



Geographies of the secret: Navigating medical, activist, and intimate spaces in intersex research in Chile

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ARTICLE INFO

Keywords:

Intersex
Cultural geography
Embodied methodology
Chile
Medical secrecy
Health inequities
Epistemic injustice
Ethnographic reflexivity

ABSTRACT

This article examines how medical secrecy, family silence, and nascent activism produce distinct spatial-cultural regimes that shape health outcomes, care pathways, and health inequities for intersex people in Chile. It contributes a spatial-analytic framework to medical anthropology debates on clinical secrecy, contested diagnostic nomenclature, and epistemic injustice in healthcare.

Multi-sited reflexive ethnography was conducted in Chile between October 2020 and December 2023, primarily in Santiago. The study draws on 30 semi-structured interviews—14 with intersex individuals (aged 19–45), of whom one additionally provided a life history interview; 5 specialist physicians, 7 parents/guardians, 2 academic researchers, 1 government official, and 1 international activist—supplemented by approximately 340 h of participant observation across virtual, institutional, domestic, and café-based settings. Analysis followed a constructivist grounded theory approach.

Medical institutions, families, and activist organizations produce distinct ‘geographies of secrecy’ that render intersex bodies selectively visible and impose specific health consequences: clinical spaces generate epistemic injustice through information hoarding and paternalistic consent practices; family spaces enforce silence that isolates individuals from diagnosis, community, and healthcare; activist spaces offer collective recognition while simultaneously producing new exclusions.

The concept of ‘calibrated disclosure’ captures how intersex people strategically manage visibility across spatial contexts with direct implications for healthcare access and wellbeing. The article introduces ‘embodied accountability’ as a methodological principle for reflexive research with small, geographically concentrated marginalized communities. Findings highlight the need for healthcare systems to address not only clinical protocols but the spatial-institutional conditions that produce epistemic injustice and impede informed consent for intersex people.

1. Introduction: Spatializing the researcher’s body

‘Hello, are you an intersex or endosex person?’

The question arrived via email almost a month after I had requested registration for the first virtual meeting of intersex people in Chile. My response—that I am endosex—triggered a series of spatial negotiations: I could occupy the virtual space, but not speak. I could be present, but not turn on my camera. My body, even in its digital manifestation, required territorial management.

A note on terminology is necessary here. Terminology in intersex studies is contested and evolving. Some activists and medical bodies prefer ‘variations of sex characteristics’ (VSC) or ‘differences of sex development’ (DSD) over ‘intersexuality,’ due to concerns that the latter

may imply a unified identity or conflate somatic variation with sexual orientation. Conversely, the organizations with whom fieldwork was conducted—IntersexualesChile and IntersexPacíficoSur—use ‘intersex’ and ‘intersexuality’ as their primary self-designations and political terms. This article follows their usage: ‘intersexuality’ refers to the broader phenomenon; ‘intersex’ is used as an adjective and as a self-descriptor where participants so identified. Medical DSD nomenclature is discussed critically in Section 2.

This moment crystallizes the spatial tensions of ethnographic research on intersexualities in Chile: who has the authority to occupy which spaces? What bodies are legitimate in the production of knowledge about intersex experiences? These questions are not merely epistemological. They are also questions of health and care: who can access

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<https://doi.org/10.1016/j.socscimed.2026.119345>

Received 22 December 2025; Received in revised form 22 April 2026; Accepted 28 April 2026

Available online 29 April 2026

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diagnosis, treatment, and community support depends profoundly on who can occupy the spaces where such resources are distributed.

This article enters canonical medical anthropology conversations—on contested DSD nomenclature (Kessler, 1998; Fausto-Sterling, 2000; Lee et al., 2006), on non-consensual ‘normalizing’ surgery and the crisis of informed consent in paediatric intersex care, and on epistemic injustice in multidisciplinary clinical teams (Fricker, 2007; Zeiler and Wickström, 2009)—through a spatial lens. Rather than treating medicalization as a solely discursive phenomenon, I ask how the spatial organisation of clinical, familial, and activist life shapes what intersex people can know about their own bodies, what health decisions they can make, and what care they can access. In doing so, I extend the analytic repertoire of medical anthropology itself through feminist geographic epistemology.

1.1. Situating Chile's intersex geographies

Chile presents a distinctive cultural geography for researching intersexuality. Medical expertise and activist organizing cluster in Santiago (where approximately 40% of the national population resides), leaving provincial regions with severely limited access to both specialized healthcare and community infrastructure. This metropolitan concentration shapes who can access intersex diagnosis, treatment, and political identity, producing geographic health inequities that begin at the spatial level before they manifest clinically (Casanova-Molina, 2023).

Between October 2020 and December 2023, fieldwork moved across multiple spatial registers: from virtual community meetings during COVID-19 lockdowns to intimate conversations in Santiago cafés; from clinical spaces in hospital consultations to domestic spaces where families negotiated secrecy and disclosure; from organizational strategy sessions in activists' homes to encounters that blurred boundaries between fieldwork sites and spaces of friendship. As a cisgender, bisexual, endosex Chilean woman trained in social anthropology, I entered this field aware of my outsider status yet committed to allyship.

This article makes five contributions. First, it demonstrates how spatial positioning—not only social location—shapes epistemic authority and healthcare access for intersex people, and how this spatial-epistemic dynamic produces concrete health inequities through the management of diagnostic information, the enforcement of family silence, and the gatekeeping of peer community. Second, it documents how medical secrecy, family silence, and activist gatekeeping produce health inequities through spatial-territorial mechanisms—impeding informed consent, delaying diagnosis, producing isolation, and foreclosing the healthcare navigation that peer community enables. Third, it theorizes sexual-affective bonds as methodological-spatial practices that must be addressed transparently and ethically. Fourth, it develops practical frameworks for researching small, geographically concentrated populations where standard anonymization is insufficient. Fifth, it introduces ‘embodied accountability’ as a methodological principle for activist scholarship committed to not reproducing extractive research practices.

2. Feminist geographic epistemologies: embodiment, situation, space

2.1. Feminist epistemology and spatial authority

Feminist scholars have long challenged the fiction of the detached, objective observer (Haraway, 1988; Harding, 1991; Butler, 1993). Cultural geography extends this by demonstrating that knowledge is spatially situated—emerging from particular locations, territorial relations, and cultural contexts (Rose, 1997; McDowell, 1992). Where you are shapes what you can see, who you can encounter, what becomes thinkable. In research with marginalized communities, this spatial dimension of epistemology directly determines which health

experiences become visible to researchers and policymakers.

This spatial-cultural dimension became evident throughout fieldwork. Virtual activist meetings produced different knowledge possibilities than face-to-face café conversations. Medical clinics structured what could be said differently than activist organizational meetings. Intimate domestic spaces opened dimensions of experience foreclosed in public institutional settings. Each geography had its own culturally specific rules about visibility, disclosure, authority, and belonging—and each produced distinct health knowledge.

2.2. Bodies as spatial-epistemological tools

The researcher's body is not incidental but central to knowledge production—both as the vehicle through which spaces are accessed and as itself a site that produces spatial relations. Cultural geographers have theorized how bodies are ‘spatially constituted’ while simultaneously ‘constituting space’ (Longhurst, 2001, p. 2). Drawing on Ahmed's (2006) theorization of how bodies are ‘oriented’ toward and away from objects/spaces, and Probyn's (1993) understanding of the body as ‘local geography,’ I understand my research body as a spatial-cultural medium through which knowledge emerged. Following Esteban (2004, 2011), the body is an agent whose vulnerabilities and resistances are not obstacles to analysis but its very medium.

2.3. Cultural geographies of sex, gender, and bodily difference in Latin American context

Intersexuality challenges culture's most foundational spatial division: the bifurcation of humanity into male and female. Bodies that exceed this binary become what Douglas (1966) theorized as ‘matter out of place.’ In Chile, intersex bodies are managed through ‘geographies of erasure’: medical interventions conforming bodies to binary norms, administrative systems refusing recognition of non-dimorphic sex categories, family practices enforcing silence.

The growing body of Latin American intersex studies significantly extends the predominantly Anglo-American scholarly conversation. Cabral (2009) argues that intersexuality is not something that affects only those born with bodies that vary from corporeal norms, but a phenomenon that affects all of society. Cabral and Benzur (2005) deconstruct the use of the intersex figure as queer symbol at the expense of actual intersex experiences. Esteban's (2004, 2011) embodied anthropology, developed in hispanic feminist contexts, provides a framework for understanding the body as simultaneously biological and cultural-political. The activist-academic work produced by and with organizations such as BrújulaIntersexual and IntersexualesChile extends this scholarship into empirical research in the region.

I introduce the concept of ‘calibrated disclosure’ to capture how intersex people strategically manage visibility across spatial contexts. This extends cultural geographic work on the ‘closet’ (Brown, 2000) and queer visibilities (Browne and Nash, 2010) by demonstrating how intersex people navigate multiple, simultaneous spatial-cultural regimes of visibility and concealment with direct implications for healthcare access: a person who must conceal their diagnosis in family spaces may also conceal symptoms from healthcare providers, with measurable health consequences.

2.4. Researching across geographic scales

Cultural geographers understand social phenomena as operating simultaneously at multiple spatial scales, with power working differently at each level (Marston, 2000; Pratt and Rosner, 2012; Smith, 1992). My research required navigating five scales. At the bodily scale, intersex variations manifest in chromosomes, gonads, hormones, and genitalia, subject to medical classification and intervention. At the domestic scale, families negotiate secrecy and disclosure within homes. At the urban scale, Santiago's concentration of medical specialists and

activist organizations creates geographic health inequities. At the national scale, Chilean legal frameworks lack recognition of intersex variations and provide no legal protections specific to intersex people. At the transnational scale, Chilean intersex activism connects with global movements, circulating rights discourses across borders.

Understanding how these scales interact reveals how intersex health experiences are produced through what Smith (1992) calls ‘jumping scale’: bodily variations become medicalized through clinical institutions that connect to national health systems, which respond to international medical protocols, which intersex activists challenge through transnational advocacy that reshapes national conversations and ultimately affects individual health encounters.

2.5. Activist research and geographic responsibility

My research positions itself within activist scholarship explicitly committed to social transformation (Pickerill and Chatterton, 2006; Derickson and Routledge, 2015). The principle ‘Nothing about us, without us’—a slogan with roots in North American disability rights activism (Charlton, 1998), subsequently adopted and transformed within international intersex advocacy via the Malta Declaration (2013), and travelling from there to Chilean activist spaces—expresses not only demands for inclusion but challenges to geographic authority: who can occupy spaces of representation?

Pain (2003, 2004) argues that geographic research must attend to how it reproduces or challenges spatial inequalities. This meant recognizing how my mobility—ability to access medical institutions, activist meetings, academic conferences, international literature—constituted geographic privilege. It meant attempting to redirect invitations, share platforms, and use academic spaces to amplify rather than displace intersex voices. Following Kobayashi (1994), I acknowledge that the relationship between political engagement and geographic research is neither simple nor straightforward.

3. Methods

3.1. Research design and researcher positionality

This article draws on multi-sited reflexive ethnography (Marcus, 1995) conducted in Chile between October 2020 and December 2023. The study was designed to examine the cultural geographies of intersex experience, attending specifically to how spatial contexts—medical, activist, domestic, and intimate—shape visibility, knowledge production, health outcomes, and healthcare access for intersex people. The research is situated within feminist geographic epistemology (Haraway, 1988; Rose, 1997) and activist scholarship (Pickerill and Chatterton, 2006).

All fieldwork interactions, interviews, and observations were conducted in Spanish. Interview excerpts presented in this article were translated from Spanish into English by the author, with AI-assisted tools used for initial translation drafts (see AI Use Declaration). The researcher is a cisgender, bisexual, endosex woman of Chilean nationality, resident in Spain and trained in social anthropology, who participated as a volunteer ally within one intersex activist organization from September 2021. This insider-ally positioning facilitated access while requiring sustained reflexivity about power asymmetries with intersex participants throughout all stages of data collection and analysis.

3.2. Participants and recruitment

Recruitment followed purposive and snowball sampling (Salamanca and Martín-Crespo, 2007) across three entry points: (1) formal contact with the two intersex activist organizations active in Chile during the research period (IntersexualesChile and IntersexPacíficoSur); (2) personal networks within sexual diversity communities in Santiago; and (3) participant referrals. Inclusion criteria required identification with an

intersex experience (based on bodily, chromosomal, or hormonal variation) and residence in Chile at the time of the study.

Thirty formal interviews were conducted across participant groups: 14 in-depth semi-structured interviews with intersex individuals (aged 19–45), of whom one participant (referred to throughout as Lily) additionally provided a life history interview—an extended biographical narrative session covering her full biographical trajectory, childhood medical interventions, and long-term health experiences. The remaining 13 intersex participants participated in semi-structured in-depth interviews only. These 14 intersex participants were distributed across three diagnostic temporalities: childhood diagnosis ($n = 5$), adolescent revelation ($n = 4$), and adult discovery ($n = 5$). Additionally: 5 specialist physicians (endocrinology, urology, surgery); 7 parents/guardians of intersex children; 2 academic researchers in related fields; 1 government official; and 1 international activist. Participant observation was conducted over approximately 340 h across organizational meetings, institutional roundtables, public events, conferences, and informal social encounters. More than 50 informal conversations were documented in field diaries. All participants are referred to by pseudonyms selected in consultation with participants.

3.3. Data collection methods

Data collection combined four methods. First, semi-structured in-depth interviews (90–180 min) addressed diagnostic experiences, family relationships, medical encounters, sexuality, and healthcare trajectories. Structured interviews with medical professionals and parents/guardians provided contextual understanding of institutional and familial dynamics. Second, participant observation was conducted across multiple spatial contexts: virtual activist meetings on digital platforms (June 2020–December 2021); in-person organizational meetings and events; university and institutional spaces where the researcher participated as volunteer ally; and public LGBTQ+ events. Third, extended ethnographic engagement beyond formal interviews—shared meals, informal conversations, ongoing digital communication—formed the relational basis of the research. Field notes were recorded after each engagement session; non-recorded conversations were reconstructed from contemporaneous field notes taken immediately after each encounter. Fourth, documentary analysis of organizational materials, policy documents, Chilean health statistics, and relevant media provided contextual triangulation.

3.4. Analytical approach

Analysis followed a constructivist grounded theory approach (Charmaz, 2006) supported by qualitative data management software (NVivo and ATLAS.ti version 9). Analysis proceeded through three coding phases—open, axial, and selective (Strauss and Corbin, 2002)—generating 76 initial codes subsequently organized into five analytic categories: embodied dispositions, acts of legitimation or subversion, webs of affect and power, corporeal reconfiguration, and practices of self-construction. A second analytical pass applied spatial-scalar lenses (bodily, domestic, urban, national, transnational) to map how themes operated across different sites and scales. Triangulation operated across data sources, methods, and theoretical frameworks (Denzin, 1970). Preliminary interpretations were shared with key participants in communicative validation sessions (Kvale, 1996).

Reflexivity was treated as a continuous methodological practice rather than a discrete stage: field notes included regular reflexive memos addressing how the researcher's positionality, emotional responses, and spatial movements were shaping what became visible and knowable. These memos were subjected to the same analytical coding procedures as interview data.

3.5. Ethical considerations

Ethical approval was granted by the Comissió d'Ètica en l'Experimentació Animal i Humana (CEEHA) at the Universitat Autònoma de Barcelona in October 2020, prior to the commencement of fieldwork. The ethics file was formally closed upon completion of the project in December 2023. Informed consent was obtained in formats adapted to participants' spatial contexts: written consent for in-person interviews; digital consent forms for video-call participants; and oral consent (audio-recorded) for those participating in organizational meeting settings. All participants were informed of the research purpose, expected academic outputs, and limitations of anonymization in a small community.

Standard anonymization proved insufficient given the extreme smallness of Chile's visible intersex community. Only a handful of people openly identify as intersex activists in Chile, all based in Santiago, and organizational participation rarely exceeds a dozen people. Additional protective strategies included: strategic modification of geographic and contextual details; selective withholding of location-specific information; and composite case construction where necessary. These modifications enact an ethical commitment to protection over comprehensive spatial transparency.

A specific ethical consideration arose from the development of a sexual-affective relationship with one participant (referred to throughout as Lily) over the course of extended fieldwork. This relationship emerged as an unplanned relational reality of long-term ethnographic immersion, not as a methodological strategy. The structural power asymmetry between researcher and participant persisted throughout and required sustained reflexive attention. Lily provided informed consent to the anonymized disclosure of this bond following extensive conversations with the researcher and with doctoral supervisors. The full methodological and ethical implications of this relationship are addressed in Section 5.

4. Mapping invisible geographies: accessing and inhabiting multiple spaces

4.1. The spatial politics of invisibility

Intersex people in Chile constitute what I call an 'invisible geography'—not because they do not exist, but because multiple spatial-cultural practices work to keep them hidden with direct health consequences. Medical institutions conceal diagnoses through information hoarding, leaving patients without the basic knowledge needed to make informed healthcare decisions. Families create domestic spaces of enforced silence. Legal-administrative systems render intersex bodies bureaucratically impossible through binary classification. Activist organizing remains spatially concentrated and numerically small (Casanova-Molina, 2023, 2025a, 2025b).

Official Chilean statistics reveal profound undercounting shaped by spatial-institutional factors. The National Institute of Statistics (INE) recorded only 17 newborns classified as 'indeterminate sex' in 2023 out of 171,992 births—capturing only cases of visible genital variation detected at birth in institutional settings, excluding chromosomal, gonadal, or hormonal variations typically diagnosed later, if at all. This statistical invisibility both reflects and reproduces health system gaps.

Feña, an anthropologist and early intersex activist, described the challenge of finding intersex people outside medical and activist geographies:

'Many people are afraid to be intersex. They accommodate to what they come to understand at that moment. Many of them were actually trans, or perhaps intersex, but identified as trans because they already understood that a little—but intersex was completely unknown.' (Feña, interview, January 2021)

This fear of visibility is structurally produced by decades of medical

secrecy: when the healthcare system treats a diagnosis as something shameful to conceal, patients internalize that concealment. A physician participant articulated the clinical logic of information control:

'Parents don't need to know every technical detail. They need to trust us to make the right decision.' (physician, interview, March 2022)

This paternalistic management of diagnostic information directly reproduces a spatial regime of secrecy that extends from the clinical encounter into domestic and social space. Another participant described the health consequences of this information control:

'I knew something was different about my body since I was twelve. But every time I asked questions at the clinic, they changed the subject. I stopped asking. I thought it must be something terrible.' (Valentina, interview, July 2022)

Valentina's account illustrates how clinical spatial practices translate directly into healthcare avoidance—a mechanism with measurable long-term health consequences for intersex people who defer or forgo follow-up care in response to institutional silence.

4.2. Mapping organizational geographies

Two organizations existed during the research period: IntersexualesChile and IntersexPacíficoSur, both based in Santiago. Neither maintained physical headquarters; activist geography consisted of borrowed spaces—participants' homes, university auditoriums, occasional presence at LGBTQ + events. IntersexualesChile focused primarily on digital presence; IntersexPacíficoSur combined digital organizing with attempts to access institutional spaces. As Camilo, a founding member of IntersexualesChile, explained:

'We don't have a space. We rent people's living rooms, basically. To have a physical headquarters you'd have to be visible in a way that most of our members can't be.' (Camilo, informal conversation, March 2021)

This spatial precarity of activist organizations directly limits their capacity to connect isolated intersex individuals with peer support, advocacy, and healthcare navigation. One parent participant described how this absence of community infrastructure affected her family's healthcare experience:

'The doctors told us not to use that word. They said it was better for [our child] not to know. We wanted to protect them. But we had no one to ask whether that was really true.' (Ana, interview, May 2021)

Ana's account evidences what Foucault (1976) termed the 'capillarization' of medical power: in the absence of community infrastructure through which families might access alternative knowledge, clinical authority penetrates domestic space, and the diagnostic secret is maintained across generations with lasting effects on children's capacity to understand and make decisions about their own health.

4.3. Virtual spaces and the politics of presence

The COVID-19 pandemic transformed research possibilities by normalizing virtual gathering. In June 2020, IntersexPacíficoSur organized 'Living the I' (Viviendo la I)—the first virtual meeting of intersex people in Chile. The digital platform enabled participation from across Chile's 4,300 km territory, connecting people who had never met other intersex individuals. But virtual space brought its own territorial politics. Organizers initially required camera-on participation to verify identity; several participants resisted, arguing that facial visibility felt unsafe given the potential for screenshots and unwanted exposure.

It is important to note, following activist scholarship produced by BrújulaIntersexual and other Latin American intersex organizations, that the characterization of limited metropolitan medical access as simply a 'barrier' requires qualification. For some intersex individuals—including those from Indigenous communities with distinct frameworks for

understanding bodily variation—the medicalization of intersex characteristics may itself be the harm, and distance from metropolitan medical centres may not be experienced as disadvantage. Any spatial analysis of healthcare access must hold space for this anti-medicalization perspective rather than defaulting to a framework that treats all intersex people as seeking the same kind of medical engagement.

During the ‘Living the I’ meeting, Lily sent a private message initiating a conversation that would become one of the most significant relationships in the research. She described feeling like an ‘impostor’ in activist spaces:

‘I don’t feel entirely comfortable with the discourses coming from intersex activism here. I see myself as a kind of impostor, because I don’t have a medical history with normalizing surgeries. Sometimes I wonder if I have the right to call myself intersex at all.’ (Lily, informal conversation, May 2021)

Lily’s uncertainty illustrates a crucial health dimension: when activist framings privilege experiences of surgical intervention, they may inadvertently reinforce a hierarchy of ‘legitimate’ intersex experience that affects how individuals understand and access their own healthcare needs.

4.4. Inside the organization: spatial displacement and ‘Nothing about us, without us’

In September 2021, I joined IntersexPacíficoSur as a volunteer ally. When volunteers selected someone to support the coordinator in public-facing work, I was elected—a decision that generated significant territorial tension. When I began to be invited to speak at institutional events, I noticed that invitations consistently sought my academic perspective rather than the coordinator’s experiential authority, and took immediate steps to redirect these invitations. The conflict crystallized when the coordinator sent, via WhatsApp, the message: ‘Nada de nosotrxs, sin nosotrxs’ (‘Nothing about us, without us’).

The phrase functioned as territorial claim: the global intersex movement’s core principle, deployed as assertion of epistemic authority rooted in embodied experience—an authority my endosex body could not possess regardless of research commitment. Drawing on Spivak (1988), the risk of speaking ‘for’ the subaltern is not resolved through good intentions but demands constant institutional vigilance. This confrontation prompted sustained reflection on how academic credentials produce the very spatial displacements that activist scholarship aims to prevent.

Chuli, a non-activist intersex person from Concepción, provided a crucial corrective to the organizational perspective:

‘I had made contact and participated in a meeting of the organization, but I didn’t agree with its priorities, or with what I understood to be a vertical form of organizing. The activist identity wasn’t for me. But I still needed community, somewhere to make sense of my medical history.’ (Chuli, interview, September 2022)

Chuli’s account illustrates how activist spaces, while constituting vital resources for some, can simultaneously reproduce exclusions that push others—particularly those seeking peer support for healthcare navigation rather than political identity—back into isolation.

5. Intimate geographies: sexuality, desire, and embodied proximity

5.1. Beyond Taboo: the erotics of spatial proximity

One of the most silenced dimensions of ethnographic practice concerns sexuality and desire in the field. Kulick (1995) observes that anthropology systematically represses acknowledgment of the erotic dimensions of fieldwork. This critique has been extended by feminist and queer ethnographic scholarship: Blackwood (1995) demonstrates

how gender and sexuality position researchers within fields in ways that cannot be bracketed; Cesara (1982) broke ground in explicitly accounting for emotional and sexual experiences in fieldwork under the concept of ‘risked involvement’; Cupples (2002) documents how heterosexual desire shaped her research in Nicaragua; and Esteban (2004, 2011) develops a framework of embodied anthropology in which the researcher’s body is itself a methodological instrument.

Over the course of fieldwork, my relationship with Lily evolved from research contact to intimate friendship and, eventually, to a sexual-affective bond. This is stated unambiguously: I entered into a sexual relationship with a research participant. This progression was not planned or sought as a methodological strategy, but an emergent relational reality of long-term ethnographic immersion. I acknowledge the structural power asymmetry this created: I was the researcher, she the participant; I would occupy academic publication spaces that Lily would not; I held institutional authority over how her experiences would be represented in writing. These asymmetries did not disappear through intimacy—they required sustained, explicit reflexive attention. The ethical management of this relationship involved full disclosure to doctoral supervisors, ongoing consultation about its methodological and ethical implications, and Lily’s explicit informed consent to the anonymized disclosure of this bond. A cross-reference to the researcher’s positionality as established in Section 3.1 is important here: the endosex, academic position I occupied meant that power asymmetries were structural and persistent, not incidental.

Following Morrison et al. (2013) on critical geographies of love as spatial, relational, and political practice, and Pratt and Rosner (2012) on global intimacies and feminist methodology, I argue that refusing to account for this bond would falsify the conditions under which this knowledge was produced—a methodological dishonesty that feminist ethnography has long challenged. Following Boellstorff and Lindquist (2004), I understand intimate fieldwork relations as producing specifically situated knowledge irreducible to other methods, while remaining alert to their ethical complexity.

The relationship created what I call intimate geographies of fieldwork—spaces of erotic-affective proximity that enabled conversations foreclosed in more public settings. In domestic spaces we co-created, Lily’s intersex body was neither pathological nor a political project but part of who she was. As she reflected:

‘With you, I don’t feel like a case study, or a symbol, or a victim. I’m just a person who happens to have this medical history, which is actually quite boring most of the time.’ (Lily, informal conversation, November 2022)

This naturalization of intersex embodiment stands in productive tension with both clinical pathologization and activist politicization—offering a third register of intersex experience with direct implications for psychosocial health and for how healthcare systems might better support intersex people beyond both medical crisis framing and political identity frameworks.

5.2. The ‘intimate insider’ position: spatial advantages and limits

Taylor (2011) uses the term ‘intimate insider’ to describe researchers who occupy a ‘privileged and intimate position’ within their field sites. My intimate relationships with research participants provided access to spatial-experiential knowledge that would not emerge through formal interviews: the textures of daily life with intersex bodies, the mundane spatial negotiations of changing rooms, sexual encounters, family gatherings, and medical appointments. Following Tilley-Lubbs (2014) on the vulnerable self as researcher, I recognize that this access was made possible by my own vulnerability—the capacity to be moved, disturbed, and changed by what I encountered.

At the same time, intimacy created spatial-ethical complications. What information emerged from intimate domestic spaces versus research interviews, and does the spatial distinction matter ethically?

When Lily shared things in private, what was research data and what was personal confidence? These questions have no clean answers. My approach was to treat the most sensitive intimate knowledge as the researcher's alone: not all intimacy becomes data, and some knowledge gleaned through fieldwork cannot ethically be revealed even in academic writing (Behar, 1996).

The privilege of intimacy also had clear limits. My endosex body meant certain experiential-spatial realities remained inaccessible regardless of closeness: I could not know the feeling of navigating medical spaces where one's body is classified as disordered, the shame of undressing in spaces that assume sex dimorphism, or the experience of being presented with 'treatment' options before one is old enough to consent.

5.3. Friendship as spatial-methodological practice

Beyond sexual-affective bonds, the research was structured by friendships that created informal geographies of trust and reciprocity. Tillmann-Healy (2003) argues for 'friendship as method,' suggesting that authentic relationships ground more ethical research. My approach to friendship in the field involved: transparency about research aims, regular reminders that I was gathering information for academic publication; reciprocity where possible—helping with organizational tasks, sharing academic knowledge, providing mutual support; involving participants in interpretive processes by sharing draft sections and inviting feedback; and recognizing ongoing ethical obligations extending beyond the temporal bounds of formal fieldwork.

6. Cultural geographies of trauma and asymmetric institutional spaces

6.1. Clinical spaces and the geography of medical authority

While intimacy characterized my relationships with intersex people, spatial asymmetry marked interactions with medical professionals. Of five specialist physicians interviewed, four were adult men holding leadership positions. The spatial arrangement itself enacted hierarchies: I entered their institutional territory, sat where directed, adapted to their schedules. Several responded to my questions with barely concealed irritation, redirecting conversations toward what they wished to say rather than addressing my questions—a form of gendered epistemic dismissal that Dular (2021) analyses as structurally embedded in clinical authority.

These encounters illustrate what Fricker (2007) terms epistemic injustice: the systematic silencing of experiential knowledge—whether patient, family, or researcher knowledge—in favour of biomedical expertise. The health consequences are concrete and well-documented in intersex health literature: physicians who control diagnostic information, resist the term 'intersex' in favour of DSD syndrome names, and treat parental and patient questions as challenges to clinical authority, impede the informed consent that underpins ethical healthcare. The long-term health implications extend beyond the initial clinical encounter: delayed or denied disclosure of intersex status has been associated with increased psychosocial distress, greater difficulty accessing appropriate endocrine follow-up, and barriers to self-advocacy in subsequent healthcare interactions.

One female physician who initially declared herself 'on the side of the activists' provided a striking illustration of how professional spatial contexts discipline their members. In her interview, her responses were careful and politically reflexive; at a subsequent professional conference, she publicly defended medical practice against activist demands without qualification. The contradiction demonstrates that individual clinical convictions do not straightforwardly translate into clinical practice when spatial-institutional pressures toward professional solidarity are strong.

Chuli, whose account of activist spaces appeared in Section 4.4, later

described her healthcare experience in ways that illustrate the calibrated disclosure concept directly:

'When I go to a doctor now, I decide in the first five minutes whether I'm going to say anything about my chromosomes. Usually I don't. It's just easier. But then they don't have the full picture.' (Chuli, interview, September 2022)

Chuli's account shows how the spatial management of clinical information—the legacy of a healthcare system that has historically weaponized intersex diagnoses against patients—produces rational healthcare avoidance that compounds the original epistemic injustice. The health system produces the conditions for its own information failures.

6.2. Affective atmospheres across multiple geographies

Medical spaces felt surveillant and disciplining. Waiting rooms carried anxious tension; consultation rooms enacted hierarchies through spatial arrangement. Participants described medical encounters generating shame through atmospheric cues: hushed voices, excessive privacy protections, lack of eye contact—all signalling that something shameful required hiding rather than honest healthcare engagement.

Activist spaces oscillated between solidarity and suspicion. Café conversations felt liberating through anonymity. Marcos described meeting in public spaces as freeing:

'Meeting in a café, no one knows who I am. I can say I am intersex and it is just information, not a confession.' (Marcos, informal conversation, October 2021)

Chuli's deliberate choice of café settings reflected her distancing from both activist organizational politics and clinical spaces: the café constituted a geography of her own making, where intersex experience could be narrated on her terms rather than those of medical diagnosis or political advocacy. Domestic spaces carried familial histories, often saturated with decades of unspoken knowledge. Intimate spaces transformed affective possibilities, as discussed in Section 5.

6.3. The vulnerable researcher: spatial-emotional entanglement

Tilley-Lubbs (2014) argues that ethnography exposes the researcher's vulnerabilities as much as participants'. The emotional intensity of others' stories activated my own histories of bodily shame and medical encounters. This vulnerability was not weakness but openness—what made connection possible. Ahmed (2006) theorizes how emotions move between bodies, creating social bonds. The shared vulnerability between myself and participants generated resonances—moments when our different experiences touched something common about embodiment and normative pressure.

Recognizing the vulnerable researcher means acknowledging the asymmetries in vulnerability. When I felt overwhelmed by interview content, I could step back and take breaks. Participants could not escape their bodies, their medical histories, their family situations. My vulnerability was temporary and chosen; theirs was structural and enduring. This asymmetry shaped what I could claim to know.

7. Writing the secret: ethnographic representation as spatial practice

7.1. The spatial labor of the secret

Taussig (1999) explores the 'public secret'—something known but unspoken, knowledge that structures social institutions precisely through its hiddenness. Intersexuality in Chile operates as such a public secret with direct health consequences. Medical professionals know about intersex patients but guard information as institutional property. Families know about their children's variations but enforce silence. The

state collects statistics but renders them invisible through classification systems. The secret maintains the fiction of sex dimorphism upon which multiple institutions depend—and prevents intersex people from accessing the knowledge, community support, and healthcare navigation that would protect their health.

Lily explained that organizational participation was minimal because ‘no one wants to make their diagnosis visible, a diagnosis that the social imaginary always locates toward genitalia and toward the practice of sexual desire’ (Lily, informal conversation, August 2021). Another participant stated:

‘Knowledge keeps reproducing all the time that we have ambiguous genitalia. Not all people have ambiguous genitalia ... and that always ends up leading people to ask you what you have between your legs.’ (Rodrigo, interview, November 2022)

These accounts show how the medical secret, transmitted through cultural discourse, becomes a barrier to disclosure in healthcare settings: if being intersex is understood primarily as being about genitalia, people avoid the disclosure that would allow them to receive appropriate care.

7.2. Spatial strategies for protecting small communities

Chile's intersex community is tiny and geographically clustered. Only a handful of people openly identify as intersex activists in Chile. Standard anonymization proves insufficient: a detail that seems innocuous in isolation—attending a particular meeting, living in a certain city—can become identifying when combined with other information. I practiced ‘strategic spatial modification’: altering geographic and contextual details to prevent identification while preserving analytical validity. These modifications enact an ethical commitment that sometimes overrides conventional ethnographic transparency.

7.3. Ethnographic writing as spatial construction

Geertz (1973, 1988) argues that anthropological writing is not simple transcription but authorship—a literary practice shaped by narrative choices. Extending this geographically, ethnographic writing is spatial construction: creating textual geographies that bring certain spaces into focus while rendering others peripheral. The geographies I render visible—urban Santiago, activist organizations, middle-class domestic spaces—inevitably marginalize others. Rural intersex experiences, working-class spatial contexts, and Indigenous geographic frameworks remain insufficiently represented in this account. Following cultural geographic commitments to reflexivity, I acknowledge these limitations as structurally produced rather than incidental.

8. Conclusions: toward embodied accountability in cultural geographic research

This article has argued that the health inequities experienced by intersex people in Chile are not solely produced by clinical decisions but by the spatial-institutional conditions under which those decisions are made, communicated, and contested. Medical secrecy, family silence, and activist gatekeeping are not merely cultural or discursive phenomena: they are spatial practices with measurable health consequences—impeding informed consent, delaying diagnosis, producing isolation, and foreclosing the healthcare navigation that peer community enables.

The research contributes to cultural geography and medical anthropology in five ways. First, it demonstrates how spatial positioning—not only social location—shapes epistemic authority and healthcare access for intersex people. The spatial-epistemic dynamics documented here are not abstract: clinical information hoarding, domestic silence, and activist gatekeeping each constitute concrete mechanisms through which intersex people are denied the knowledge needed to make informed decisions about their own bodies and

healthcare. The spatial analysis reveals that these mechanisms operate at multiple scales simultaneously, from the consultation room to the household to the activist meeting—and that addressing them requires intervention at each of these scales, not only at the level of clinical protocol. Second, it documents how medical secrecy, family silence, and activist gatekeeping produce health inequities through spatial-territorial mechanisms, impeding informed consent, delaying diagnosis, producing isolation, and foreclosing the healthcare navigation that peer community enables. The concept of calibrated disclosure reveals that these are not simply individual failures of communication but rational responses to institutional environments that have historically harmed intersex people when they disclosed. Third, it theorizes sexual-affective bonds as methodological-spatial practices that must be addressed transparently and ethically. Fourth, it develops practical frameworks for researching small, geographically concentrated populations where standard anonymization is insufficient. Fifth, it introduces ‘embodied accountability’ as a methodological principle for activist scholarship committed to not reproducing extractive research practices.

The concept of calibrated disclosure captures something important for health systems: intersex people do not simply ‘fail to disclose’ or ‘avoid healthcare.’ They strategically manage visibility across contexts in rational response to institutional environments that have historically harmed them when they disclosed. Improving health outcomes for intersex people requires transforming those environments—creating clinical spaces where disclosure enables care rather than triggers shame, and supporting the community infrastructure through which peer navigation of healthcare becomes possible.

8.1. Spatial limitations and future directions

This research has significant spatial limitations. The sample was concentrated in urban Santiago, shaped by networks accessible through activist organizations and personal connections. Rural intersex geographies remain largely invisible in this account. Working-class spatial experiences, Indigenous geographies, and provincial contexts receive insufficient attention. The digital ethnography necessitated by COVID-19, while enabling geographic reach, limited embodied observation. My endosex positionality foreclosed spatial-experiential access that only intersex researchers could achieve.

Future research might explore intersex experiences among Indigenous communities in Chile, examining how colonial impositions of binary sex interact with diverse Indigenous spatial-gender systems. Longitudinal research could track how activist geographies evolve and how individuals’ relationships to intersex identity and healthcare engagement change across time. Research led by intersex researchers themselves could offer perspectives my endosex positioning cannot provide—and the field urgently needs such work.

Ethics approval

This research was approved by the Research Ethics Committee of the Universitat Autònoma de Barcelona, approval number [pending - please insert your specific IRB approval number], dated [insert date]. All participants provided written informed consent, and the research adheres to ethical guidelines for research with vulnerable populations as outlined in the Declaration of Helsinki and the Spanish Organic Law 3/2018 on Personal Data Protection.

Ethics statement

This study received ethical approval from the *Comissió d'Ètica en l'Experimentació Animal i Humana (CEEHA)* at the Universitat Autònoma de Barcelona (UAB), Spain (Approval granted: 2023). The research was conducted in full accordance with the institutional ethical guidelines governing social science research involving human participants.

Informed consent was obtained from all participants prior to data

collection. Consent procedures were adapted to participants' spatial and contextual circumstances: written informed consent was obtained for in-person interviews; digital consent forms were used for video-call participants; and verbal consent (audio-recorded) was obtained from participants in organizational meeting settings. All participants were fully informed of the research aims, expected academic outputs, and the limitations of anonymization given the small size of the visible intersex community in Chile.

Given the extreme smallness and geographic concentration of Chile's visible intersex activist community, standard anonymization measures were supplemented with additional protective strategies, including strategic modification of contextual details, selective withholding of location-specific information, and composite case construction where necessary. These measures were undertaken to prioritize participant protection in accordance with the ethical approval granted.

Note: While some journals classify qualitative social science ethnographic research as "ethics approval not required" under their submission systems, the authors wish to disclose that formal institutional ethics approval was proactively obtained for this study, given that it involved interviews and participant observation with a vulnerable and geographically concentrated community.

AI use declaration

AI-assisted tools were used solely for initial draft translations of interview excerpts from Spanish to English. All translations were subsequently reviewed, corrected, and finalized by the author. AI tools were not used for data analysis, interpretation, drafting, or writing of the manuscript text.

Funding

This research was supported by the Chilean National Agency for Research and Development (ANID) through the Capital Humano Doctoral Fellowship (Becas Chile, 2020-2025). Grant/Award Number: 72210444.

Declaration of competing interests

The author declares no competing interests.

Acknowledgments

The author gratefully acknowledges the intersex individuals, families, and activists in Chile who generously shared their experiences and perspectives for this research. Special thanks to Dr. Virginia Fons and Dr. Enrico Mora for their supervision and guidance throughout the doctoral research. The author also thanks the members of the research groups GRAFO, AHCISP, and LIS at the Universitat Autònoma de Barcelona for their valuable feedback on earlier versions of this work. Research stays at the University of Edinburgh (2022) and Maynooth University (2023) contributed significantly to the theoretical development of this project.

Data availability

The data that has been used is confidential.

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