

A commentary on the need for support with mental as well as physical health for people with endometriosis during the COVID-19 pandemic and beyond.

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The coronavirus disease 2019 (COVID-19) pandemic meant an abrupt change in healthcare provision around the world. Whilst the primary focus was (rightly) on the care of those infected with SARS-CoV-2 and public health measures to prevent transmission/identify those most at risk, individuals with chronic conditions saw their treatments halted, cancelled or changed, with little information available and extremely limited access to clinicians¹⁻³. As the first wave settled, many units began to restart their benign gynaecology services, however, this was within the limitations of social distancing, reduced staffing (due to sickness, shielding or COVID-19 contact) and the continued need for personal protective equipment (PPE). At a global level, the focus remained on public health measures and the search for a vaccine⁴.

Everyone had their own personal experience of the initial lockdowns and ongoing restrictions, the extent and timing of which varied throughout the world. Many were able to find at least some positives to contrast with the limitation on freedom and continuing background threat from the virus. These included more time to spend with their nuclear family, reigniting interest in or starting new hobbies, the opportunity to tackle home improvements and more time to exercise. However, data also began to emerge on the significant impact the pandemic was having on mental health^{5, 6}. Of particular relevance to Obstetricians and Gynaecologists was the finding that along with young people and those with small children at home, mental health was deteriorating most in women⁶.

As endometriosis is a chronic disease, many of those affected rely on long term medication, whilst others require one or more procedures (surgery or fertility treatment). We were concerned as to the impact the pandemic might be having on the access to treatment for those with endometriosis. We therefore conducted an online survey study to determine this impact and understand priorities going forwards. The survey (open 11th May to 8th June 2020; University of Oxford Central University Research Ethics Committee approval reference: R69636/RE001) was available in English, French, German, Spanish and Portuguese and had 7246 respondents. 6729 of these met inclusion criteria (≥ 18 years old; self-reported endometriosis diagnosis by surgery or imaging) covering most regions of the world (Europe: n=4502; North America: n=973; Latin America and Caribbean: n=662; Oceania: n=379; Asia: n=35; Africa: n=28; Unknown: n=150).

Overall, 80.7% (95% CI [79.7, 81.6]) reported an impact on their current or planned treatments. Based on enquiries to Endometriosis UK and what we were hearing clinically, we had expected many challenges with accessing medications especially injectables. However, 64.6% reported no impact of the pandemic on the availability of their usual treatments for endometriosis (n=4267). Although 20.3% (n=1337) did report difficulty obtaining repeat prescriptions, 10.5% having to change their hormone and/or painkiller (4.5% and 7.0% respectively), whilst 9.5% had to stop a medication altogether (hormones: 3.4%; painkillers 6.6%). The impact on planned care was much greater: 50.0% of responders reported cancelled/postponed appointments with gynaecologists and 14.7% described cancelled/postponed primary care appointments; 37.2% had procedures cancelled/postponed (surgery: 27.0%; fertility: 12.0%). These proportions were similar around the world (Table 1).

Our data demonstrate the considerable impact the COVID-19 pandemic has had on the care of people around the world with endometriosis. These findings agree with studies in Urology⁷, Dermatology² and a smaller Turkish endometriosis cohort (n=261)³, suggesting a significant impact on benign services. Concerns have also been expressed about the impact on those with chronic pain, both in terms of difficulties accessing treatments including physiotherapy and psychology and the possibility of medication issues due to telephone prescribing⁸. During this second wave and as we move forwards, it is essential that we minimise the impact on those with chronic conditions. Redesigning services with the priorities of those suffering with the conditions in mind will be essential to achieving this aim.

In our survey we also asked “*During the pandemic, what one thing would be most helpful to you, relating to endometriosis?*” and “*As restrictions begin to ease and healthcare starts to go back to normal, what one thing do you think should be prioritised with regards to endometriosis?*”. Respondents considered that during the pandemic the most helpful things would be: contact with their gynaecologist (32.6%); dates booked for future surgery/fertility treatments (20.5%); and mental health support (20.3%). Improving availability of medication and contact with primary care were less popular (11.1% and 8.6% respectively). As restrictions ease, priorities are: arranging cancelled/postponed procedures (42.7%) or appointments with their gynaecologists (32.1%) and mental health support (13.0%). Considerably less chose medication availability (5.3%) or primary care appointments (3.8%). Figure 1 illustrates how similar these priorities were around the world.

It was notable that the top three priorities during and immediately after the pandemic were remarkably consistent around the world. Given how rapidly telemedicine has been adopted globally, it should not be a challenge to arrange contact between patients and their gynaecologists by either telephone or video. However, this does necessitate gynaecologists being available to provide this service and argues against them being redeployed to cover emergency services as commonly occurred during the height of the first wave.

We do not believe that primary care appointments should be recommended as a substitute for gynaecology appointments. These are clearly not the priority for those with endometriosis and primary care services have been placed under considerable pressures during the pandemic⁹. Whilst little can be done to reduce waiting times for procedures (both surgical and fertility treatments), we should at least be open with patients, giving a realistic timeframe in which we expect to be able to offer these.

Although these first two priorities were not surprising, we did not expect to see such a high proportion prioritising mental health over and above all other aspects of their endometriosis care. There has been an increasing focus on comorbid mental health conditions in people with endometriosis over recent years, including two high profile UK investigations^{10, 11}, yet guidance on the management of the condition does not reflect this. Whilst the pandemic continues, mental health support can be delivered virtually, both standalone and in the context of pain management¹². However, this is one change we believe should continue for the long-term and therefore investment in psychology, ideally embedded within gynaecology services, will be essential. Integrating mental health support into the standard of care for endometriosis could be one positive to come out of this pandemic and might be expected to have a real impact on quality of life.

Finally, we were concerned to see that more than half of respondents worried that their endometriosis makes them more vulnerable to COVID-19 (n=3635, 54.2% 95% CI [53.0, 55.4]; only n=22 did not answer this question). This may be because the known link to altered immunological responses has been misinterpreted as endometriosis being an autoimmune condition⁷, with additional concerns for those with thoracic endometriosis. Given that so far there is no evidence to support this belief, we consider it essential that clinicians address this issue with their patients, and education campaigns should be considered. Worries about their vulnerability to COVID-19 may add to the feelings of threat experienced during the pandemic and thus contribute to worsening mental health.

In conclusion, COVID-19 has clearly had a devastating effect on health and healthcare around the world. At least in the initial phases, those with chronic conditions (including endometriosis) experienced a significant impact on their care, the longer-lasting effects of which remain to be determined. Moving forwards, it will be essential to take patient priorities into consideration as financially-strained healthcare providers redesign their services. We hope that this additional evidence of the desire for support with mental health in combination with other work highlighting this as an area of real need leads to a sustained change in the availability of psychologists within gynaecology services.

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Contribution to authorship

KV conceived the study. EC, CL, CB, AI, BM, MK, KG, EE, EF, KZ AND KV designed the study including translations. LD, CB, AI, BM and MK analysed the data. KV drafted the manuscript. All authors contributed to revising the manuscript.

Disclosure of interests

There are no competing interests directly relevant to this work. Completed ICMJE disclosure of interest forms for each author are available.

Ethics approval

The study was approved by the University of Oxford Central University Research Ethics Committee approval reference: R69636/RE001.

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Alterations to treatments	Global (N= 6603)		Europe (N= 4433)		Oceania (N= 374)		North America (N= 961)		Latin America and Caribbean (N= 649)	
	No.	%	No.	%	No.	%	No.	%	No.	%
No impact	4267	64.62	2898	65.37	231	61.76	597	62.12	419	64.56
Difficulty with repeat prescriptions	1337	20.25	853	19.24	105	28.07	205	21.33	127	19.57
Change hormone treatments	295	4.47	207	4.67	9	2.41	42	4.37	25	3.85
Change painkillers	459	6.95	331	7.47	29	7.75	50	5.20	34	5.24
Stop hormone treatments	222	3.36	150	3.38	7	1.87	24	2.50	32	4.93
Stop painkillers	434	6.57	295	6.65	26	6.95	55	5.72	44	6.78
Alterations to planned treatments	Global (N= 4943)		Europe (N= 3266)		Oceania (N= 264)		North America (N= 676)		Latin America and Caribbean (N= 587)	
	No.	%	No.	%	No.	%	No.	%	No.	%
Gynaecologist appointments cancelled/postponed	2473	50.03	1696	51.93	88	33.33	294	43.49	321	54.68
GP appointments cancelled/postponed	726	14.69	455	13.93	27	10.23	121	17.90	96	16.35
Surgeries cancelled/postponed	1333	26.97	840	25.72	112	42.42	222	32.84	128	21.81
Fertility treatments cancelled/postponed	591	11.96	400	12.25	25	9.47	75	11.09	76	12.95

\protectTable

Table 1. Alterations to current and planned treatments. Global and regional results for Europe, Oceania, North America, Latin America and Caribbean to the questions “Has the pandemic altered the availability of your treatments for endometriosis?” and “Has the pandemic altered your planned treatments relating to endometriosis?”. For clarity, the table include answers that had more than 5% frequency. Regions are defined as per WHO recommendations (<https://www.ghsindex.org/>). Data presented as frequencies (No.) and percentages (%). Percentages are calculated using the number of responders in each region for each question as denominator.

Figure Legend

Figure 1. Regional results for: **(a) Priorities during the pandemic.** Regional results for Europe (N=4398), Oceania (N=370), North America (N=939), Latin America and Caribbean (N=642) to the question “During the pandemic, what one thing would be most helpful to you, relating to endometriosis?”. **(b) Priorities as restrictions ease.** Regional results for Europe (N=6334), Oceania (N=370), North America (N=951), Latin America and Caribbean (N=649) to the question “As restrictions begin to ease and healthcare starts to go back to normal, what one thing do you think should be prioritised with regards to endometriosis?”. For clarity, the graphs include answers that had more than 2% frequency. Regions are defined as per WHO recommendations. Data presented as frequencies (No.).

