Stressful experiences impact on pain, fatigue and mental health in people with endometriosis: a questionnaire study during the COVID-19 pandemic

Lysia Demetriou¹, Christian Becker¹, Beatriz Martínez-Burgo¹, Adriana Invitti², Marina Kvaskoff³, Razneen Shah¹, Emma Evans⁴, Claire Lunde¹, Emma Cox⁵, Kurtis Garbutt¹, Krina Zondervan¹, Elaine Fox¹, and Katy Vincent¹

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Abstract

Objective To explore the impact of the COVID-19 pandemic on pain and fatigue symptoms and their interactions with the impact on mental health in people with endometriosis. Design Global cross-sectional survey. Setting Online survey. Sample A total of 4717 adults with a surgical or radiological diagnosis of endometriosis. Methods An online global study collected data in 5 languages between 11th May to 8th June 2020. The survey included questions on current-status and changes of endometriosis-symptoms, mental health, demographics, and the impact of the COVID-19 pandemic on the respondents' lives. Main Outcome Measures Self-reported changes to endometriosis-associated symptoms (pelvic pain, tiredness/fatigue, bleeding) and to mental health during the early stages of the COVID-19 pandemic. Results Respondents reported a marked worsening of their endometriosis symptoms (endo-associated pain (39.3%; 95% CI [37.7, 40.5]), tiredness/fatigue (49.9%; 95% CI [48.4, 51.2]) and bleeding (39.6%; 95% CI [38.2, 41])) and mental health (38.6%; 95% CI [37.2, 39.9]). Those with a pre-existing mental health diagnosis (38.8%) were more negatively impacted. The worsening of pain and TF were significantly correlated with worsening of mental health (p<0.001) and these relationships were found to be weakly mediated by pain catastrophising scores (pain: effect size: 0.071, LLCI= 0.060, ULCI= 0.082, TF: effect size: 0.050, LLCI= 0.040, ULCI= 0.060). Conclusions This study demonstrates that stressful experiences impact the physical and mental health of people with endometriosis. The findings highlight the need to consider psychological approaches in the holistic management of people with endometriosis.

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¹University of Oxford

²Universidade Federal de Sao Paulo Escola Paulista de Medicina

³Universite Paris-Saclay

⁴Oxford University Hospitals NHS Foundation Trust

⁵Endometriosis UK

 $\textbf{Table 1.} \ \, \textbf{Summary of altered medications, altered planned treatments, mental health diagnosis and Covid-19 impact, presented as frequencies and percentages (%).}$

	Frequency	Percent (%)
Altered medication and planned treatments	3663	78.4
Altered medication treatment	1476	31.3
Altered planned treatment	3151	66.8
Mental Health Diagnosis	1831	38.8
COVID-19 Impact		
Had symptoms of COVID-19	753	16
Had a positive test for COVID-19	79	1.7
Been admitted to hospital because of COVID-19	18	0.4
Has anyone you live with had symptoms of COVID-19	591	12.6
Has anyone you live with had a positive test for COVID-19	67	1.4
Has someone close to you (family or friend) died because of COVID-19	381	8.1
Are you considered "vulnerable"/at high risk from COVID-19	990	21.1
Live with someone considered "vulnerable"/at high risk from COVID-19	1162	24.7
Worry that endometriosis makes you more vulnerable to COVID-19	2534	53.9
COVID-19 pandemic impact on major life changes		
No, nothing more than for most people	2397	50.8
I have lost my job	352	7.5
I have had to work much longer hours	662	14
I have had a significant decrease in my earnings	824	17.5
I can't run my business	239	5.1
I have had to move out of my home	132	2.8
My relationship with my partner has fallen apart	241	5.1
I have had to postpone/cancel my wedding	115	2.4
Most important/bothersome before the pandemic		
Pelvic pain	2602	55.3
Heavy and/or irregular bleeding	395	8.4
Fatigue	293	6.2
Bowel problems	403	8.6
Urinary/bladder problems	109	2.3
Pain during or after sex	263	5.6
Infertility/difficulty getting pregnant	410	8.7









