

**Resisting But Embracing Fragility:
Exploring Prominent Themes Emerging
From Online Feminist Activists
and Advocates' Posts Addressing
Conditions Characterized by Chronic
Pelvic Pain on Instagram**

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Abstract

The proposed research will explore how Italian feminist digital activists and advocates address issues surrounding endometriosis, adenomyosis, vulvodynia and painful bladder syndrome on Instagram. It emerges that activists and advocates aim to foster the circulation of counter-discourses on these conditions, which we identified as explicitly or implicitly informed by feminist practices and discourses with the purpose of tackling the institutional and mainstream dismissal of their pain and experiences. This is by simultaneously distancing and resignifying the notion of fragility in relation to their identities and bodies through mutual support and information sharing.

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1. Introduction

Vulvodynia, endometriosis, adenomyosis and painful bladder syndrome (PBS) have a huge impact on how women and people assigned female at birth (AFAB) see themselves, leaving them struggling with feelings of inadequacy and isolation. The identity of people suffering from conditions characterized by chronic pelvic pain is in fact often absorbed by their health condition or by the uncertainty related to the lack of information, care and research dedicated to these diseases. This negatively affects their social functioning, emotional well-being, relationships with professional and personal networks, sex life and employment opportunities, resulting in a feeling of powerlessness and the construction of a self-perceived fragile individual. For many of them, social media, and Instagram in particular, serve as platforms of information seeking and support in dealing with their disease(s)/condition(s) (Holowka 2022), allowing them to partially reconstruct their sense of agency and empowerment.

This paper will present the prominent narratives and themes deployed by Italian feminist activists and advocates on Instagram addressing the pain and experiences of people dealing with vulvodynia, adenomyosis, endometriosis and PBS. The Italian context, in particular, stands out as one in which Instagram activism/advocacy surrounding chronic pelvic pain has experienced exponential growth over the last few years, and in which the medical and social construction of chronic pelvic pain is under-explored as well as women and people AFAB's experiences in handling the societal and institutional dismissal of their conditions. What emerges is that activists and advocates aim to foster the circulation of counter-discourses on these conditions which we identified as explicitly or

implicitly informed by feminist practices and discourses with the purpose of tackling the institutional and mainstream dismissal of their pain and experiences. They share narratives that oppose the androcentrism permeating the medical practice that constructs women as biologically vulnerable to or carriers of disease and thus inherently fragile (Dubriwny 2013). This is by simultaneously distancing from and resignifying the notion of fragility, commonly deployed by the general public to describe women and people AFAB identities and bodies, through mutual support and information sharing.

We have decided to narrow down the scope of our research by including only diseases and conditions characterized by chronic pelvic pain due to its negative impact on women and people AFAB's quality of life. Chronic pelvic pain is, in fact, one of the most frequent symptoms affecting the female genital system that push women and people AFAB to seek gynecological care (Howard 2003, Steege 1998) and is also a common cause of disability among them, as the management of this condition is very challenging, and the rate of long-term remission is low (Mellado *et al.* 2019). Possible pathological causes of chronic pelvic pain include both gynecological and urological diseases/conditions such as endometriosis, adenomyosis and painful bladder syndrome. However, when the chronic vulvar pain has no identifiable cause, it is called vulvodynia¹. These diseases and conditions have a high incidence of comorbidity (Reed *et al.* 2012). We present a quick rundown of the most addressed diseases and conditions in feminist activists' discourses:

- Vulvodynia is an idiopathic chronic vulvar pain condition, in the form of burning, soreness, or throbbing. It is very common, as it affects 25% of all women and AFAB at some point in their lives (Harlow *et al.* 2014).

¹ <https://www.nva.org/what-is-vulvodynia/>

Vulvodynia negatively affects women and AFAB's sexuality (Berglund *et al.* 2002; Lamont *et al.* 2001; Reed *et al.* 2000), psychological well-being (Gates 2000; Masheb *et al.* 2002), self-esteem (Katz 1996) and relationship adjustment (Meana *et al.* 1997; Sackett *et al.* 2001).

- Endometriosis and adenomyosis are chronic diseases associated with severe pelvic pain caused by the presence of endometrial-like tissue outside the uterus. It is estimated that endometriosis could affect 10% (Eskenazi and Warner 1997) and adenomyosis 0.8% of all women and AFAB (Yu *et al.* 2020). Individuals with a diagnosis of endometriosis associate the disease with its negative impact on their romantic and sexual relationships (Bernuit *et al.* 2011; Moradi *et al.* 2014; Cox *et al.* 2003c), education opportunities (de Graaff *et al.* 2013; Moradi *et al.* 2014; Huntington and Glimour 2005), work opportunities and income (de Graaff *et al.* 2013; Moradi *et al.* 2014; Nnoaham *et al.* 2011) and psychological well-being (Cox *et al.* 2003a; Moradi *et al.* 2014; Whelan 2007). In addition, those dealing with adenomyosis report burdensome self-care, hygiene (Nelsen *et al.* 2018) and fatigue (Huang *et al.* 2021; Nelsen *et al.* 2018).
- Painful bladder syndrome (PBS) is a chronic condition that affects the walls of the urinary bladder, causing chronic pelvic pain, pressure or discomfort, accompanied by urinary urgency, frequent urination and/or nocturia (van de Merwe *et al.* 2008). PBS has been associated with limitations impacting the patients' sex life (Butrick 2003; Propert *et al.* 2008), significant limitations in long travel (Nickel *et al.* 2009), a negative impact on partner relationships and family life (Nickel *et al.* 2009), fatigue and insomnia (Tincello and Walker 2005) and lower work-related quality of life (Beckett *et al.* 2014).

Obtaining a diagnosis for these diseases/conditions is often complicated and time-consuming (Seear 2009; Shallcross *et al.* 2019). In Italy, patient associations and specialized medical centers report that patients wait on average 4.5 years for vulvodynia² and between 7 and 8 years for endometriosis/adenomyosis^{3 4} in order to receive a diagnosis. While no data is available for PBS in regard to Italy, it has been reported that in the United States the condition is symptomatic for between 4 and 7 years before diagnosis (Butrick 2003).

2. Androcentrism of the medical practice and diagnostic delay

The reason for the diagnostic delay is multifactorial as it partially depends on the diagnostic complexity of these diseases and conditions (Agarwal *et al.* 2019; Cox and Neville 2012; Peric and Fraser 2006; van de Merwe *et al.* 2008), partially on the lack of familiarity/knowledge of healthcare professionals (Butrick 2003; Toeima and Nieto 2011) and partially on the general normalization of women's pain and menstrual irregularities (Seear 2009). Thus, these factors are not just strictly medical, but they draw from a secular tradition of clinical practices that suffer from androcentric assumptions. Women's health has been confined to their roles as wives and mothers, with women's needs assumed to be met through maternal care. For this reason, non-reproductive health has long been disregarded

² <https://www.vulvodinia.online/>

³ <https://www.endometriosi.it/che-cose-lendometriosi/diagnosi/>

⁴ We decided to use “Fondazione Italiana Endometriosi” as reference since it is the only source that provides statistical (albeit likely underestimated) data concerning endometriosis diagnostic delays in Italy. However, we strongly distance ourselves from controversial or non-scientific content and information often disseminated by the Fondazione. This especially in relation to the myth of a salvific diet that might cure endometriosis and the unsound definition of endometriosis as endometrium. Endometriosis is characterized by the presence of tissue similar to the lining of the uterus (endometrial-like) located outside the uterus. These fragments are different structurally, and behave differently, from the normal endometrium which is shed during a period. For more information: <https://nancysnookendo.com/what-is-endometriosis/> and <https://extrapelvicnotrare.org/>

by the medical community (Coreil 1995). In this regard, feminist sexology literature has shed light on how the medical profession has been characterized by phallogentrism and laid its foundations on an androcentric view of sexuality (Maines 1999), which led to restricting views on women's sexuality as limited in possibilities to penetration.

Studies on endometriosis have also emphasized the normalization, the dismissal and the trivialization of menstrual pain and irregularities by doctors, which result in patients feeling ignored and disbelieved (Ballard *et al.* 2006; Cox *et al.* 2003a; Denny 2009; Jones *et al.* 2004). As a consequence, patients are commonly misdiagnosed and/or referred to inappropriate secondary care (Ballard *et al.* 2006; Denny and Mann 2008; Jones *et al.* 2004). This perception of menstrual irregularities and menstrual pain as 'normal' often extends to the family and friends of the patients, leading to delays in seeking help (Ballard *et al.* 2006; Cox *et al.* 2003b; Denny 2004b), especially when they experience pain during sexual intercourse (Cox *et al.* 2003b; Denny 2004a). Similar issues during the diagnostic process have been reported by patients suffering from PBS, who oftentimes have to undergo multiple tests with various clinicians before receiving their diagnosis (Kirkham and Swainston 2021).

Receiving a proper diagnosis proves to be of prime importance. Upon receiving a diagnosis, patients oftentimes report feeling a sense of relief, legitimation, liberation and empowerment (Ballard *et al.* 2006; Kirkham and Swainston 2021; Seear 2009; Shallcross *et al.* 2019) as it provides them with the vocabulary to communicate their pain to family and friends (Ballard *et al.* 2006; Kirkham and Swainston 2021; Shallcross *et al.* 2019). Due to the androcentrism that permeates medical practice, women are constructed as biologically vulnerable to or carriers of disease (Dubriwny 2013) and thus inherently fragile. This paper describes how feminist activists and advocates are promoting and circulating counter-discourses

on the negative connotation of vulnerability by subverting this paradigm through mutual support and information sharing practices.

3. Feminist social media activism

In the past decade, digital feminist activism has skyrocketed. According to Baer (2016), since 2010 there has been a global explosion of social media activism dealing with a plethora of topics such as patriarchy, sexism, misogyny, gendered violence and inequality.

Feminist social media activism is broadly considered to be a new form of feminist activism, with new tools and strategies. Activists have been using digital spaces as sites to increase the visibility of feminist causes and social justice issues and to mobilize both online and offline activism while, at the same time, a climate of backlash against feminism and, more generally, against women, has swallowed up the Internet with the intent to attack, humiliate, delegitimize and silence them (Menzies 2008; Farci and Righetti 2019; Vingelli 2019; Banet-Weiser 2018). Some authors such as Munro (2013) and Benn (2013) have further argued that new technologies enabled new directions in feminism, launching a burgeoning fourth wave of feminism (Turley and Fisher 2018) described by Retallack *et al.* (2016) as a global and globalized sharing of voices with an intersectional approach at its core and unmatched levels of popularity. Whether we can talk of a new feminist wave or not, the internet has changed the locus of political practices, especially in the last years and among younger generations. In this regard, it's worth mentioning that this online feminism is peculiar in its socio-demographic composition since it is mostly comprised of young intersectional feminists that use digital platforms as a way to share information and communicate with an audience (Keller 2015; Schuster 2013).

It is nonetheless important to highlight the duality of digital feminist activism and its individualistic dimension in neoliberal times (McRobbies 2009). Digital media offer the potential for advancing feminist agendas by disseminating feminist ideas and allowing creative forms of activism (Baer 2016; Crossley 2015), facilitating the connection between people beyond their locality and involving people that are not able to engage in face-to-face contact. It also provides a framework that enables the “interplay of individual stories and collective modalities” in everyday life (Baer 2012, 18) in what Clark-Parsons (2014) defines as “a more personal feminist politics than ever before”, giving potential voice to a multiplicity of subjects. This has partially disturbed the established boundaries between what we consider public and private (Marwick and boyd 2014; McLean and Maalsen 2013). On the other hand, authors such as Gill (2016) and Rottenberg (2019) argue that doing feminism in cyberspaces means embracing the performative and economic profit-oriented logics of neoliberalism, with the result that the focus of feminism is rerouted on individualism, choice and agency, poorly affecting collective action and reinforcing the idea of women as entrepreneurial subjects that have to solve every issue by themselves. In this sense, the emphasis on the individual capacity of resolving personal problems through individual achievement, and the shift from public politics to the private, personal and intimate sphere, may have reframed the modes of feminism.

Concerning women’s health, Dubriwny (2013) argues that postfeminist logics are replacing collective feminist actions by making women responsible for preventing and eliminating their health risks through careful and informed medical choices. To put it bluntly, women have to seek help, find the right informants and discard false or inaccurate information, making a decision ultimately based on their judgment. This widespread logic may have two consequences: on one hand, women and people AFAB are searching for information on their health on non-official channels, also due to a structural inadequacy of information on the mentioned

diseases and conditions within the medical community; on the other hand, new feminist activists and advocates are growing in number and are intensifying their activity to meet these needs.

Many studies have shown how women use the Internet more often to retrieve health-related information than men, especially from individuals of their gender (Bidmon 2015; Manierre 2015). In particular, social media have emerged as important emancipatory spaces for all those women and queer individuals whose bodies and experiences have long been invisibilized and deemed less important, contributing to the rise of interest surrounding “new” public health topics and testimonials of medical injustice and malpractice (Miani and Namer 2021), such as the biomedical pathologization of fatness (Bacon 2010), the mis/underdiagnosis of women with autism (Hull *et al.* 2017) and gynecological and obstetric violence (Miani and Namer 2021).

As we will argue, Instagram represents an important space in which women and people AFAB obtain both information and support in dealing with their disease(s), which potentially allows them to reconstruct their sense of agency and empowerment in the frame of popular feminism. In particular, our analysis will explore how feminist activists and advocates provide support, knowledge and counter-discourses on vulvodynia, adenomyosis, endometriosis and PBS on the platform, and on their ability to resist the linking of these diseases/conditions to fragile identities and bodies by the general public.

4. Data and methods

To explore how Italian feminist activists and advocates address issues surrounding vulvodynia, adenomyosis, endometriosis and PBS online, we engaged in a thematic

analysis of the Instagram posts' of nine profiles belonging to equally as many activists and advocates, by focusing on their textual content and/or caption.

We decided to focus our research on Instagram as it is a platform for sharing stories, identity-oriented narratives and creating connections for both tellers and audiences, thus facilitating the construction of communities, intimate and supportive interactions and personalized day-to-day narratives. Moreover, the abundance of research on digital activism on Instagram demonstrates that the social medium represents an important platform in which activist movements can rise and operate (Cornet *et al.* 2017; Caldeira and De Ridder 2017; Stanley 2020). In this regard, Instagram can be considered as a visibility-oriented platform that could be used as a strategic tool to counteract the invisibilization of conditions characterized by chronic pelvic pain (Holowka 2022).

Instagram provides textual and visual corpora that are willingly and spontaneously authored by millions of users. The data extracted from public profiles are public and the terms and conditions of Instagram would have allowed us to use them for our research without informed consent. However, we critically and ethically questioned the way in which commercial platforms such as Instagram consider users' data as mere commodities to be extracted for potential profit. Therefore, we decided to directly contact through a private message the activists and advocates in our sample to negotiate with them their willingness to provide their data. In doing so, we shared with them a draft of this paper and asked for their feedback, which contributed to guide our analysis. We also conducted informal follow-up interviews with 7 out of the 9 activists, during which they verbally formalized their consent⁵.

We opted to define them as activists and advocates since they are consciously working to bring about political and/or social changes through public campaigning.

⁵ Another activist formalized her consent through a private message. The only case in which we did not manage to establish contact is that of @giorgiasoleri_. However, we still decided to include her in our sample based on her self-identification as a public figure.

However, when conducting the follow-up interviews, we learned that although some of them self-define their actions as activism or advocacy, part of our sample was cautious in defining their work as activism. This may account for a limitation in our study albeit, on the basis of the aforementioned interviews, the definition of activism/advocacy is often linked by the people in our sample to a collective dimension and social movements' actions, rather than to the individual digital one in which they operate. When referring to our sample we therefore decided to use both terms at the same time to reflect the activists/advocates preferences.

The main challenge of our methodological framework was selecting a sample of activists defined as feminists since there is no singular definition of what feminism is and, therefore, what characterizes a feminist activist/advocates. We tried to avoid a rigid conceptualization of activism/advocacy and feminism and, thus, the selection of feminist activists/advocates was based on two indicators. The first one is the engagement in feminist activities with an explicit focus on women's issues and health. The second indicator is the presence of explicit and implicit connections and shared narratives with other online feminist networks, such as the use of the same hashtags, inclusive language, reposts and pictures that show the involvement in feminist collectives, riots and demonstrations. We started by searching for keywords and hashtags related to the diseases and conditions under study including #endo #endometriosi #vulvo #vulvodinia #adeno #adenomiosi #cistite and manually scanning all the resulting public posts and the associated profiles.

Starting from these profiles we engaged in the secondary stage of our sampling strategy, which consisted of a snowball sampling employed by clicking on profiles mentioned in the captions of the posts and tagged in the posts themselves and/or in the highlighted stories. We decided to retain the profiles that matched the aforementioned indicators and that presented more followers and thus, we hypothesized, more engagement. This process resulted in a non-probabilistic

sample of nine Instagram profiles. We manually extracted 229 posts pertaining to the research topics out of the original database of 1097 posts from the mentioned profiles, posted between March 2020 and the time of data collection in February 2022, covering a span of two years. This sample size prevents us from generalizing our findings and is not representative of all the feminist activists/advocates on these topics in Italy. The predominance of cisgender white women among the activists/advocates requires future reflections on the structural absence of trans and non-binary people and people of color's experiences from feminist practices and activism. Fig. 1 provides the profile bio of each selected Instagram profile, in addition to the followers' count at the time of data collection.

Pseudonym	Profile caption	Followers	Following
<i>giorgiasoleri</i> –	Giorgia Soleri she/her Personaggio pubblico poso, amo, mostro il culo su Instagram e mangio l'amatriciana. nel mentre scrivo poesie e faccio la femminista guastafeste*	520k	2.2k
<i>vania.mento</i>	Vania Mento 🏳️‍🌈 Blogger Attivista dell'endometriosi 🏳️‍🌈 Presidente dell'associazione no profit: @lavocediunaelavoceditutteodv www.facebook.com/vania.mento*	4k	800
<i>endo.metriosi</i>	endometriosiè 🌻 Provo a convivere con l'endometriosi e l'adenomiosi. 🏳️‍🌈 🌻 🍷 Celiaca @viaggiosenzaglutine 🧬 Trombofilica ❌ NON SONO UN MEDICO 📺 sono anche su YouTube 📺 linktr.ee/endo.metriosi	12.5k	1k
<i>the_sexpositive_translator</i>	Sara la Spoonie she/her Blog personale Patient Advocate @infoendometriosi Malattie invisibilizzate Diritti Sessualità Endometriosi Vulvodinia Fibromialgia Se mi muovo, scricchiolo www.isteriche.com	4k	562
<i>mi.lamendo</i>	mi.lamENDO 🌻 Blog personale Lamentiamoci e memiamo liberamente insieme. 🌻 🏳️‍🌈	2k	1.5k

	Endometriosi, Adenomiosi, Vulvodinia, Tiroidite di Hashimoto (e Fibromialgia???) 👉 Link utili: linktr.ee/mi.lamendo		
<i>lapelvi1987</i>	Chiara-Vulvodinia&Ipertono ✨ Creator digitale 👤 Racconto storie vere 👥 Faccio un uso smodato dell'ironia 🚫 Non sono un medico*.	10.5k	519
<i>anne_comet_lully_medica</i>	Anne Comet Lully Blog personale Demisessuale & Queer 🏳️‍🌈 Medica 🩺 🗳️ Attivista 🗣️ Endometriosi + Adenomiosi & PID patient 🌻 Endo Surgery: 4/2/22 #abusesurvivor	7.9k	898
<i>endoepsiche</i>	Sona Haroni Psicoterapeuta • Ho l'Endometriosi • Ti aiuto ad affrontare i problemi psicologici che questa malattia comporta. • Info: endoepsiche@gmail.com 📧*	1.5k	141
<i>endoetica</i>	C. [She / Her] 🟡 Dolore cronico ⚔️ Endometriosi - Adenomiosi 💛 Salute riproduttiva 🔥 Decostruire/Ricostruire 📚 A tratti, scuola e crescita	1.4k	410
Single asterisk (*) indicates content in the profile bio has been adjusted in order to avoid commercial sponsorship. The listed profiles are sorted randomly to avoid any implied hierarchy.			

Fig. 1 - Activists' profiles bio (verbatim author's translation)

While we acknowledge the image-centric nature of Instagram, we decided to devote our attention to the posts' captions and/or textual content for several reasons. Firstly, much of the images shared by the sample contain text expanding the content of the caption, subverting the visual logic of Instagram's affordances. Secondly, some of the images are personal pictures showing intimate moments of the activists/advocates life and their pain, described textually in the captions.

Thirdly, we wanted to avoid any personal interpretation and textualization of the images depicting their bodies, and therefore decided to rely solely on their voices and to refrain from imposing a top-down analysis produced and consumed by us as researchers. Lastly, while it would have been interesting to compare how each activist/advocate relies on very different communicative and visual strategies, from meme-oriented humor to personal photography-based images, we decided to focus our analysis on the major themes developed in their narratives.

Finally, we investigated the data corpus through a constructionist thematic analysis following Braun and Clarke's (2006) framework. This methodology allowed us to inquire and explore in detail the topics, ideas and patterns of meaning that come up repeatedly in the narratives. All the quotes cited throughout the paper are translated verbatim from Italian to English.

5. Coding of the themes

The thematic analysis allowed us to identify three major themes in the activists/advocates' discourses, identified as follows: (1) structural fragility; (2) delegitimation as fragility; (3) counter-discourses on fragility.

5.1. *Structural fragility*

Doctors who roll their eyes, doctors who snort impatiently, who raise their voices intolerant of your desperation [...], who mock you in your face in order to look good in front of a beautiful resident by telling you: "Aah now I remember, you are my special patient" (intended as psychiatric patient [...]) (@anne_comet_lully_medica).

The first phase of the thematic analysis was mainly focused on activists/advocates' posts on structural fragilities. As we will explore in this paragraph, patients are

forced to deal with the structural invisibilization and dismissal of their pain both at the hands of the State and the National Healthcare System and of the healthcare community.

5.1.1. *“The State does not recognize us”*

Here is my whole story, consisting of chronic pain and diagnostic delay, which includes vulvodynia, pelvic hypertonus, endometriosis and adenomyosis. Because my story is the story of many people, and we are tired of being considered invisible (@giorgiasoleri_).

The most recurrent expression of the structural fragility that people with vulvodynia, adenomyosis, endometriosis and/or PBS are forced to deal with is the lack of formal recognition of their conditions, sufferings and needs from the State and the National Health System. For example, at the time of research, vulvodynia unfortunately lacks recognition as a chronic and potentially disabling condition. As a consequence, patients cannot register in the medical exemption database, which would allow them to be exempted from paying the prescription charges for medications and healthcare services related to the disease. This kind of recognition by the National Healthcare System would be instrumental in addressing these diseases and conditions, as it would better support patients' right to work (for example, by allowing for flexible work arrangements and access to paid sick leave) and study, as well as day to day accommodations such as free and easy access to all public restrooms. In most regions, a diagnosis of endometriosis and/or adenomyosis grants access to the exemption only when it has already reached the third stage⁶ and the ease of access to specialized care varies substantially region

⁶ Several classification/staging systems of endometriosis have been developed over the last 35 years. Generally, they refer to 4 stages of endometriosis according to the number of lesions and

by region. Similar inconsistencies in the access to care apply to PBS as well. In regard to the economic burden she experiences, @lapelvi1987, who suffers from vulvodynia, writes: “we have to shell out everything out of pocket, which makes it a luxury disease. We do not benefit from overtime leave from work to receive treatment”.

5.1.2. “Work through your phallophobia”

If it hurts to have sex, it just means that you haven't met the penis that will take the pain away yet (@endoepsiche).

The diagnostic delay and the trivialization of the symptoms by the medical staff contribute to producing the structural fragilities faced by women and AFAB with vulvodynia, adenomyosis, endometriosis and/or PBS. One of the most pervasive themes in activists' posts is their frustration with the medical community. A high number of posts in our sample narrate activists/advocates' experiences with doctors, who have oftentimes labeled them as crazy, liars, frigid, hysterical, suggesting that “all women suffer” and that, in turn, they might need to consult a psychologist, work through their phallophobia, buy a vibrator and/or masturbate more. According to @giorgiasoleri_, “the fault lies in a medical system that consistently underestimates and denies the pain of women and people AFAB, minimizing it and judging it as normal”. These practices are called medical gaslighting (Sebring 2021), a term used to describe the denial and dismissal of a patient's illness or the attribution of symptoms to psychological factors.

depth of infiltration. The escalating severity of these stages does not indicate that endometriosis starts off in one part of the body before spreading, since the disease can be widespread from the beginning. This also means that the stages don't necessarily give guidance on how to treat endometriosis for different patients. They are medical constructs and therefore should not be considered as indicators of pain and distress experienced by patients.

Activists/advocates also reflect on how the constant trivialization of their pain has led them to self-diagnose through online information-gathering and to change doctor after doctor in a quest to find an understanding practitioner that is also familiar with their condition(s). @lapelvi1987 recounts: “Do you know how many gynecologists have seen my gorgeous vagina? Eight, if we do not consider the trainees at the Polyclinic, who observed me as if I were a Faberge egg inside a goldsmith’s workshop”.

In these circumstances, receiving a diagnosis is constructed by many patients as a relief, because the trivialization of their symptoms by medical professionals has led many of them to doubt their own bodily experiences. However, even after the diagnosis, patients with endometriosis and adenomyosis who undergo surgery face the downplay of its severity by the National Healthcare System and are offered no psychological support once out of the operating room. As @vania.mento notes: “A destructive and invasive surgery changes your life forever. We need someone to help us ‘pick up the pieces’, a hand to help us get up before hitting rock bottom. The specialized endometriosis centers need to provide psychological help after surgery”.

5.2. Delegitimation as fragility

I have heard everything: that I am crazy, anxious, frigid, a liar. That I am afraid of sex, that I should masturbate more. The worst part was the extreme solitude in which you are confined, judged by who surrounds you and dismissed by who should find a diagnosis. [...] When I finally gave a name to all of this, I discovered that not only I was not alone, but that women that suffer from this pathology are so many, and all of them share this feeling of being completely abandoned in their pain (@giorgiasoleri_).

In this section, we will explore the invisibilization and the difficulties in gaining legitimation experienced by people with vulvodynia, adenomyosis, endometriosis and/or PBS. Specifically, we will focus on the mainstream delegitimation and social dismissal, as well as on the fragility produced by gendered and ableist stereotypes and biases on invisibilized illnesses and disabilities and the phallogentric-patriarchal construction of the medical practice.

5.2.1. *“Living with an invisibilized illness does not mean it is imaginary”*

In recent years I have been hurt and humiliated many times, not only in the professional field where I received the worst treatment but also in the social and family sphere. My soul was devastated. I know that I will never recover from these [...]. I'll repeat it over and over: endometriosis leaves you alone, out of breath. Because you can't see it. And, in the eyes of others, if something is not seen, it simply is not there. 'You took this disease a little too seriously', 'Vania is a disappointment', 'You? Disabled? Please!!!'. These words echo inside me and hurt me as much as the pain of endometriosis. I cannot forget the physical and moral pain and so I will never be able to (@vania.mento).

Most of the analyzed activists/advocates decided to start their activism/advocacy to share their experiences and their knowledge, to fight back the mainstream disbelief on the existence of these diseases and conditions and to make their stories visible. By analyzing and comparing the 229 posts in our sample, it was possible to find a common theme related to the difficulty of expression and verbalization of their illnesses and needs. All the activists/advocates state that, in their experience, since their conditions are not medically and socially recognized as disabling diseases, their sufferance is met with disbelief and their symptoms are often treated as imaginary in agreement with the mainstream gendered narrative on women faking illness (Werner *et al.* 2004). The activist

@vania.mento wrote on a post that she was fired after receiving the official disability certification with the sentence “you take this illness too seriously”. The activists/advocates were defined by doctors and medical staff, friends, family and colleagues as “excessive”, “with a low pain threshold”, “liars” because “it is not true that you are in pain, I cannot see anything”, “there are people that really suffer” or “who really suffers does not look like you” or “disabled people have scars”. Furthermore, they are often referred to as “lazy” and “hysterical” on the basis that such diseases and conditions are “mental illnesses”. Hysteria has been often attached to a series of different “feminine disorders” throughout history, ranging from illnesses related to the sexual and reproductive organs to those of the nervous system. The label “hysteria” is a catch-all diagnosis that has functioned as a means to avoid addressing the real underlying pathologies that were affecting women or people AFAB and it is still one of the major gender stigmas and prejudices in the medical discipline. The (mis)diagnosis that links these diseases and conditions to hysteria is well established and is still present in feminist activists/advocates’ online posts. To explain this association, @the_sexpositive_translator quotes Gilman *et al.*’s (1993) *Hysteria Beyond Freud* saying that it is “the reflection of the culture of a specific society concerning the idea of gender and class and the role attached to women inside the related structures”.

Moreover, their painful experiences are minimized with sentences such as “everyone has their period, suffering is a normal condition [for women]”; “if you feel pain when having sex, it means that you did not encounter the right penis that can take away your pain”; “it’s just a matter of growing up, it will pass”. All the activists/advocates recount the same experiences, using the exact words or synonyms. The activist @vania.mento reports being addressed with even stronger words such as “just shut up, you have nothing to complain about. You have to stop bothering us all. You’re just whiny, all women have their period” or (using

hyperbolic language) “you complain too much there is nothing wrong with you! When I’m on my period I skydive, I practice extreme skiing, somersaults and I cross the Atlantic windsurfing”. She states that other women oftentimes opposed her, instead of providing support. As stated by @giorgiasoleri_, these attitudes towards vulvodynia, adenomyosis, endometriosis and PBS fit perfectly with the sexist construction of the medical practice and the idea that women are biologically inclined to suffer since they are both inherently fragile subjects and naturally meant to suffer through maternity and the pain of reproduction:

We are women and as such we are culturally inclined to bear the pain. Even when it is unbearable. Even when that pain makes you give up sex, your career, opportunities and life in all its facets. We are forgotten, unheard, abandoned. And when we tell our stories of pain, agony and loneliness, the protocol is always the same: we are not believed. We are tired of proving how much our suffering is debilitating in a society where our pleasure is optional and our health is an opinion on which we can agree or not.

This constant external, institutional and social rejection often results in psychological conditions such as depression or anxiety disorders, which reinforce the self-isolation and the loneliness felt by people with vulvodynia, adenomyosis, endometriosis and/or PBS. As @endoepsiche states, that people suffering from these diseases are “in a condition of perceived inferiority also at a social level that makes them experience endless refusals” while @vania.mento writes: “you scream and no one listens. You learn to scream in silence. You learn to cry during the night, silently, in the darkness. Endometriosis is not visible. It is a solitary desperate pain”.

Activists/advocates often report their need to be “heard, loved as they are, understood, not judged” the need for “the pain to not be minimized, for the disease to not be compared with others, to be taken seriously” (@endo.metriosisi),

which result in the shame of talking about it and fear of being rejected and devalued once more. Thus, the invisibilization of their pain is not just inscribed in their bodies, but it is also reproduced by the steady dismissal of their experiences with a pain that is not acknowledged by the outside world. It is precisely this dismissal, along with the macho doubts cast on the existence of these diseases and conditions, that produces the risk of a strongly internalized fragility or, better, a fragile identity that is not legitimate and thus doesn't have the right to exist and be taken care of.

5.2.2. "Don't laugh, don't take care of yourself, don't dress up otherwise they will think that you are fine"

We are beautiful, we take care of ourselves, we wear makeup, we color our hair, we paint our nails, we dress how we like and we have #endometriosis, an invisible, chronic and highly disabling disease that affects about three million women in Italy [...] Taking care of our physical appearance does NOT mean NOT being sick (@vania.mento).

In this paragraph, we focus on the consequences of the previously discussed lack of external recognition of these illnesses and the related needs for care. The analysis of the activists/advocates' posts shows how pain, sufferings and struggles need to be constantly performed to be perceived and legitimated as real and true. The activist @giorgiasoleri_ reports how it is essential for people with vulvodynia, adenomyosis, endometriosis and/or PBS to "demonstrate to have something debilitating". Both in medical and broader social contexts, they need to broadcast their fragility to receive legitimation further aggravating their vulnerable condition. Furthermore, the unpredictability of these diseases and conditions reinforces the idea that they derive from psychosomatic illnesses, as stated by @lapelvi87:

It is always difficult to plan something. Missed dinners, postponed dates and holidays. The fickleness of the symptoms makes it difficult for others to understand our pain and suffering. We are looked at with suspicion: she was okay until 10 minutes ago!.

In line with the issue of pain performativity with the scope to see their needs legitimized, @giorgiasoleri_ lists some sacrifices that society at large perceives as trivial and frivolous, but that impact patients' daily quality of life: "no skinny jeans, no tights, no acidic food, no alcohol, no sugars, no colorful or synthetic underwear, no nights out, nothing. Even planning a trip is a nightmare, knowing that you might stay in bed suffering".

Our analysis unveils that the constant mainstream delegitimation of the sacrifices and suffering of people with such diseases and conditions deepened the often-problematic relationship of the activists/advocates with their bodies. The activists narrate how the lack of control over their bodies, which don't work as they are supposed to, makes them feel like half-women, incomplete, socially useless, lacking and limited in their capacity of moving and living freely. @the_sexpositive_translator reports the contradiction between these feelings and her activism in the following post: "I think about all the discourses on chronic pain that I am trying to push, and I think that I would throw them away if I could have a perfectly functioning body in exchange".

Finally, all the activists/advocates narrate how, when it comes to the body's dimension, their sexual desire and pleasure are often neglected, since the focus is solely on male satisfaction. A lot of people with vulvodynia, adenomyosis, endometriosis and/or PBS experience dyspareunia, a kind of pain that arises during sexual intercourse, whether penetrative or not, both vaginal and anal. The advocate @endoetica reports that the first question when the sexual and relational

sphere of people with endometriosis is touched is always the same “how does [fill the gap with a random masculine name] do it?”, always assuming a heteronormative, stable couple. According to all the activists/advocates, the stress is on what the man feels and what he thinks, and on the fact that if you do not satisfy him, he will leave for someone else that does not have the same whims. This male-oriented and gendered narrative is rooted in the idea that women are sexual objects, ready to please their men and perform their sensuality. Paraphrasing @lapelvi87, if a woman is not able to satisfy her man, and he still decides to stay with her, “she has to cheer him, to feel lucky and give him a treat”.

According to our analysis, the medical incompetence, the structural and institutional dismissal and the neglect of the pain and sufferings of people with these diseases and conditions produce fragilities that are amplified, reinforced and inscribed in their bodies, which are perceived as limited, defective and fragile.

5.3. Counter-discourses on fragility

[When I received the diagnosis] I was happy, because I finally had answers, because someone finally believed my pain (@endo.metriosis).

In this section, we will show that the nine activists/advocates in our sample have been attempting to change the hegemonic narratives in different ways: by sharing their knowledge, by reframing the discourse on fragile bodies through the recognition and acceptance of their limits and by fostering communities for people with vulvodynia, adenomyosis, endometriosis and/or PBS.

5.3.1. *“If I can help even just one person, then my pain was worth something”*

Once declared, fragility ceases to be such and becomes a strength! Let us not be ashamed of ourselves or our condition. Endometriosis is a little-known disease and we can talk about it. Declaring ourselves allows others to understand more about us and promotes empathy (@endoepsiche).

The most transversal theme among activists/advocates' counter-discourses is that of information sharing. Acknowledging that a high number of women and people AFAB can't obtain a proper diagnosis from their doctors, all the activists/advocates in our sample decided to partake in practices of information sharing, to fight back against the widespread trivialization of the symptoms and structural fragility that patients experience. This is of particular importance, as an early diagnosis prevents the chronicization of several symptoms and helps contain the damage caused by endometriosis and adenomyosis.

I started writing my story because many girls, many women, do not know what endometriosis is (as I did not know) and suffer for years without reaching a diagnosis. My activism aims to raise awareness, to inform, to allow the adolescents of today, who will be the women of tomorrow, to obtain an early diagnosis (@vania.mento).

For the activists/advocates, it's important to share information on their pain, symptoms and needs not only for those women and people AFAB that are currently looking for answers and suggestions but also to spread awareness among the general population: they want to make their pain visible and to challenge the constant dismissal of their experiences.

I hope it will be useful, as it was for me, to read the testimonies of those who have had a diagnosis and have decided to share it to carry on this battle. We deserve recognition and respect, humane diagnostic times and affordable therapies. And we deserve to be heard (@giorgiasoleri_).

At the same time, few activists/advocates, when contextualizing their activity on the platform, have also expressly acknowledged their privilege in being able to share their experiences. All the activists/advocates with a high followers count are cisgender women, a fact that reflects how the fragilities connected to vulvodynia, adenomyosis, endometriosis and PBS are reinforced by other possible dimensions of vulnerability such as non-heteronormative sexual orientations, the non-conformity to the binary construction of genders or the belonging to stigmatized and racialized groups such as BIPOC. In particular, @the_sexpositive_translator writes: “I think it’s right to reflect on the fact that the possibility of narrating oneself is not within everyone’s reach and that being able to do so can be considered a privilege” and tagging another activist/advocate, she notes “last week he spoke on the fears and consequences of his ‘coming out’ as a trans man suffering from endometriosis, in which the emphasis was on ‘coming out’ in relation to the disease”.

However, these difficulties extend beyond the LGBTAIQ+ community, as they affect everyone with “a precarious job situation [...] for fear of bullying, prejudice, even dismissal” hindering their opportunities to “even just ask for help and access treatment”, a situation in which social exclusion and dismissal work as multipliers of pre-existing fragilities.

5.3.2. “Let me embrace my own pain”

If there is one thing that this disease has taught me, it is that life is unpredictable. It was when it decided to make me sick, as much as when I looked in the mirror wearing white cotton underwear and felt as confident as ever. I went from hating and cursing this body that had betrayed me, to embracing and accepting it for what it is: a body with limits (@giorgiasoleri_).

As discussed previously, through their posts activists/advocates reported struggling with accepting the limitations that the condition(s) pose on their bodies. Oftentimes, the lack of control makes them feel incomplete, half-women who are limited in their capacity of living a fulfilling life. At the same time, activists/advocates have also challenged this narrative by sharing with their followers how they reached acceptance over the limits imposed by the disease(s) and invited them to reject their internalized fragility by rethinking their relationship with their bodies. For example, @lapelvi1987 writes “I felt broken, a half-woman, exposed, vulnerable, different, almost useless. If I think about it now, I want to go back and hug myself tightly”, while @the_sexpositive_translator decided to talk about how their negative emotions surrounding their experiences, pains and limitations should not be processed as a weakness, but rather a normal component of dealing with chronic pain:

try not to be angry at your body, get rid of your envy of able-bodied people [...], don't be ashamed and don't feel guilty. All the emotions that we already have to live with normally and that make us feel at fault (even towards any partners) [sic], while self-esteem is tearing us up at the game of hide and seek.

In addition, when talking about how the change in the discourses surrounding their bodies and their experience with vulvodynia, adenomyosis, endometriosis

and/or PBS should extend to society at large, @the_sexpositive_translator clearly states that just because part of them “doesn’t work as expected” it doesn’t mean they are “half people” and that their value as members of society shouldn’t be “measured in these terms”, noting that they don’t “owe anything to anyone. [...] Never. Under no circumstances”.

While sharing her difficult experience of post-op recovery the activist @vania.mento also openly criticizes discourses that represent surgeries (or other kinds of treatment) as the catch-all solution to all their struggles:

In February 2013 I underwent a six-hour-long surgery [...]. I was in an induced coma and had a stoma for about two months. It took me more than a year to recover from the surgery but I didn’t even have the time to feel a little better: a sacral neuromodulator was inserted in my back to allow me a ‘dignified’ life, as my sacral nerves, completely compromised by endometriosis, no longer worked. These severe and painful surgeries, the dozens of invasive examinations, the debilitated body, led me to a severe form of depression, which came in conjunction with the dismissal, without warning, from my job.

These kinds of counter-discourses are shared by other activists/advocates as well, such as @endo.metriosis (after 6 months, my body is still not back to how it was before, I still have pain) and @lapelvi1987 (when you ask me for how long I have been on the treatment I feel sorry to answer you, I do not want you to be disheartened).

5.3.3. “Thank you, sisters”

Mine is a story of activism, an activism born a few years ago, when I received the diagnosis of endometriosis. [...] Activism was my rebirth, my second chance at life (@vania.mento).

After prolonged periods of times in which they experienced external, institutional and social rejection, activists and advocates have worked to create a safe and welcoming online community for people dealing with these diseases and conditions. A key feature of their posts is the words of encouragement to their followers and the invitation to share their own experiences in the comments (“if you’d like, you can share your experience, we’ll listen to you” (@lapelvi1987)), along with resources that can prove helpful for other members of the community (“if you know any, point out other useful resources in the comments” (@the_sexpositive_translator)). Mutual support as a way to counteract structural fragility is one of the main goals and pillars of the community and it empowers both the activists and the members of the community themselves, who can find in the activists and their fellow members a judgment-free, nurturing and safe space in which their pain and their needs are legitimated, understood and not dismissed:

Thanks to all the people who have decided to share their experience with vulvodynia and to make their pain a starting point to help others, giving themselves and spending themselves without getting anything in return. I won't tag you, but you know who you are. Without you, I wouldn't have a diagnosis (@giorgiasoleri_).

My thanks are for all for you, for your sweetness, your love and, above all, for your strength in this life with ENDOMETRIOSIS! (@endo.metriosi).

[On the need of receiving the appropriate support when dealing with endometriosis] If you are interested in learning more about the subject of this post, we can talk about it in the comments or contact me privately (@endoepsiche).

For some of the women in our sample, their participation in online activism/advocacy is only part of their involvement in activism/advocacy at large. For example, with the slogan THE VOICE OF ONE IS THE VOICE OF ALL, @vania.mento has, in 2021, started the homonymous association, whose goal is to provide information and support to people with endometriosis and to raise awareness of the disease, while @giorgiasoleri_ has been a keynote speaker at the first national conference on vulvodynia, pudendal neuropathy and fibromyalgia, that took place on November 12, 2021, as well as many other informal events.

Finally, it is important to acknowledge that the activism/advocacy performed by the women in our sample, along with that of all other activists/advocates, both online and offline, has led to an increase in the attention paid to vulvodynia, adenomyosis, endometriosis and PBS both by the media and the medical community. Some of the principal newspapers and news agencies in Italy (including, but not limited to, SkyTG24, Il Resto del Carlino, Il Fatto Quotidiano, ANSA, TGCom24, La Gazzetta dello Sport, LaRepubblica, Internazionale), have started or increased their coverage on these matters, oftentimes including interviews or testimonies from the activists themselves⁷. On March 28 and on April 1, 2022, two bills, the former in the Chamber of Deputies and the latter in the Senate, were presented for the recognition of vulvodynia by the National Healthcare System and the State as a chronic and disabling condition to be

⁷ Patologie delle Donne, al Presidio di Non Una Di Meno Giorgia Soleri: “Il Dolore Non Viene Creduto”, disponibile al link: <https://video.repubblica.it/edizione/roma/patologie-delle-donne-al-presidio-di-non-una-di-meno-giorgia-soleri-il-dolore-non-viene-creduto/399662/400372>

included in the Essential Levels of Care of the National Health System. A press conference was then held at the Chamber of Deputies on May 3, where Giuditta Pini presented the proposal together with activist @giorgiasoleri_ and Silvia Cabarelli, representative of the Vulvodynia and Pudendal Neuropathy Committee, which collaborated in drafting both proposals.

6. Conclusions

The concepts of vulnerability and fragility related to women and people AFAB's health and needs have, thus far, not explicitly nor widely been investigated in the literature. Nonetheless, as Dubriwny (2013) argues, women and people AFAB are socially constructed as subjects at risk of being ill and, as such, more vulnerable and fragile to diseases. Fragility, therefore, tends to be socially and medically inscribed in their bodies and ends up being considered a core dimension of what being "a true woman" means. This explains the duality in popular narratives about health in which women and people AFAB are presumed to be biologically vulnerable to disease(s) or carriers of the same disease(s) (*Ibidem*). Women, in particular, are considered vulnerable because of the social and binary construction of their very femininity.

Our research shows how terms such as vulnerable, defected, neurotic and crazy are often used as synonyms for fragile in the experiences of women with vulvodynia, adenomyosis, endometriosis and/or PBS, which results in a struggle to find meaningful, coherent and not fragmented identities that can reconcile their personal life histories (Werner *et al.* 2004). The textual analysis of activists and advocates' Instagram posts indicates how chronic illnesses and pain constitute a disruption in people's biographies and cause a transformation in their sense of self and identity.

Through this research, we suggest that Instagram may serve as a platform to address the lack of recognition of these conditions and diseases by the National Healthcare System, the inconsistencies in the access to care, the diagnostic delay and the trivialization of the symptoms by the medical community. On this platform, in fact, feminist activists and advocates try to deconstruct mainstream discourses that depict their symptoms as imaginary and the product of hysterical women faking illnesses. By addressing these conditions as medical and social diseases that have long lacked recognition due to patriarchal and sexist constructions of the medical practice, and by denouncing the mainstream and institutional dismissal of their experiences, the activists/advocates contribute to building familiarity with transformative feminist narratives, practices and vocabularies in relation to topics such as health, sexual and reproductive rights, consent, self-pleasure and body-positivity, gender stereotypes and biases. Through the filter of visibility enabled by Instagram's socio-technical infrastructures and affordances, the activists/advocates seem to have contributed to the creation of a collective identity that is the expression of a set of shared meanings that originates and ends in "the sharing (in the sense of "pooling together") of private individual experiences" (Milan 2013): a "us, people with chronic pelvic pain" in which the collective is experienced through the voices of prominent individuals and is functional to peer recognition (Benkler 2006).

Finally, according to their experience, the medical, institutional and social dismissal actively produce fragilities and vulnerabilities by reinforcing self-isolation, loneliness and the performativity of their pain in order to be believed and legitimized by the external, ableist world. Thereby, they share identity models that move away from those of the fragile individual (per mainstream definition) by trying to subvert this paradigm. It is essential to highlight that, as it emerges from the analyzed posts, terms such as "fragile" and "vulnerable" are not essentially negative, but are socially constructed as such by discourses that reproduce

paternalistic and macho power hierarchies. Therefore, as Judith Butler reminds us (2016), it is important to re-evaluate vulnerability and allow care: being vulnerable is a forming human and not-human condition that traverses our social relations and, contrary to the common assumption, fosters and does not impede practices of resistance.

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