Bodies and Words on Fire.

Pelvic and Vulvar Pain on TikTok and Instagram Between Invisibilization and Voices that Fight.

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Over the last years, in Italy, digital platforms and social media have taken on a central role in raising public awareness and in prompting processes of destigmatization of conditions characterized by chronic pelvic and vulvar pain, such as vulvodynia, endometriosis, painful bladder syndrome, and other "neglected" diseases and conditions. Although they affect at least one-tenth of all bodies assigned female at birth (Harlow *et al.*, 2014; Buck Louis *et al.*, 2011), obtaining a diagnosis for these diseases and conditions is consistently made complicated, frustrating and time-consuming (Seear, 2009; Shallcross *et al.*, 2019) by the lack of scientific knowledge rooted in a cultural approach that taboos and stigmatizes people with vulvas' and women's sexuality (Bertone *et al.*, 2011) and that normalizes what is medically rubricated as "female genital" and menstrual pain (Manfredi, 2024) and irregularities (Seear, 2009).

People with vulva's health has historically been confined to their potential roles as wives and mothers, and their needs have been assumed to be met through maternal care, regardless of how they identify. For these reasons, the non-reproductive health of people with vulvas has long been disregarded by the medical community (Bueter, 2015). 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). Within this context, digital platforms and social media have been used by many as spaces for information, influence, mutual support, advocacy, struggle and resistance, both individual and collective, against experiences characterized by pain and medical, institutional, and social delegitimization of women, trans*, gender-fluid and non-binary people, and, more generally, people with vulvas (Holowka, 2022; Buonaguidi and Perin, 2023).

This research therefore aims to analyze and make visible the main discourses and narratives about bodies and health, and needs, created and shared by the users of these platforms, and to highlight their transformative (or not) potential in relation to issues intersecting pelvic and/or vulvar pain, specifically thematizing the invisibilization and normalization of pain as a result of the reproduction of an androcentric and heteropatriarchal medical-social knowledge. To this end, a collaborative feminist ethnography was conducted on Instagram and TikTok, adopting a critical approach to their affordances and the algorithmic structuring of platform-generated content. The study

underscores the need for a situated, transfeminist methodological and theoretical approach to knowledge production as a political commitment to recognizing the epistemic value of embodied experiences of power and oppression.

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