during childhood. Later in the interview, however, the same participant recognized the necessity to engage in dialogue with health professionals, mainly because they serve as access points to provide information to other persons with intersex variations:

> But if you mean collaboration as going and talking with doctors, this is necessary. I'm doing this regularly. Because I think they need to… I mean, like if you want to be working with patient support organizations, they bring patients to you. You need some contact with them because they won't just send intersex people to anyone. You need to build some kind of trust relationship. You need to also be able to tell them when they fuck up. (Participant 18, Switzerland)

Another participant also spoke about the need for collaborative-adversarial tactics for engagement with medical professionals:

> I mean, you have to confront the perpetrators. I mean fortunately, there are not many people and activists who really do this. Mostly in the self-help groups, they want to collaborate with doctors, which is another approach, and we feel it needs both. It's like good cop and bad cop. But there are very little people ready to play bad cop. So, we focused a bit on this part of the work. (Markus, Switzerland)

Other participants acknowledged the need to collaborate or actively engage with doctors. This perspective was reflected in a number of interviews, like the one below.

> I am working with the medical system; I do that. I give workshops for midwives, and I give workshops for medical students since two years now. I work with nurses, with caretakers, with caretakers in elderly housings, things like that. (…) And I also think it is important to work together with the medical system, but also in a human rights based way. I am not working with doctors who don't accept my voice, you know? (Participant 1, Austria)

Participants also spoke about the need for a diagnosis to access health care in many situations.

> They didn't give me the certification. It would mean that I don't pay any visits for my intersex variation, or I pay nothing for medicines if I wanted to take them. They didn't want to give me the certification, and I still don't have that because I don't want to take medicines that are not for my health but for aesthetic reasons, and that's a manipulation. (Participant 10, Italy)

P. Brown et al. (2004) point out that the relationship between EHMs and medicine is a complicated one. According to their analysis, on the one hand, because of medical conditions, EHMs need access to health care, and many focus their efforts on securing such access. Also, to move their political goals, they often turn to scientific evidence, commonly from the clinical and health sciences, to support such claims (P. Brown et al., 2004).

P. Brown et al. (2004) also talk about complications groups challenge or contest medical knowledge or practice, institutions, and/or practitioners. When EHMs challenge the condition of 'illness' or 'disorder' itself, often they cannot turn to the kind of evidence used in clinical settings, and their embodied experience needs to take the forefront. This creates a sort of negotiation in terms of the contestation of knowledge and needs in terms of access to health care, which is not always easy to navigate (P. Brown et al., 2004).

The dynamics of collaborations-contestations with doctors and medicine also influence internal and inter groups dynamics, especially between intersex activism groups and patient support groups. These dynamics between different groups and strategies have been noted by previous research, for example, Crocetti et al. (2020) state that:

> [T]here continues to be differences in approach between patient advocates, who push for better medical care founded on long-term medical data and collective subjective experience, and intersex activists who no longer believe in medical self-reform and therefore push for criminalization of non-consensual, unnecessary practices. (Crocetti et al., 2020, p. 947)

My research supports the idea that dynamics of collaborations-contestations with doctors and medicine are key aspects and influence how some participants mobilize their political efforts. These dynamics also mark a division between some intersex organizations and some patient support groups, where the first ones tend to have a more adversarial stance and the second kind tend to support collaborations. My research findings suggest that some intersex activists do see the need and are open to engaging with medical professionals; however, they are willing to work or collaborate with health professionals if their opinions and voices are valued. They are not willing to be an object or passive person but pursue an active role.

Embodied knowledge and epistemic injustice

One of the critical harms spoken about by participants was that their experience is neither being listened to nor taken into consideration by medical professionals. A number of participants reflected on how they felt their embodied expertise was not considered by their doctors, medical institutions, or policymakers.

> They don't listen to us if we, the intersex persons, who are the experts of our body, are saying that we don't want intersex genital mutilation; are saying that we don't want unnecessary medical interventions on our body. They should pay attention to these things because is all affected, is affecting our life, is affecting our existence, affecting our good, is even affecting our relationships with people. They should be able to listen to us and understand where we are coming from, why we are saying these things. (Participant 25_A, Nigeria)

Other participants reflected on the general lack of knowledge about intersex persons and variations; this also affected them when trying to access health care when doctors are not familiar with variations of sex characteristics.

> In university, they don't make courses of intersex variations, and if they know something about intersex, it is just as some rare diseases, that are bad, that have to be normalized with hormones, surgeries and things like that, (…) They don't want to make some changes because they think their opinion is right. (Participant 10, Italy)

Concerning knowledge production, P. Brown et al. (2004) highlight how the embodied experience is vital in the advocacy efforts of EHMs, especially those that are critical and challenge standardized, naturalized, and institutionalized medical diagnoses about their health status; this is also true for intersex movements. Additionally, given the lack of longitudinal quantitative data about the effects of unconsented medical interventions and surgeries during childhood (T. Jones, 2018), there are a lot of efforts in collecting and making visible qualitative data from those with lived intersex experiences. However, this kind of qualitative data is not always given the value it should.

Fricker (2007) has extensively written on “epistemic injustice” (p.1), a term she uses to describe harms in knowledge production that result in the silencing of voices, this kind of injustice manifests in two ways. First, where the knowledge of a certain individual or a certain group of people is not valued because their status is seen as inferior; to this she calls "testimonial injustice" (Fricker, 2007, p.9). She also speaks about "hermeneutical injustice," which happens when there is a lack of understandings, terminology, or concepts that can truly convey the meaning of the speaker's experience (Fricker, 2007, p.147).

Carel and Kidd (2014) have considered epistemic analysis to be relevant regarding health care. They argue that “health professionals are considered to be epistemically privileged, in both warranted and unwarranted ways, by virtue of their training, expertise, and third-person psychology” (p. 530). Consequently, they decide “which patients are assigned undeservedly low credibility with cases in which patients’ credibility is undeservedly high” (Carel and Kidd, 2014, p. 530).

Carpenter (2023) argues different ways in which intersex persons have suffered from epistemic injustice, among them, the adoption of the term disorders of sex development to medically refer to variations in one’s sex characteristics, the secrecy in the medical history and treatments, and the rhetorics of change and improvement of ‘new’ medical treatments. According to his analysis, these have resulted in or are a consequence of not providing the appropriate value to the voices and expertise of intersex persons (Carpenter, 2023).

Similarly, Merrick (2019) argues that not only the change of nomenclature from intersex to DSD is a case of epistemic injustice but also the lack of attention and consideration given to the critics and demands for change coming from intersex human rights organizations and persons with lived experience.

Roen (2004) has pointed out a problem in how the ‘evidence’ debate is framed, where clinical evidence is mostly used regarding surgical interventions and other treatments. Then, there is qualitative data from people with embodied experience and people who speak openly about their experiences and concerns. She underscores that “When clinical texts do draw on social scientists and intersex authors texts, they tend to refer briefly to the concerns being raised but rarely engage in more depth with complexities and wide-raging implications” (Roen, 2004, p. 128).

I understand the above to be cases of testimonial injustice that have resulted both as caused by and as consequences of not listening and valuing the expertise of people with embodied experience.

I must note also that in terms of activism and inter-group dynamics research participants also underscored instances that can be understood as cases of hermeneutical injustice. An interesting example of this hermeneutical injustice has to do with the conflation of intersex persons and demands with those of lesbian, gay, bisexual, trans, queer, and nonbinary persons. As one participant stated:

> I think at the beginning, we were very open to all LGBT organizations and people and being like, ‘We're like the same, we are allies, let's collaborate on something .’And while I think this has helped us a lot because it gave us the know-how and stuff like this, now I am much more careful. Just because I think that due to LGBT experiences

> and objectives, intersex issues can be very easily and unintentionally, and I'm not saying this in a mean way, (…) But there was like this scheme of interpretations that there is something they just don't get. (Participant 18, Switzerland)

Carpenter (2016) has noted that "[i]dentity-focused language" often used by LGBT-Queer groups "mischaracterises intersex human rights issues as matters of sexual orientation and gender identity. It prioritises issues of performativity and identity over deeper, more intractable issues of bodily autonomy" (p. 79). This also resonates with Garland and Travis's (2022) perspectives about how the characterization of intersex persons under an LGBTQ or third gender embodiment risks changing the priorities of the movement towards anti-discrimination goals or third gender recognition.

Based in the above, I understand that the mischaracterizations of intersex persons as LGBTQ or nonbinary persons or the conflation of their demands, even if unintentional, represent a case of hermeneutical injustice. Intersex persons have been left for the longest time without specific discursive framings to convey meanings about their experience and their demands other than those set by medical authorities. Consequently, intersex activist groups have often turned to alliances with groups that came before them that have more 'mainstream' or 'recognizable' framings to convey meanings to society in general, such as LGBTQ groups.

As stated above, in some cases, collaborations with LGBTQ groups have turned beneficial by opening opportunities and expanding networks. In other cases alliances have resulted in the change of political priorities, framings, or cooption of demands that do not represent intersex activism. This as a result of not listening to what the community needs or not understanding their demands; what one participant referred to as "I-washing" (Claudia, Italy).

In order to counter the epistemic injustice experienced by intersex persons, Roen (2004) highlights the need for more comprehensive approaches, for example, where clinical researchers include sociological approaches in their research. Carpenter (2023) similarly highlights the role of bioethics in challenging injustice.

Based on my research, I argue that a similar stand needs to be taken in activism. Groups that are not intersex but want to support intersex activism need to actively listen to their demands and actively engage with the community.

Conclusions

My research shows how the body is central to the experience of many participants engaged in intersex activism. Their embodied experience influences their personal perspectives, but also their groups' dynamics, actions, demands and political goals.

I conclude that P. Brown et al.'s (2004) EHMs framework is helpful for understanding the importance of the body going from the personal to the social. This framework was useful for exploring aspects such as identity formation, coalition building strategies, activists' relationship to medicine, and others discussed above.

Based on my analysis of interview data and literature on health movements and embodied health movements, I conclude that many intersex groups share elements for which they can be considered both HSMs in general and particularly EHMs. The first kind because of the closeness of demands regarding medicine and health care, and the second kind because of the importance of the body concerning their activist efforts. Another similarity stems from the fact that these groups challenge medicine on etiology, the understanding of being intersex as a medical condition or pathology, as well as treatment course and access to it.

Many intersex groups, however, are also particular in that their activism goes beyond health care matters. The demand to end non-consensual surgeries aimed at ‘fixing’ the appearance of genitalia and the contestation of the ‘disorder of sex development’ diagnosis are essential aspects of intersex activism. Both of these aspects have a strong relation to social and medical constructions around sex and gender; thus, the claims of intersex groups are not purely related to health or related only to medical practice.

The above has influenced many activists’ strategies and actions. Some research participants were invested in promoting education about being intersex and promoting sensitization around bodily diversity, as well as challenging normative conceptions about sex and gender. These efforts are similar to trans or body acceptance movements that challenge medicalization, pathologization, and sociocultural perspectives of bodies (Duffy, 2021; Hird, 2000; Kwan, 2009; Monro & Warren, 2004). This shows intersex groups are also interested in sociocultural changes.

Finally, a lack of understanding of the embodied experiences of intersex people poses a challenge when they interact with health practitioners, clinicians, or even other activists; this can be understood as a form of epistemic injustice.

As a limitation, I would like to point out the small number of interviews carried out which contrasts with the vast geographical locations represented in this study. While my research does not aim to make generalizations about intersex activists everywhere, future studies may benefit from limiting the geographical scope to a country or a number of countries or regions to understand better how the local context influences and is experienced through intersex bodies.

Another aspect that might be needed for future research is including patient support groups in social movements research. As stated before, I did not actively sought out these groups for this study as the literature points out they do not consider themselves activists, which was essential for my research. Nonetheless, one of the participants contested this view, considering patient support groups engage in politics and activism. In any case, this is also a reason to consider research from a social movements perspective. P. Brown et al.’s framework about HSM might also be helpful in this scenario.

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Conflicts of Interest

The author declares no conflict of interest.

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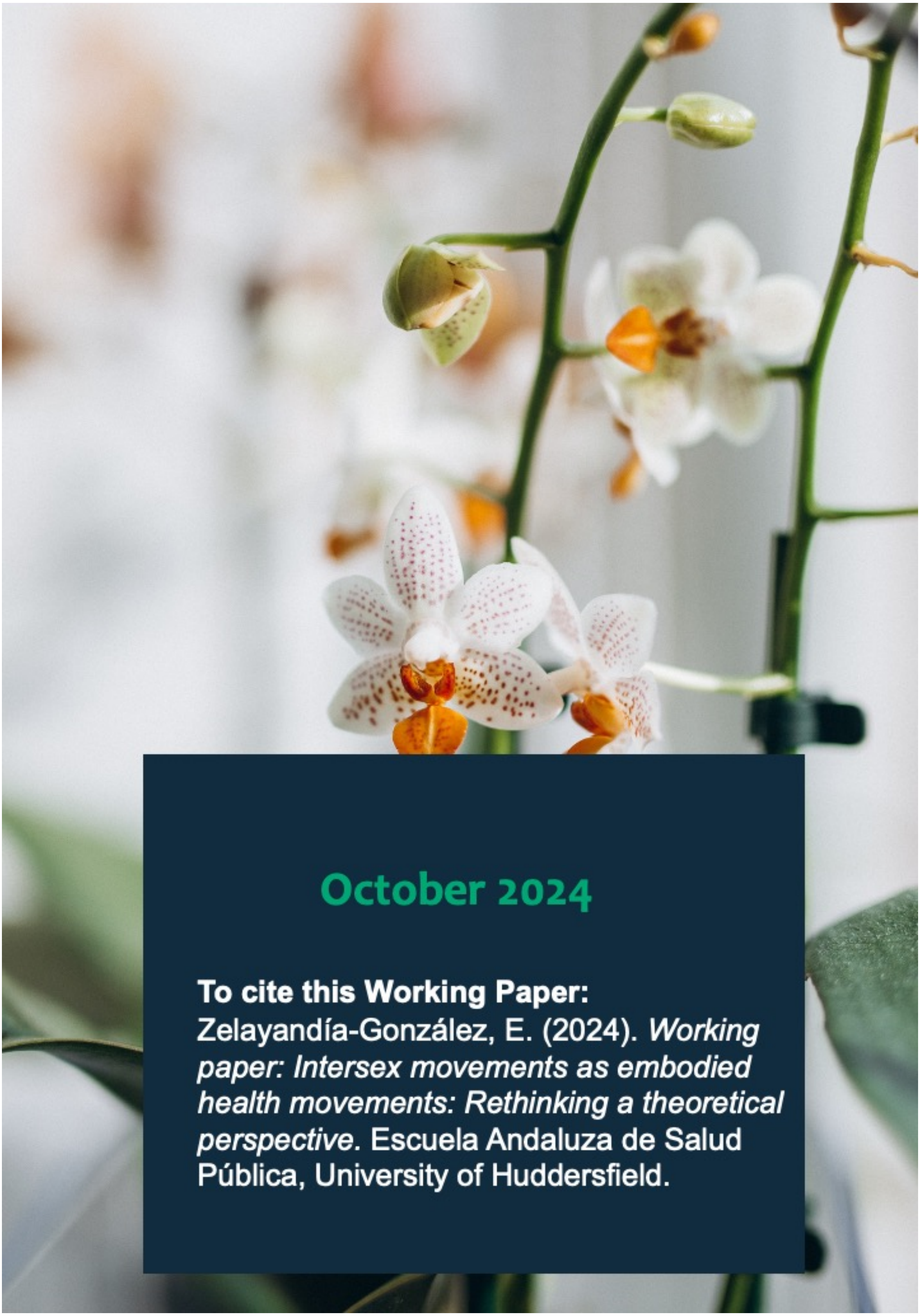

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