

Recognizing Endo

How Gender and Recognition Shape Experiences of Endometriosis

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Abstract

Endometriosis is a common and painful condition affecting millions worldwide. In recent years, it has also emerged as a site of gender justice struggles. This thesis offers an empirically informed phenomenology of this frequently overlooked condition, interpreting patients' experiences and demands for change as a contemporary struggle for recognition.

Based on in-depth interviews with 15 individuals in Sweden diagnosed with endometriosis, the study aims to deepen the understanding of how gendered dynamics and processes of recognition shape lived experiences of the condition. The analysis draws on the Hegelian concept of recognition, primarily as developed in Axel Honneth's recognition theory, to examine how recognition shapes relations to self and others and motivates struggles for change. Approaching endometriosis as the phenomenon of "endo," the thesis develops empirically informed concepts that capture its characteristic manifestations in the interviewees' lifeworlds. These concepts are elaborated across three articles.

The first article (I) introduces the notion of *endo time*, analyzing how the recognition of endo appears as a specific orchestration of time, in experiences of waiting time, cyclical or chronic time, and sedimented time. The second article (II) develops the concept of *endo episteme*, examining how recognition and everyday epistemic practices shape the journey to diagnosis and treatment, including the processes of becoming a knower, becoming a patient, and becoming knowledge. The third article (III) articulates *endo politics*, exploring how quests for diagnosis and treatment evolve into a struggle for recognition that involves developing a fighting spirit, becoming a "we," and struggling to be included.

Through these themes, the dissertation makes both empirical and theoretical contributions to gender studies, endometriosis research, and contemporary philosophical debates on gender and recognition.

Keywords: *chronic illness, endometriosis, gender, phenomenology, recognition.*

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