

# **“It’s like a constant black cloud”: a qualitative investigation of the impact of endometriosis on quality of life**

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**Introduction:** Endometriosis is linked to adverse mental health outcomes, as well as impairments to quality of life (QoL). Although there is increasing interest in the lived experiences of individuals diagnosed with endometriosis, traditionally endometriosis has been little researched from a qualitative perspective. Research suggests that people experiencing endometriosis feel unheard due to the lack of understanding surrounding the condition, which can fuel detriments to mental wellbeing. To aid our understanding of this condition further, it is vital to convey the perspectives of those living with endometriosis.

**Aim:** This research aims to gain an in-depth understanding of the impact of endometriosis on the lives of individuals diagnosed with the condition.

**Materials and methods:** 30 individuals with an endometriosis diagnosis participated in semi-structured interviews. Interviews were designed to gain an in-depth understanding of participant experiences and perspectives in relation to endometriosis. Interviews were audio-recorded and thematic analysis was used to identify themes.

**Results:** Four themes were developed: life trajectory and fears for the future; emotional burden of experiencing endometriosis; sense of self; and powerlessness. Each theme uniquely and simultaneously affected QoL and wellbeing.

**Conclusions and impact:** Participants emphasised the adverse impact of endometriosis upon their lives. Specifically, disruptions to life trajectory had a considerable impact on an individual’s identity and contributed to the emotional burden of experiencing endometriosis. Understanding participant experiences is an important step in increasing awareness about the impact of endometriosis, giving a voice to individuals who have traditionally felt unheard. Increased understanding and awareness can lead to advancements in psychological support whilst effective and long-lasting treatments are sought.

### **Short background and symptoms**

Endometriosis is a progressive, incurable condition characterised by the presence of endometrium-like tissue outside the uterus (Chapron et al., 2019). Endometriosis-derived tissue forms lesions on the organs and tissue it infiltrates, resulting in a multitude of commonly-reported symptoms including chronic pelvic pain, menorrhagia, dyspareunia, sub-fertility and fatigue (Haydardedeoglu et al., 2016; Maddern et al., 2020; Ramin-Wright et al., 2018). Endometriosis is thought to affect 1 in 10 women and people assigned female at birth globally (World Health Organization, 2021).

### **Mental health and QoL in endometriosis**

Endometriosis has a detrimental impact upon mental health and wellbeing (Chi Chen et al., 2016; Li et al., 2017; Estes et al., 2020). Up to 64.4% and 63.5% of individuals diagnosed with endometriosis experience depression and anxiety respectively (Sepulcri & Amaral, 2009), whilst approximately 56% meet the clinical parameters for psychiatric diagnosis (Pope et al., 2015). Endometriosis is also associated with an adverse impact on quality of life (QoL; Corte et al., 2020; Jia et al., 2012; Marinho et al., 2018), although there is ongoing debate surrounding the mechanisms by which endometriosis leads to reduced QoL.

### **Known drivers of QoL in endometriosis**

Pain is a major driver of endometriosis-related QoL outcomes (Facchin et al., 2015). As pain severity increases, so too does the likelihood of anxiety and depression (Facchin et al., 2017) and adverse QoL outcomes (Culley et al., 2013). Furthermore, those experiencing chronic pelvic pain (CPP) without endometriosis report similar detriments to QoL (Souza et al., 2011), suggesting that pelvic pain is the main driver of endometriosis-related QoL. However, individuals living with CPP may experience symptoms similar to endometriosis, such as functioning impairments, fatigue and heavy bleeding, which may also contribute to reduced QoL alongside pain (Roomaney et al., 2016). Furthermore, Low et al. (1993) reported that, although perceived pain was similar in those experiencing CPP and endometriosis, people diagnosed with endometriosis reported more negative QoL outcomes, suggesting that factors aside from pain contribute to the QoL of those experiencing endometriosis. Additionally, although aspects of QoL are often improved following surgery to remove endometriosis and reduce pain, QoL still remains lower in individuals diagnosed with endometriosis compared to the general population (Ford et al., 2004; Garry et al., 2005). The high recurrence rate of endometriosis (REF) also suggests that surgery is a temporary fix for many. Therefore, it is important that the role of additional factors in influencing QoL and mental wellbeing are considered so that detriments to QoL in this population may be addressed.

Beyond pain, numerous factors have been implicated in contributing to reduced QoL in endometriosis, including but not limited to: reduced functioning (especially in work, sexual and social relationships; REF); diagnostic delays (REF); fertility (REF); and coping strategies (REF). Rather than one single factor underlying endometriosis-related QoL, it is likely that QoL and wellbeing outcomes are determined by a complex interplay of several physical, social and psychological factors. Qualitative research suggests that perceived control over the impact of endometriosis plays a key role in QoL outcomes (REF).

### **IPs**

Perceived control in the context of a health threat or medical condition is a core dimension of illness perceptions (IPs) as posited by Leventhal et al.'s (1997) common sense model of self-regulation (CSM-SR). IPs refer to the ways in which an individual frames and experiences a health threat, and, according to the CSM-SR, these cognitions work in unison with the emotional response to the health threat to drive responses and coping behaviours (Leventhal et al., 2016). Broadly, IPs are concentrated in 5 main areas: 1) identity: ; 2) timeline: the expected duration of the condition; 3) consequences: the anticipated impact of the condition on the individual's life; 4) causes: the perceived origin of symptoms; 5) control: the perceived effectiveness of self-treatment and/or medical treatment in regulating or lessening symptoms (Leventhal et al., 2016).

#### **IPs and QoL/ why important to study?**

To our knowledge, IPs have not yet been studied in the context of endometriosis, however they are important drivers of mental health and QoL in several other chronic conditions including fibromyalgia (REF), irritable bowel disease (REF) and rheumatoid arthritis (Hyphantis et al., 2013). Interventions directly targeting IPs have led to improvements in treatment outcomes and QoL in several conditions such as diabetes, asthma and myocardial infarction (Alyami et al., 2021; Petrie et al., 2011; Sararoudi et al., 2016), suggesting that interventions of this kind may support the QoL and wellbeing of individuals living with endometriosis. Previous qualitative literature strongly suggests that perceptions surrounding control and the consequences of endometriosis are related to QoL (REFs), but due to the complexity of the condition it is important to determine whether the pre-existing dimensions of IPs are applicable to endometriosis, or whether the IPs of those living with the condition transcend this framework.

#### **Aims of the current paper**

The current research aims to gain an understanding of how endometriosis is perceived and experienced by people living with the condition. Specifically, this study aims to establish whether the pre-defined IPs categories as described by Leventhal et al. (1997) sufficiently capture the perceptions of individuals experiencing endometriosis. Furthermore, this research aims to provide a rich account of the ways in which endometriosis-related IPs affect QoL. Adopting a qualitative approach allows us to go beyond the confines of established quantitative data collection tools to gain a deeper understanding of participant experiences and cognitions. Furthermore, individuals with endometriosis have traditionally felt unheard due to a lack of research and understanding of the condition (REF), and as such this research presents an opportunity to convey the perspectives of those living with endometriosis.