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The Neglected Reflections of Vulvar Pain.

An anthropological research-action through Art and Science

Visual Ethnography

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Abstract

Italian society does not acknowledge vulvar pain sufferers as patients affected by legitimate pain: the condition is not supported by the national healthcare system, besides being medically unexplored and socially invisibilized. Patients do not see themselves as deserving care until sexual intercourse is compromised. Vulva health gains awareness when feminine sexual performance deviates from heteronormative models and coital imperatives.

In a feminist gendered perspective, this paper presents the artistic and scientific exhibition “Vulvar Pain”, based on anthropological research to explore vulvar pain experiences through qualitative participatory methods. Research partners co-produced symbolic handicrafts revealing the difficulties of being seen as bodies deserving care. This effort aims to present scientific results through a public engagement event, including arts, workshops, and roundtables with health professionals and patient associations.

The exhibition “Vulvar Pain” advocates considering genital pain beyond the cultural taboo of sexuality, privileging visual narratives to facilitate dialogue between biomedical discourse, social sciences, and the embodied knowledge of sufferers. Considering the multiple lens of this case study, the paper presents collaborations between ethnographers, artists and designers, engaging in the co-construction of new forms of knowledge that can be seen, touched, smelled, sat upon, and circulated to unfold vulvar taboos.

Keywords

Vulvodynia; Pain; Sexuality; Health discrimination; Art

The author

Federica Manfredi completed her PhD degree in Medical Anthropology at the Institute of Social Sciences - University of Lisbon (2022), working on extreme body modifications and experimental qualitative methodologies. Member of the project *Excel-The Pursuit of Excellence*, she provided outreaching activities with the workshop series *The Hacked Barbie*, and she co-organized the art exhibition “Be F**King Perfect” (Lisbon, 2022). Today she is researcher at the University of Torino exploring the stigma of vulvar pain conditions and developing multi-sensory approaches for the restitution of scientific data to the public.

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Introduction: vulvas fighting for their mirror's image

The mirror is a surface designed to reflect an image. Often, we internalize the reflection as reality, representing the way we appear to others and, consequently, how we perceive ourselves. The mirror plays a role in constructing our self-awareness and, in this sense, supports reflections – meaning the cognitive processes we might develop about ourselves.

This paper aims to present a case study of an artistic and scientific exhibition dedicated to vulvar pain that took place in Italy in early 2024, and it was based on an anthropological research that explored vulvar pain meanings with Italian women. The discussion seeks to explore the different shades of visibility, understood in terms of self-awareness, that corporeality might have, especially concerning feminine genitals. The exhibition, titled “Vulvar Pain. Art. Science. Resistance” is based on post-doctoral research on the medicalization of women’s sexuality, and ethnographic data indicate that the understanding of vulvar pain is an experience delegitimized culturally and medically unexplored, hindering women’s access to sexual health. Sufferers often do not perceive vulvar pain as an alarm signal or a condition deserving medical attention; they normalize painful sexual intercourses, postponing medical consultations. When the pain becomes unbearable, and sufferers seek gynecological advice, their suffering is usually disqualified by practitioners. Clinical practice reproduces cultural biases that construct vulvar pain as an illegitimate suffering, devaluing the illness experience and denying social recognition (Buonaguidi, Perin 2023; Shallcross et al. 2019).

Looking at ourselves in a mirror is an everyday action we perform automatically, often without paying it much attention. While it may seem obvious, individuals need to be educated to recognize the reflected image. In other words, they need to have the cultural sensitivity to ‘see’ what they are looking at. In this sense, the act of looking in a mirror is not merely mechanical but a matter of interpretation. The image reflected by the mirror is shaped by how individuals have been socialized and how they interpret the experience of being in the world (Csorda 1990; Merleau-Ponty 1945). The expression ‘in the eye of the beholder’ is usually associated with the recognition of beauty, illustrating how the perception of an image is molded by the adopted perspective. Therefore, the observer influences the mirror’s work, especially concerning the cultural values and meanings associated with the act of observing our own image. However, the individual is not the sole actor in this process. The looking-glass self theory (Cooley 2009) posits that human behaviors are shaped based on the anticipation of how others will perceive us, suggesting that self-image is profoundly connected to social interactions rather than a concept developed in solitude. Applying this theory to the ethnographical case underscores that the meanings of vulvar pain (and the patients’ perception of pain) result from a collective process of cultural signification, including sufferers’ partners, the family entourage, friends, peers and health specialists. The silence around the vulvar pain and vulvar health perpetuates unequal access to genital health for individuals with vulvas. This silence is socially co-enacted by the members of the society, in different measures, as an accepted behavior.

In the title of this paper, *The Neglected Reflection of Vulvar Pain*, the term ‘neglected’ serves as a linguistic play, inviting a dual interpretation. Firstly, it highlights the unfortunate reality that the reflection or consideration of vulvar pain has been overlooked, ignored, or not granted the attention it deserves within broader societal discussions. Secondly, the term subtly alludes to the metaphorical concept of a mirror that does not reflect, emphasizing the hidden nature of vulvar pain, its invisibility, and the need to bring this concealed issue to light. This dual sense sets the stage for our exploration, utilizing an artistic and scientific exhibition as an anthropological case study to unveil and understand the nuances surrounding the meanings of vulvar diseases.

Peeling back the veil in vulvas

I've had pain down there for years now. Three or four, I don't remember exactly. It's very difficult to manage my daily life. I can't go out with my friends whenever I want, I can't ride a bicycle or go to the beach... And then, my relationship with my partner is hard; I don't have a normal sexual life anymore. And I'm just 26 years old! Of course, my partner has certain needs. I try to avoid it [penetrative sex] as much as possible, but sometimes I know I have to do it. My partner is understanding and doesn't pressure me, but I know it's hard for him because he's a man. When we do have it, I hope it will be quick. We use a lot of lubricant, but it burns every time. I know that later it will continue to burn, and I'll be in pain for a few days, but what can I do? (interview with Sara, 26 years old).

In this paper, I argue that the invisibilization of vulvar pain is linked to the social construction of its meanings, which devalue women's experiences of pain, particularly regarding sexuality and the anatomical knowledge of the genital apparatus. Using the metaphor of looking in a mirror, the anthropological case study reveals that vulva health lacks social consideration beyond the context of penetration. Adopting an intersectional approach and considering the coital heteronormative imperative, data indicate that feminine genital pain garners attention only when the penetration of a penis in a vagina (PIV) becomes impracticable. At that juncture, vulvas metaphorically claim their image in front of the mirror, becoming the focal points of patients' narratives that demand care and cure. Suffering becomes the price to pay for visibility. The possibility of being seen and heard initiates reflection, nurturing the demand for social visibility for a pain that has long been dismissed.

The Italian national health care system (SSN) does not recognize vulvar painful conditions such as vulvodynia or pudendal neuropathy. This means that social care does not provide economic support for medical consultations, exams, pharmacological therapies, and the disease is not part of educational training in medical schools. Only in July 2021 did patient associations initiate the legal process to include these diseases in the SSN, following a previous unsuccessful attempt in 2014 (Ferritti 2023). The institutional silence around vulvar pain is associated with the moralized meanings of Western society regarding genitals, a body part that is highly controversial in its socialization. It is considered the epitome of a private body part, whose nudity in social places is problematic (Górnicka 2016), and is even forbidden by Italian law as 'obscene act'.

Genitals also attract a creative array of epithets and periphrasis just to name them, and anatomical terminology is far from being used with a sense of neutrality. The exhibition's original name was planned to be "Vulve in Mostra" [Showing the Vulvas], a title referring both to the artistic exhibition and the feminization of 'mostro' [monster] to connect with the cultural taboo surrounding this part. However, the proposal was discouraged by medical partners because it was deemed 'disrespectful for women' and 'too pornographic' (fieldwork notes, October 2023). This ethnographic episode effectively illustrates the taboo surrounding female genitals to the extent that the anatomical term provokes discomfort and concerns of immoral intentions even among those trained to cure human bodies. In common language, the term 'vulva' is almost completely removed, as Liv Strömquist noted in high school science books and advertisement of products for 'intimate itching' (Strömquist 2044: 40-41). This intuition was confirmed during the fieldwork, that the next paragraphs will present along with the artistic exhibition of its results. During interviews, only political activists and some clinicians used anatomical terms for genitals. In the interview except opening this paragraph, Sara is the anonymized name of a patient: she is a university student in health studies and she is familiar with anatomical terms. Nevertheless, she refers to her genitals with the expression

“down there”, creating room to wonder how linguistic choices contribute to the invisibilization of vulvas and their experiences.

From a constructivist approach to cultures and languages, the absence of a name for a concept or an emotion indicates a lack of cultural richness, similar to what has been observed regarding the transformation of certain behavioral codes to deal with death (Manfredi 2022) or the lack of a law to identify abuses, as with obstetric violence (Quattrocchi 2019). The absence of genitals from the social scene, which entails the lack of open discussions, questions, and observations regarding them, is, I believe, connected with a cultural thinness that contributes to the normalization of feminine genital pain in solitude. Individuals internalize social norms that forbid discussing this part of the body and, consequently, everything related to it, including the pain, do not have space on public narratives. Vulvar suffering is privatized, becoming unsharable with others, until it is completely invisibilized from a social perspective.

Nevertheless, the possibility to experience genitals in private is problematic too, as recent research on sexual behaviors among pre-adolescents and young adults indicates concerning the moral stigmatization of self-erotic practices (Scarcelli 2020, Foust et al. 2022). Given that contemporary Western culture lacks a rich cultural discourse about genitals (and sex) beyond a moralized approach, the absence of scientific knowledge and preventive protocols to monitor genitals is unsurprising, as they are culturally influenced. In this sense, while efforts for preventive and educational campaigns have been realized in the last decades concerning the importance of periodical self-exams to prevent breast cancer, very few efforts have been dedicated to gynecological tumors, which are often diagnosed late (AAVV, 2022).

Specifically, vulvar cancer occurs in the outer surface area of feminine genitals, a body part that could be easily inspected by the person with a mirror. However, this is a source of self-body knowledge that nobody met in the fieldwork have been educated to perform. Even though vulvar inspections were a well-known practice, especially in the feminist self-help movement (Murphy 2004), today girls are not systematically educated to look and inspect their vulvas. This is unsurprising, since they do not even mention genitals directly. As ironically titled in an article *When did the vulva become obscene?* (Schwentzel 2019), feminine genitals are often missing from the social scene because they are perceived as taboo. The geography of the body parts suggests a hierarchy in their socialization, encompassing different levels of appropriateness in their social exposure (Kirmayer 1992; Le Hénaff et al. 2007). However, how can individuals with vulvas construct anatomical knowledge about their genitals and gain the confidence to initiate medical consultations when societal norms discourage open discussions?

The exhibition “Vulvar Pain. Art. Science. Resistance” adopts a visual language to contribute to the cultural raise of awareness concerning the lack of recognition of vulvar health and to facilitate a re-signification of the genital pain experience as a legitimate form of suffering. Vulvar pain can result in chronic pain, worsened by the delay of diagnosis and the absence of medical treatment protocols, highlighting the urgency of prevention programs, research to improve scientific knowledge, and cultural awareness. In a research-action perspective of applied anthropology, the exhibition project involved four different artistic installations that this paper is going to present, discussing the multiplicity of forms of knowledge co-produced by the ethnographer in collaboration with the designer Sofia Rampanelli, the artist Lucia Bessone, and 17 research participants who joined a creative laboratory to explore vulvar pain experiences by manipulating pieces of cloth to symbolically express silenced aspects of the pain.

An exhibition merging art and science

The exhibition “Vulvar Pain. Art. Science. Resistance” emerged as a convergence of artistic and scientific elements, featuring multiple contributions.

Inaugurated on a winter Friday in February 2024, I curated the exhibition that took place in the main hall of the Luigi Einaudi University Campus in Torino, Italy (Fig. 1). Housed within Norman Foster's futuristic design along the banks of the Dora River, the campus provided an urban space characterized by undulated lines, from high glass façades to hillside gardens.



Figure 1 © The exhibition Vulvar Pain at the Campus Einaudi, Torino 2024. Photo by Francesco Dragone, 2024.

This exhibition, an extension of the medical anthropological research titled “The Cloth of Pain”, that I developed as post-doctoral research from March 2023 to February 2024, sought to amplify the voices of those affected by vulvar pain. Its goal was to act as a dynamic catalyst for cultural transformation, reshaping how society perceives and signifies vulvar pain.

Conditions such as vulvodynia, endometriosis, pelvic contractions, and other pelvic-vulvar pathologies significantly impact the quality of life for individuals assigned female at birth (AFAB), transgender individuals, and those with fluid identities. Similar to other forms of chronic pain (Moretti 2013), vulvar diseases often exist in the shadows, with sufferers hesitating to recognize symptoms as warranting medical attention due to limited biomedical knowledge. Consequently, a society is shaped where many, including health specialists, patients, and their social circles, fail to acknowledge vulvar pain as a legitimate medical condition or *disease* (Kleinman 1985). However, the repercussions of vulvar diseases are substantial, leading to social isolation and affecting economic, professional, relational, and sexual aspects of sufferers’ lives.

“Vulvar Pain. Art. Science. Resistance” emerged as a response to ethnography, serving as an act of militant public engagement targeting citizens, clinicians, patients, their family members, friends, co-workers, and all individuals with vulva or without it. Its purpose was to dismantle stigmas and taboos that hinder the care, treatment, and discussion of vulvar pain.

The research process and exhibition project were carried out under the scientific supervision of Raffaella Ferrero Camoletto, who pioneered male studies in Italy, particularly concerning the medicalization of sexuality for erectile dysfunction (Ferrero Camoletto, Bertone, 2016). A group of fourteen BA and MA students eager to support the exhibition’s organization from November 2023.

We activated an educational program tailored to their requests, forming the organizing committee, self-dubbed “The Vulva-Team”. The committee also benefited from the engagement of two talented researchers from the University of Torino: Alessia Toldo, a social geographer with interests in the socialization of pain and the geography of the body, and Angela Zottola, a socio-linguist and gender studies researcher exploring the medicalization of controversial bodies (Zottola et al. 2023).

The exhibition project received funding as a public engagement initiative from the Department of Cultures, Politics and Society at the University of Torino and the exhibition was strategically located on the university campus to prioritize student access, recognizing that individuals aged 20-40 face a higher risk of developing chronic pain related to undiagnosed vulvar diseases. While designed with students in mind, the event was open to the public, extending its reach beyond the university community.

Inaugurated on February 23, 2024, the exhibition occupied the main hall of the campus for a duration of two weeks, offering the option to book guided tours. To extend the exhibition’s life beyond the confines of university spaces, an online platform, www.dolorevulvare.a.s.r.blogspot.com, was created by the students involved. The online space not only hosted visual content but also featured audio records that verbalized the exhibition panels. This addition aimed to facilitate access for individuals with visual disabilities and those unable to physically attend the campus. The opening ceremony was enriched by scientific activities, including roundtable discussions with health professionals, researchers, and patient associations. It featured the screening of the documentary *Our Body Burns* by Angela Tullio Cataldo (2022) and a series of participative laboratories. These labs sought to challenge perceptions of vulva anatomy and explore the role of cultural taboos in shaping our relationship with genitals. Participation in these activities was limited, and virtual booking options were offered. Additionally, provisions were made for Italian sign language translation for interested participants.

The exhibition, encapsulated in the captivating imagery of the publicly announced flyer (Fig. 2), embarked on a nuanced journey that seamlessly blended artistic expression and scientific inquiry.



Figure 2 © Exhibition flyer, Photo by Federica Manfredi and Sofia Rampanelli, 2024.

Within this immersive experience, four distinctive contributions unfolded, each offering a unique perspective on the intricate tapestry of vulvar pain.

- a. *La Stoffa del Dolore* [The Cloth of Pain]: This narrative exploration stems from a year-long ethnographic endeavor that I realized, commencing in March 2023 and concluding in February 2024. Its purpose was to disseminate anthropological insights into the profound meanings woven into the fabric of vulvar pain experiences.
- b. *Sediamoci con la Vulvodinia* [Sitting with Vulvodinia]: A visionary project in exhibition design, conceived by Sofia Rampanelli, became the driving force behind the entire “Vulvar Pain” initiative. It transcended mere aesthetics, aiming to create an environment that intimately engaged visitors with the complexities of vulvodinia.
- c. *Mostro Oro, Silenzio Spine* [Showing Gold, Silence Thorns]: In a poignant artistic gesture, Lucia Bessone contributed a ceramic piece. Crafted during the ethnographic journey, it visually encapsulated the silent struggle and invisibility surrounding vulvar pain, bearing the title “Showing Gold, Silence Thorns.”
- d. *Oggetti del Dolore, Oggetti della Resistenza* [Objects of Pain, Objects of Resistance]: Collaboratively envisioned by Sofia Rampanelli and myself, a designer and ethnographer, this installation sought to transform the perspective on everyday objects. It delved into the dual role these objects played, either as triggers for pain attacks or as sources of support for individuals navigating the complexities of vulvar pain.

Beyond the tangible contributions, Sofia Rampanelli and I intricately crafted the graphics used for event promotion, including the evocative imagery featured in Fig.2. Together, these elements formed a cohesive narrative, inviting visitors to explore and contemplate the multifaceted dimensions of vulvar pain through the lens of art and science.

This paper seeks to delve into the nuanced and multi-sensory essence of the artistic and scientific exhibition. It contemplates the diverse insights offered by the event, with a particular emphasis on the visual and artistic components. From ceramic sculptures to cloths, graphics, seats, and everyday objects like jeans, swimsuits, chairs, bottles of water, and coffee boxes, the range of materials reflects the myriad roles I embraced during the fieldwork and in the dissemination. These roles spanned from being an ethnographer, interviewer, and facilitator of creative-based workshops during the research phase to taking on the positions of curator, co-designer of installations, students’ educator, and artist’s partner in the ethnography-based art project during the multi-modal restitution.

This contemplation extends beyond the mere examination of materials and roles; it delves into the intricate relationships established in the research process. These relationships vary from those with patients to professional artists, each contributing unique languages to enrich the communicative experience. Anchored in the relational foundation of every ethnographic interaction (Estalella, Sánchez Criado 2023), the exhibition serves as a compelling case study, showcasing how artistic handicrafts have the potential to multiply perspectives, findings, engagements, and applications of anthropological knowledge. This, in turn, contributes to the empowerment of participants and facilitates enhanced access to knowledge by a wider audience.

Intertwining art and anthropology: the Cloth of Pain

In recent years, the intersection of art and social research has become a focus for anthropologists, exploring artistic practices in engagements with participants, curators, and performers. Recognizing the value of multi-sensory languages in ethnography, this integration has opened new avenues for

understanding social phenomena (Foster 1995; Schneider 2008; Leavy 2009; Schneider & Wright 2010). In projects such as Excel-The Pursuit of Excellence, collaboration with professional artists, like photographers Evija Laivinia and Jessica Ledwich, has provided insights into practices of human enhancement, dissecting normative beauty standards as indicators of individual success (Pussetti et al. 2022; Manfredi 2023).

Art and anthropology can intersect not only in research but also in data presentation. For instance, Susana de Noronha utilized drawing as a complementary technique to interview and report on endometrial cancer (Noronha 2019). De Noronha's approach democratized science by incorporating creative scientific illustrations, offering accessible support for the public to engage with the research.

Considering creative practices as both epistemic and ethnographic data (Pussetti 2018), particularly for methodological experimentation (Estalella, Sánchez Criado 2018), I employed creative methods to expand my ethnographic approach, especially in exploring experiences resistant to verbalization, such as voluntary pain (Manfredi 2024). These practices enabled a transcending of my own preconceptions, empowering research participants during the fieldwork and fostering an intimate connection.

The Torino exhibition was grounded in the anthropological project The Cloth of Pain, stemming from a post-doctoral research initiative on the medicalization of feminine sexuality at the University of Torino. The project uncovered that sufferers of feminine genital pain are often disregarded, both in medical settings and social environments, resulting in an invisible condition forcing silence upon those affected. This ignorance increases the risk of chronic pain and self-administration of painkillers, straining patient-health specialist relationships. The qualitative approach involved semi-structured interviews exploring vulvar pain experiences with 28 Italian heterosexual and cisgender women.

Seventeen participants, ranging in age from 19 to 61 years, collaborated in a series of creative workshops creating cloth pieces. These artworks served as metaphorical expressions, delving into unspoken aspects of the genital pain. Ethnographic sessions included participant observation in Italian Facebook patient-groups dedicated to vulvar diseases, medical congresses, and meetings with activists and patient associations from March 2023 to February 2024. Interviewees have been recruited during ethnographic sessions, through calls shared in Facebook groups and the newsletter and social profiles of three patient associations (*Cistite.Info*, *La voce di una è la voce di tutte*, and *Comitato Vulvodinia e Neuropatia del Pudendo*). Interviews have been voice recorded and personally transcribed, anonymizing the names of informants according to their preference. Informed consent was presented to each of them before starting the interviews, offering the possibility to indicate a pseudonym and informing them about the use of data for academic presentations or future publications. Additionally, interviewees were informed at the beginning of the meeting that the recorder could be stopped at any moment during the interview, and they were free to withdraw from the study at any stage of the research.

I used interviews to both explore illness experiences and recruit participants for the creative laboratory. The recruitment process was slow and challenging because many participants felt incapable of expressing themselves and their pain experiences through artistic methods, especially due to pain attacks that eroded their time. The invitation to explore creative practices was motivated by difficulties in oral communication declared by interviewees, as I had already experienced in other fieldwork about pain (Manfredi 2024). Pain deconstructs our relation with the world and with language (Scarry 1985), rendering verbal communication an unfit strategy of expression. This frustration led interlocutors incapable of fully expressing themselves, prompting the need for a methodological adaptation. As I had done in other contexts (Manfredi

2021), creative practices and arts-based methods have been elected to address the challenge of the incommunicability. I proposed using pieces of cloth, and this decision gave the name to the entire research: “The Cloth of Pain”.

The creative workshops, conducted both in group and individual sessions, allowed participants to symbolically express memories related to vulvar pain experiences. The subsequent presentations of their cloth pieces in focus groups, led to discussions highlighting shared experiences, creating an emotional atmosphere of solidarity: finally workshops’ attendees found a legitimate social space to share about vulvar pain experiences. The online format facilitated attendance for working mothers and those with health conditions hindering travel, enhancing accessibility.

The ongoing analysis reveals that vulvar pain shapes participants’ daily lives, limiting activities and influencing career choices. The pain becomes a private matter, structuring life perspectives and causing participants to adopt preventive measures, such as not crossing their legs when sitting or dressing selection according to cloth’s materials. Guilt arises from an inability to engage in penetrative intercourse, impacting gender identity, sexual life, and relationships with partners. Cloth-handicrafts serve as communicative tools, documenting the multi-faceted impact of vulvar pain on women’s lives.

My objective was to disseminate scientific knowledge beyond academia and engage in an extensive restitution process with the epistemic partners and with public. Adopting a militant position of applied anthropology, I sought to utilize the findings in service of the wider population, promoting visibility for stigmatized conditions and structural fragilities affecting the quality of life, specifically in terms of access to sexual health and a pain-free existence.

A new vocabulary of pain

Walking through the exhibition, visitors encountered fourteen out of seventeen hand-modified cloths created during the Spring and Summer of 2023. Some participants expressed a desire to remain connected to their handicrafts, while others severed contact with the ethnographer after the creative experience. Each cloth in the fieldwork collection, displayed in Torino, featured a QR code linked to an online audio file. Research participants were asked to record voice messages describing what their cloth represented and explaining the meanings behind the symbols they used: a transcription of it was provided in the website of the exhibition, along with images of the cloth. This choice was driven by an ethical stance that refrains from having the ethnographer speak for the participants, aiming to restore their voices in the dissemination process. In instances of more anonymity, a couple of participants provided a written text, and a member of the vulva-team recorded the audio.

The selection of cloths was not curated by the ethnographer; all submitted cloths were displayed, creating a rich portrayal mirroring the anthropological analysis. The diverse group of meaningful elements illustrated aspects merged from qualitative interviews and online ethnography.

One cloth, crafted by Clara, a 27-year-old psychologist, revealed a sense of guilt and inadequacy prompted by vulvodynia (from online focus group 22nd June 2023). This condition, characterized by a challenging diagnostic process due to its unknown etiology (Harlow, Stewart 2003), led her to express a profound sense of guilt and inadequacy. Starting with a bidet-towel that was frayed and featured holes, Clara aimed to symbolize the overuse of this essential tool. During peak episodes of vulvar pain, the act of cleaning her genitals with fresh water provided relief, becoming a crucial coping mechanism. However, this necessity came with significant sacrifices. Clara had to relinquish numerous life projects, including her dream of traveling the world with her life partner. According to Clara, the couple had built their relationship around a shared passion for camping, where intimate care became a challenging task. Gradually reducing her involvement in this activity, Clara found herself reevaluating her identity and feeling burdened by a body deemed insufficient. The



Figure 3 © The handcraft of Clara. Photo by Federica Manfredi, 2024.

The materials chosen for the cloth creation played a crucial role in enhancing communication between Clara and the ethnographer. Through multi-sensory strategies involving color selection, dyeing, and operational decisions, Clara's handcraft allowed for a nuanced portrayal of her illness experience. The worn-out towel emphasized the repetitive nature of self-help practices, exacerbating the challenges in daily life. The color choices, particularly the red letters, served as more than a reference to menstrual blood; they embodied Clara's resilience, representing her ongoing quest for solutions and a future free from pain, where she could rebuild the fragments of her life.

Another participant in the workshop, Lucia, approached vulvar pain from a different perspective, focusing on the positive aspects it brought to her life. As a blind employee in the North of Italy, she began experiencing vulvar pain, specifically around the entrance of the vagina (medically called vestibule), almost a decade ago, which became a challenge, especially during her initial sexual experiences. During the interview at the age of 36, Lucia shared that she had never experienced orgasms or pleasure during penetrative sex, stating, "the pain was never too strong to force me to stop" (interview 19.4.2023). This question about why she continued to engage in sexual activity despite the pain marked a crucial moment in several ethnographic meetings. The data revealed a crucial aspect of being a vulvar pain sufferer – the difficulty, and sometimes impossibility, of engaging in penetrative intercourse. This condition led to anxiety, discomfort, and elaborate strategies to shorten sexual encounters, such as fake orgasms or interrupting with excuses.

Despite the pain, interviewees did not consider it a sufficient condition to stop or avoid penetrative sex, at least not explicitly addressing the topic with their partners. Only one research participant shared her vulvar health troubles with her partner, emphasizing the importance of respect for genital pain as a prerequisite for their relationship and sexual encounters. Alice, a 24-year-old woman with a master's degree in gender studies, found herself in a position "to conquer a feminist literacy on sex and sexuality" through this experience.

In addition to Alice's case, research participants (cisgender women with heterosexual orientations) expressed concern that refusing sex could jeopard-

ize their relationships with their partners. They felt a moral obligation to sexually perform, providing a penetrable vagina despite the absence of pleasure and, more importantly, the presence of pain. In some cases, the pain extended beyond penetration, lasting for days with irritations and sensations of burning, itching, and stabbing. In serious cases, pain persisted for an extended period, becoming chronic, forcing patients to increase the type and dose of medications and painkillers, with considerable side effects.

As reported by feminist scholars who have worked on neglected diseases (Kaler 2006, Labuski 2015), female patients unable to participate in penetrative sex understand the disability as a failure of their womanhood – an imperfect performance of their gender role.

Of course it [penetrative sex] hurts, but it's normal, right? For everybody, it is painful. All of us [women] feel pain during penetration. We know that it is the way it is, and there is nothing that we can do. Sometimes it can be pleasurable; actually, it was very pleasurable when I was younger, but then vulvodynia arrived, and now it's very different... But it depends on the moment... Usually, it hurts, but I am careful not to show it to my partner; otherwise, he feels guilty, and it takes even longer. Oh no [laughing]! (Francesca, 46 years old).

Even if it hurts, I can't stop having sex, or my partner will leave me. It's normal; he's a man, and he has his needs. I don't want him to find satisfaction with other girls. Of course, we don't have to do it every day, but I can't always say no either. So I try to do my best; I want to be a decent partner for him because I love him, and he loves me. (Rebecca, 33 years old).

Women feel the responsibility to perform in penetrative sex even in case of pain because this is interpreted as emotional commitment in the romantic relationship. Vulvar pain is normalized as a general condition of suffering (by Francesca), while masculinity is understood as being shaped by natural and legitimate sexual needs (Rebecca) that a proper partner should satisfy. Otherwise, the male partner will be justified in looking for sexual satisfaction elsewhere, regardless of the emotional bond. Only after years of normalization of pain, when the penetrative sex becomes unbearable due to the vulvar pain, provoking burning symptoms during urination and lasting for hours (or days) after intercourse, does a sign of alarm switch on.

Lucia's realization that feeling pain during intercourse was not "normal" came from a podcast in which a sexologist shared her personal experience of pain during penetrative sex. This encouraged the public to investigate with health specialists in case someone experienced similar symptoms. For Lucia, this revelation marked a turning point in her patient journey toward the diagnosis of localized vulvodynia. Giving a name to her pathology corresponded with the socio-medical recognition of her subjective illness experience as a disease (Kleinman 2020). In a medical anthropological approach, the formulation of the diagnosis is a crucial social moment, recognizing the pain experience of the sufferer as a real event and providing a sanctioned vocabulary of suffering. Lucia received a name for her pain in 2022, after eight years of gynecological visits during which her vulvar pain was disqualified as not deserving medical attention. As she shared during the workshop, she was used to hearing sentences like, "It will be okay, it's a normal pain. Don't worry, it will disappear on its own." These dismissive responses nourished the idea that her pain experience was nonsense and temporary, but that turned out not to be the case.

After the diagnosis, with the guidance of a physiotherapist specializing in pelvic floor rehabilitation, Lucia began to witness improvements and could engage in penetrative sex without experiencing pain. Lucia discovered that the healing process, especially the daily self-massages assigned as part of her

physiotherapy routine, transformed into acts of self-care. She described this as a dedicated time: “I take my time when I have to do my exercises of manipulation, lowering the lights and playing relaxing music. It’s a moment just for me that I’ve learned to appreciate,” she reported.

Lucia’s handicraft (Fig. 4 - 5) beautifully reflects this positive aspect of her illness experience, as she shared during an individual interview and later during an online focus group in May 2023. She ingeniously assembled four sponges to create a pocket that is intentionally unpleasant to touch, symbolizing the essence of pain itself. The internal darkness of the pocket represents the obscure side of pain, something negative that made us scarred, something unpredictable. Lucia chose to emphasize the sense of touch to metaphorically express her pain, utilizing four abrasive sponges typically used for removing stubborn stains from pots to materialize the pain experience. Within the sponge-pocket, she carefully placed four pieces of exceptionally smooth cloths—silk, pile, organza, and velvet—filling the pain-container (Fig. 5). These materials represent the positive side of the illness, signifying the time she dedicated to herself for recovery. They are not opposite to pain, but included in the experience. The colored cloths are smooth, and touching them brings unexpected pleasure. In essence, these materials metaphorically convey that the time spent on healing became a time of care, specifically self-care. Lucia’s perception of the pain shifted, recognizing that she deserved to be better. However, the soft pieces of cloth remain hidden inside the pocket, underscoring that self-care is an unexpected aspect of her pain experience.



Figure 4 © The handicraft of Lucia (front perspective). Photo by Francesco Dragone, 2024.

These ethnographic handicrafts affirm that every experience of discrimination, encompassing issues related to sexual health and the acknowledgment of vulvar pain as a legitimate form of suffering deserving medical atten-



Figure 5 © Lucia's cloths from above. Photo by Francesco Dragone, 2024

tion and social recognition, can be scrutinized through the intersectional paradigm (Crenshaw 1991). Lucia's disability and Clara's long-established romantic relationship exemplify conditions shaping access to health and sexual rights, yielding specific instances of pain invisibilization. These experiences are intricately woven with various factors, such as gender identity, sexual orientation, marital status, parenting projects, skin color, age, economic power, residency condition, educational level, social capital, etc.

Rather than merely acknowledging the variability of aspects influencing the delegitimization of vulvar pain, I adopted a broad perspective to explore the invisibilization of pain. I considered each of these variables from a queer perspective, recognizing their interdependence. Among these variables, heterosexuality emerges as a factor assuming that penetrable vaginas must be consistently available as part of a sanctioned gender performance (Goffman 1976). This assumption implies a fallocentric view of intercourse, which is expected to cater to the pleasure of the penetrative component (a penis), rather than the container of penetration (the vagina).

Sexual performance is often reduced to the penetrative act, focusing on one party's pleasure, disqualifying alternative forms of sexuality as 'fake' or 'less important' compared to penis-in-vagina (PIV) penetration. This vision of PIV as a natural and healthy form of sexual behavior, legitimized on procreative grounds, corresponds to symbolic meanings and cultural expectations internalized by individuals—an aspect known as the 'coital imperative' (Jackson 1984). It implies that other forms of sexual behavior are not equally legitimate or meaningful compared to PIV.

As Serena, a 22-year-old research participant, expressed during an interview, "I try to make preliminaries, but then we both know that we are waiting for [PIV], and that sex means this, not oral jokes or hand stimulations." This underscores the expectation that PIV intercourse is the anticipated performance needed to achieve *real sex* and provide an appropriate gender performance (Kaler 2006). Consequently, pain becomes a hindrance to a perceived proper womanhood performance in



Figure 6 © Visitor at the exhibition. Photo by Francesco Dragone, 2024.

Ethnographic data reveal that research participants have, for years, silenced their pain, denying themselves the consideration that their genitals deserve compassion and care to safeguard their gender identity.

In conclusion, the cloths crafted by Clara and Lucia prompt reflection on the process they underwent to recognize the necessity for biomedical support for their health conditions. Clara grappled with guilt because vulvar pain is not equated with a stomachache or a migraine. Some dolor are culturally constructed as deserving less attention compared to others. The bidet-cloth expresses the tragedy of feeling inadequate for an unattained goal of success, particularly in terms of gender performance. In a neoliberal society where individuals are held responsible for their happiness and social success, even a disease can be construed as an indicator of a moral failing in self-promotion. The challenge of accepting that vulvar pain is not a normal female condition is also evident in Lucia's cloth. She began to reject the notion that her pain during PIV was normal, thanks to an activist podcast. However, relying on chance is not a solution. Cultural change is imperative to transform the societal perception of vulvar pain from a state of women's meaningless suffering to a legitimate condition deserving care and cure.

Handcrafts like those created by Lucia and Clara were exhibited in the main hall of the campus to sensitize visitors about the legitimate clinical consideration that vulvar pain deserves. The aim was to raise awareness on the urgency of not silencing the voices of sufferers, and many students who visited the exhibition left positive comments on an online created to collect feedbacks from visitors. During a guided tour that I led in early March 2024, just a week after the opening, I was deeply moved by a member of the small group I had accompanied through the six scaffolds of cloths, objects, and stories. Carla, an elegant woman over 60, identified herself as a vulvodynia sufferer and expressed appreciation for the exhibition, particularly its educational impact on future generation. "This is the exhibition that I needed to see 40 years ago, because vulvar pain has profoundly shaped my life and it caught me completely off guard", she commented.

A different perspective was shared by a university student who stumbled upon the exhibition without prior intention: she took her time to express to a member of the Vulva Team her belief in the inadequacy of the proposal, as it was not located in the Medicine Faculty. She found the public display of personal stories of medical history inappropriate and suggested removing

them to protect the informants. However, upon being informed that research participants had agreed to share their information, she shifted her approach, attempting to understand why such private experiences of pain would benefit from public exposure.

The reactions of visitors, as those mentioned here, indicate that the exhibition had a powerful impact: the installations provoked thoughts and strong emotions, leading to tears and debates that were sometimes shared with the organizers. The rare dissident perspectives collected reinforce the mainstream interpretation of vulvar pain as a private matter that does not deserve social space. However, the exhibition also invited discussion and challenged such perspectives, fostering dialogues and raising awareness about the right to access vulvar health care.

Collaborating with artists

Some of the workshop participants do not consider themselves as artists because they attended an ethnographical process based with creative methods. At the opposite, some people that participated in the research process, self-define as creators, artisans or artists, and this paragraph is dedicated to their contribution.

Throughout the ethnography, I found myself deeply moved by the illness experiences I was documenting, perhaps because they offered a glimpse into a realm of life experiences unknown to me. Personally, I had never encountered severe vulvar pain attacks or other genital diseases, nor did I have discussed with other people facing similar conditions before starting this research. The pervasive culture of silence surrounding vulvar pain may have contributed to its status as an illegitimate topic of conversation in my own life experience. The ethnographical distance nourished my emotional reaction to the research topic, and I began sharing my research hypothesis with close friends and family, including Lucia Bessone, a talented artist specializing in handmade ceramic crafts and coincidentally, my mother.

Despite the conventional practice among anthropologists to downplay the influence of personal life in academic papers (Günel et al. 2020), I choose to challenge this norm and I break the traditional silence surrounding personal life of ethnographer in academic work. I shared with my mum the drama of guilt and feelings of inadequacy revealed through interviews and cloth manipulation. She was profoundly moved by the ethnographic data on the invisibilization of vulvar pain, leading her to express herself through her art: ceramic modeling and painting.

We organized working meetings where we brainstormed and discussed the pressures of sexual capital and women's availability in PIV. We worked through interviews' data, participants' meanings and her aesthetic sense, resulting in the creation of a clay piece that she later painted and placed on a ceramic cloth. The art piece was subsequently chosen to graphically enhance manifests and flyers for the exhibition (Fig. 2).

The artwork, titled "Showing Gold, Silence Thorns", is a reproduction of a vulva adorned with nails in the vestibule to symbolize pain and gold details to emphasize sufferers' concerns about maintaining the role of good sexual partners despite their suffering (Fig. 7 - 8). At the base, the clay artifact rested on a white cloth tissue that Lucia engraved by pressing a laze on the mud. The choice of the white cloth was not only a nod to the cloths co-created during the ethnography but also a representation of the cultural silence surrounding the vulvar pain phenomenon, described by Lucia as "a white page without words."



Figure 7 © Showing Gold, Silence Thorns. Photo by Francesco Dragone, 2024.



Figure 8 © Ceramic art piece by Lucia Bessone. Photo by Francesco Dragone, 2024.

This art piece emerged as a complementary product of the ethnography, materializing some of the results that Lucia Bessone processed in a visual and tangible manner—what Chiara Pussetti might term *ethnography-based art* (Pussetti 2018). This expression refers to art pieces originating from ethnographic experiences, as opposed to *art-based ethnography*, which involves ethnographic research embedded with artistic practices, as the manipulation of cloths in the ethnographic laboratory that I developed. Lucia’s work embodied epistemic data in a unique way, fostering a reflection on the connections between illness and societal expectations about womanhood through the materiality of the piece and its integration with selected symbolic elements, such as the cloth and the thorns.

The artist, who had never experienced vulvar pain herself, chose thorns to represent the pain symptoms reported in interviews. When I asked her why she adorned the limits of the vulva with gold color, she asserted, “Because it’s

still beautiful, isn't it? It has to be. Even amidst pain, we do all we can to present ourselves at our very best" (fieldwork notes, December 2023).

Her contribution prompted me to connect the beauty work documented in the field—comprising therapies, exercises, depilation, and clothing choices—to the preservation of the gender capital. In neoliberal society, individuals are held responsible for who they are, and the body serves as an indicator of their commitment to social success. The beauty work can be a strategy to compensate the erotic capital that is menaced by the limits in sexual penetration.

As part of the ethnographic process, I invited Lucia to exhibit her work, confident that her visualization of vulvar pain would enhance the audience's understanding of the phenomenon, generating increased interest and insights for visitors (Fig. 9).



Figure 9 © Lucia Bessone's art piece photographed by a visitor of the exhibition. Photo by Francesco Dragone, 2024.

During the ethnography, I connected with women who were not only sufferers but also musicians, teachers, mothers, lovers, students, and so on. Some of them waited for years for a diagnosis, a recognized term to identify their illness experiences, going through mistakes and countless therapies, while others recovered. The latter was the case for the interior designer Sofia Rampanelli, who experienced vulvodynia during her academic studies. She got in touch with a patient association that inspired her to develop an exhibition project called "Sediamoci con la Vulvodinia" [Sitting with Vulvodynia], which artistically highlighted vulvodynia's symptoms, such as burning and irritation, and the difficulty for patients to sit for even a few minutes. She produced the exhibition design as her graduation project at the Nuova Accademia di Belle Arti (NABA) in Milan (Rampanelli 2022). Analyzing the role of arts and European installations aimed at sensitizing about chronic and invisible diseases, Sofia designed an exhibition path whose centerpiece consisted of six chairs with modified surfaces, using nails and other objects to create uncomfortable seats (Fig. 10).



Figure 10 © Layout of the exhibition from the project of Sofia Rampanelli (Rampanelli 2022: 140–141). Used with permission of the author.

Her project sparked many conversations and mutual sharing during the fieldwork, leading us to explore the possibility of transforming her work from paper to reality. In the springtime, the call for applications for the public engagement grant from the Department of Cultures, Politics and Society, where I was working, provided the opportunity we had been waiting for. We embarked on a rethinking of her design proposal, aiming to incorporate the textiles from the ethnography and the ceramic vulva. This involved negotiations regarding our aspirations, space constraints, time, and available funding.

The installation “Sitting with Vulvodynia” assumed a dedicated space in the exhibition, with six stools that invited visitors to physically accommodate on metal cylinders (for the feeling of pins), on metal strips (for the stabs feeling), on a red hot-water bottle (for the burning feeling), on a vibrator (for the feeling of electric shock), on a cup-cake backing tray (to reproduce a wavy surface for the feeling of discomfort), and on a metal salad bowl (for the feeling of a foreign body), as visible in Fig. 11.

The chairs’ aim is neither to replicate the illness experience, nor to limit its experience solely to the sitting action. The installation is a knowledge tool to facilitate the sensorial understanding of the pain that those who suffer from vulvar pain feel. Many of them co-live with chronic pain, and even sitting for more than 15 minutes can become impossible. The most common symptoms are burning and irritation (by contact or spontaneous) feeling of abrasion and electric shock. The sitting wanted to reproduce some of the symptoms both from a tactile and visual perspective, to facilitate a phenomenological experience for visitors. They support an embodied understanding of suffering doing a very daily activity, such as sitting in a university campus.

At the opening, visitors were hesitant to experience the seating area: some were concerned about damaging the installations, while others felt that the action might push them out of their comfort zone. Among those brave enough to try, a young male student reported that it would be impossible to actually follow an entire university class while sitting in a similar condition. Painful experiences were also reported when a visitor attempted to tie their laces, altering the balance on a smaller portion of the seating surface.



Figure 11 © *Sitting with Vulvodynia*, by Sofia Rampanelli. Photo by Federica Manfredi, 2024.

During the fieldwork, Sofia and I worked on the symptoms of vulvodynia that she experienced and those collected during the ethnographical work. The results brought us to add a final segment to the exhibition, merging a section of Sofia's thesis with the interview data. Working remotely, with Sofia in Paris and myself in Rome, we envisioned two groups of objects—one dedicated to narratives of pain and the other connected with strategies to cope with pain. In the first group, we selected objects that trigger pain and associated sentences from qualitative interviews referring to them. Examples include tight-fitting jeans, or food packages like chocolate, coffee, and wine that can have inflammatory consequences. Similarly, we created a second group to highlight the strategies interviewees implemented to cope with chronic pain, prevent attacks, or address their pathology. This group included empty drug boxes, train tickets for specialist consultations, a round pillow used for outings or during university classes, white cotton underwear (as dyed ones can cause itching due to coloring components), a bike saddle with a customized shape to

reduce pelvic pressure, and bottles of water that could be used for emergency bidets, such as at the beach.

In close collaboration, we selected six symbolic objects for each group, along with corresponding interview extracts, and decided to name them “Oggetti del Dolore, Oggetti della Resistenza” [Objects of Pain, Objects of Resistance] (fig. 12).

The co-designed installation mirrors the anthropological analysis and it aimed to offer a different perspective on everyday objects that restructure the horizon of possible actions that sufferers signify. The proposal invited visitors to touch the objects and read testimonies from interviews, providing an opportunity to compare how they approach a common object when it is not embedded in a chronic pain experience. This exercise can facilitate mutual understanding between visitors and sufferers, breaking down barriers of untold pain and silencing the everyday dramas experienced by those who cannot sit



Figure 12 © The Objects of Pain , installation by Federica Manfredi and Sofia Rampanelli. Photo by Federica Manfredi, 2024.

for more than fifteen minutes on a chair or plan a beach day without being sure that a bottle of water is available for an emergency shower. Artistic installations provided multi-sensory materials to rethink pain and vulvar health, offering the occasion to develop new forms of knowledge and understanding beyond a logocentric approach. They privileged touch, smell, body positions, and visual products to promote empathy, awareness and a cultural transformation.

Conclusions

This case study presented a dissemination experience centered around a medically invisibilized condition, employing multiple visual languages to facilitate social (re)actions. In contemporary Italian society, vulvas are not the subject of health education, and women are not educated to monitor or care their sexual health, leading to the normalization of pelvic and vulvar pain. The term ‘vulva’ can be controversially perceived with a vulgar, almost pornographic meaning, as highlighted by the ethnographic episode concerning the exhibition title.

Vulvar pain is not only a clinical condition. The cultural dimension shapes the experience of the pain. Cultural values associated with female reproductive function and genitals influence the ‘normalization’ and acceptance of female genital pain, suppressing the recognition of symptoms and the willingness to seek medical care. In this context, I propose the metaphor of a missing mirror reflection: the absence of social consideration for vulvar pain corresponds to the lack of cultural meanings concerning feminine genital consideration. The failure of the mirror work is revealed by the experience of pain, indicating that only when a vagina is impenetrable does her pain become a sign of alarm.

Dolore Vulvare. Arte. Scienza. Resistenza [Vulvar Pain. Art. Science. Resistance] stands not only as an exhibition but as a call to action—a poignant reminder that cultural narratives surrounding vulvar pain are both clinical and deeply embedded in societal values. The project transcends traditional ethnographical boundaries, engaging a diverse range of voices, from patients and artists to health specialists and beyond. Through the fusion of art and science, this exhibition challenges the prevailing silence and stigma surrounding vulvar pain, inviting individuals to rethink their understanding of this complex condition.

The exhibited artifacts, crafted through collaboration and creativity, mirror the often-overlooked struggles of those experiencing vulvar pain. By offering a multisensory experience, the project fosters empathy, understanding, and a shared commitment to cultural transformation. The term ‘resistance’ in the exhibition’s subtitle signifies not only defiance against the invisibilization of vulvar pain but also a collective endeavor to reshape societal perceptions. In 2024 the exhibition will travel in other locations of Torino, starting an itinerant phase to multiply audiences.

As the curtains fall on *Dolore Vulvare*, its impact reverberates beyond the gallery walls. It prompts society to recognize the intricate intersections of pain, power dynamics, and gender norms. The project, rooted in qualitative research and visual methodologies, demonstrates that human experiences, particularly those associated with pain, require nuanced approaches for comprehension.

By fostering dialogue and dismantling cultural taboos, *Dolore Vulvare* emerges as a catalyst for change, a catalyst urging us to create a society that mirrors and accommodates the diverse experiences of vulvar pain. In the face of silence, the exhibition invites individuals to become active agents in co-constructing a more empathetic, informed, and inclusive narrative surrounding vulvar health. In doing so, it paves the way for a future where vulvar pain is neither invisible nor stigmatized but embraced as an integral part of the broader spectrum of human experiences.

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