# A Case for a Critical Examination of Diagnostic Delays Among Women

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There are a number of diseases and conditions that have notoriously long diagnostic periods, many of which disproportionately manifest among women (Clarke, 1983; Kempner, 2014). Endometriosis, for instance, takes on average three to ten years to diagnose (Sims et al., 2021), and cardiovascular disease (Johnson, et al., 2021), ADHD (Young, et al., 2020), and pain conditions such as fibromyalgia (Qureshi, et al., 2021) and rheumatoid arthritis (Rosa, et al., 2020) represent other common examples. This phenomenon has also been identified in conditions not typically regarded as "women's diseases" such as diabetes and cancer (Westergaard et al., 2019). During a diagnostic delay – when the period becomes prolonged between experiencing a health challenge until the point at which a diagnosis is made – women continue to suffer from symptoms, lose confidence in healthcare providers and systems, and experience interruptions to their lives, relationships, and sense of self. While it appears evident that the timing and type of diagnoses are not distributed evenly across genders, what remains unclear is why – what is contributing to the reproduction of diagnostic delays for women?

While limited in number, there has been some promising work that has sought to explain this phenomenon. Several investigations have identified reasons for delayed diagnoses among women with endometriosis or cardiovascular disease. These include ineffective diagnostic testing (Ballard, et al., 2006; Almond et al., 2012), deprioritization in hospitals and emergency departments (Almond et al., 2012), pharmacological suppression of symptoms (Ballard, et al., 2006; Davenport, et al., 2022), a lack of physician knowledge or training about disease presentation (Denny & Mann, 2008; Almond et al., 2012; Davenport, et al., 2022), physicians' doubts about the value of a diagnosis (Davenport, et al., 2022), physicians' dismissive attitudes and the normalization of symptoms by both patients and physicians (Ballard, et al., 2006; Denny & Mann, 2008; Almond et al., 2012; Davenport, et al., 2022; Drinkell et al., 2023), poor or imbalanced relationships between patients and providers (Denny & Mann, 2008; Drinkell et al., 2023); a patient's demographic characteristics (Drinkell et al., 2023), and a lack of patient knowledge, use of self-advocacy, or self-prioritization (Sjöström-Strand & Fridlund, 2008; Almond et al., 2012; Drinkell et al., 2023).

While the identification of these reasons for diagnostic delays are an important step, the majority of investigations fall short of explicating the context in which these factors are located, such as the socio-political structures and power relations that shape and constitute the very circumstances themselves. A notable exception is discussions of stigma surrounding women's health (Drinkell, et al., 2023) and more specifically, stigma surrounding menstruation, in the case of endometriosis (Ballard, et al., 2006; Seear, 2009; Davenport, et al., 2022). However, the only investigation, to our knowledge, which takes its central focus toward such structures is Seear's (2009) explication of how stigma plays a role in delaying help-seeking behaviour among women. Seear articulates the social sanctioning acts of stigma, such as ostracism, criticism, or the trivialization of pain, as evidence of how menstruating women are regarded as 'discreditable individuals' (Goffman, 1963). As a result of this stigma, they are deeply motivated to strategically conceal any discussion of, or materials related to menstruation. This concealment, labeled 'menstrual etiquette' (Laws, 1990), effectively inhibits any willingness to disclose menstrual normalcy, let alone menstrual problems, and offers a sociological explanation as to why women may hesitate to enact help-seeking behaviours regarding menstrual dysfunction. Seear concludes that further critical examination of diagnostic delays for women with endometriosis is needed, such as an exploration of why women's menstrual pain is normalized or who might benefit from such acts, in order to sharpen our understanding of this phenomenon (Seear, 2009).

Another significant gap in research on diagnostic delay is the experiences that women have with this phenomenon (Ashton, 1999; Ballard, et al., 2006; Denny & Mann, 2008; Almond, et al., 2012; Colella et al., 2021). When one considers the extensive research on the experiences of illness among women (see for example Werner & Malterud, 2003; Banks & Malone, 2005; Cho, 2019; Lajoie & Douglas; 2020; Heggen & Berg, 2021; Clerkley, 2022; Hintz, 2022), this gap is all the more apparent, particularly regarding the role of women's embodied knowledge in the process of diagnosis. The contribution of embodied experience to meaning-making processes is well established (Magrí & McOueen, 2022), and yet the salience of their embodied experience in the context of the diagnostic process has yet to be explored in relation to their help seeking behaviour. Based on Havi Carel's (2016) work in the phenomenology of illness, which characterizes illness in one's lifecourse as an interruption or divergence, it may be of significance to consider how women's lifeworlds are stretched and altered during periods of diagnostic delay, and how women make meaning of an absence of diagnosis that would have provided an explanatory framework and sense of motion towards a trajectory of care. Such alterity represents another important direction for research on the gendered nature of diagnostic delay.

The impetus for this commentary arises from a deep concern about the lack of specific and critical discourse on the ways in which gender has shaped the phenomenon of delayed diagnosis for women. Studies which have done so are few and have compartmentalized and decontextualized their findings. As a result, how social structures are intertwined with embodied experiences of diagnostic delay, and the ways the relationship between them serves to enable and/or constrain this phenomenon is poorly theorized and understood. Further still, there has yet to be an investigation which takes an intersectional consideration of gender as an interlocking and co-constituting social force that interacts with a range of other social characteristics; this is vital to appreciate the multiplicity of ways in which gender shapes diagnostic delays for a multiplicity of women. The social forces of gender are ever-present, from our social norms and expectations to our relational and embodied ways of being. As such, engaging a theoretical framework that holds the capacity to examine the interrelationship between these micro and macro dimensions, is imperative. In light of such a task, critical phenomenology holds much methodological potential.

From its inception, phenomenology has understood that a rendering of the world into facts of objectivity imparts an impoverished sense of meaning (Husserl, 1970). Through the refinement of many scholars, the tenents of phenomenology articulated the importance of subjectivity in the development of a fulsome understanding of the world, such as that of Alfred Schutz who broadened phenomenology's reach into the social sciences. Following the work of Simone De Beauvoir and Frantz Fanon who interrogated how uneven distributions of power shaped one's lived experience and opportunities, critical phenomenology has articulated how such a withholding of lived experience from our descriptions of the world acts to further marginalize those already at its margins (Stanier, Miglio & Dolezal, 2022). While Husserlian phenomenology has been typically concerned with the investigation of lived experience, an explicit inquiry into how social, political, and other structural influences shape this experience brings a critical lens and a praxis of social justice to the tradition (Guenther, 2020; Magrí & McOueen, 2022). By engaging with a wide range of critical disciplines, such as philosophies of race and coloniality, disability studies, social and feminist philosophies, and the medical humanities, critical phenomenology has drawn its focus toward the relations between self, social experience, and social norms, and pays close attention to how categories of social identity, such as gender, are involved in self- and other-experience (Magrí & McOueen, 2022). Both classical and critical phenomenologies fundamentally understand lived experience as embodied; that the body has both material and perspectival qualities (Merleau-Ponty, 1945 [2013]). As a result, the body is understood both as an object that can be understood by medicine, but also as what it means to be human and contend with, or navigate through, human experiences such as health, illness, or death (Welsh, 2022). A method of understanding how the body is lived by women is paramount to understanding the gendered nature of diagnostic delays.

Critical phenomenology aims to expose forms of injustice that are hidden in the familiarity of our routine ways of being and thinking, by demonstrating how social norms such as white supremacy, patriarchy, or heteronormativity not only inform our social worlds, but also inform who we are and how we make sense of our experience (Guenther, 2020). It offers a carefully contextualized approach that stresses the active and the acted upon nature of the body, both of which are of paramount importance for feminist struggle and social change. As such it is our contention that critical phenomenology is well-positioned to capture the complexity of the gendered nature of diagnostic delay for women, support continued discussion and advocacy, and help effect change to this enduring and wicked problem.

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