

The Lived Experience of Women with Endometriosis: From Diagnosis onwards

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Introduction

Endometriosis is a chronic gynaecological condition characterised by endometrial tissue located outside of the uterine cavity (1). The condition affects up to 1 in 10 women globally and is associated with physical and emotional distress. Diagnosis takes approximately 6-8 years. Living with a chronic health condition has a known impact on one's wellbeing whether that is physical, social or psychological. This thematic analysis interviews 40 women living with Endometriosis. We aim to provide insights into the lived experience and comment on the journey of diagnosis and treatment.

Methods

Medical students delivered semi-structured interviews in Primary Care Networks (PCN) during their placements. The participants were women living with a known diagnosis of endometriosis within the PCN and aged under 50 years. Participants were recruited by registering their interest via a recruitment poster at each practice within the PCN. A thematic analysis was performed using NVIVO.

Results

The key findings of the thematic analysis were divided into categories: (1) Perceptions in the healthcare setting; (2) Relationships; (3) Family planning; and (4) Diagnosis and Treatment. Highlights from the categories included drug-seeking behaviours perceived in healthcare, feeling hopeless and lack of support. 78% of women interviewed stated endometriosis had a negative impact on their careers.

Discussion

This qualitative study gathers evidence of the experiences living with Endometriosis and factors affecting mental health associated with the condition. Similar studies such as those investigating stigma associated with the condition found similar findings including chronic delay and lack of awareness (2). This is a small cohort sample due to the availability of medical students and size of the practice. A national scale of this project could highlight the potential postcode lottery of endometriosis diagnosis, management and support.

To what impact has endometriosis had on your career?



Quotes:

"I lost my job of 7 years because of a condition that took 9 years to diagnose. I had a battle with HR because I couldn't prove how ill I was."

"I felt hopeless at one stage. I was told that carrying a pregnancy to 40 weeks could kill me."

References:

1. Horne AW, Missmer SA. Pathophysiology, diagnosis, and management of endometriosis. *BMJ*. 2022 Nov 14;e070750.
2. Sims OT, Gupta J, Missmer SA, Aninye IO. Stigma and Endometriosis: A Brief Overview and Recommendations to Improve Psychosocial Well-Being and Diagnostic Delay. *Int J Environ Res Public Health*. 2021 Aug 3;18(15).