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“I’m in iso all the time anyway”: A mixed methods study on the impact of COVID-19 on women with endometriosis

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ABSTRACT

Objective: The COVID-19 pandemic has resulted in restrictions and social isolation measures, which carry mental health risks. Cancellation of surgery and appointments, medication shortages and fear of the virus itself may have further challenged wellbeing. We aimed to understand how COVID-19 has affected people with endometriosis. **Methods:** Using a mixed methods design, we examined; 1) the impact of COVID-19 on endometriosis related healthcare, symptoms and functioning; and 2) the relationship between a measure of fear of COVID-19 and qualitative impact in 162 women with endometriosis. **Results:** We found that 60% of women reported impact of the pandemic upon healthcare, with sub-themes documenting the difficulty of cancelled and delayed treatment, specific COVID-19 barriers, and the advantages and disadvantages of telehealth. Only 23% reported negative impact on symptoms, specifically stress; 76% reported impact on daily functioning, with sub-themes related to compromised work, social life and healthy living. A ‘hidden benefits’ theme revealed ways that COVID-19 had improved some women’s lives, including working from home, and the opportunity for healthy lifestyle choices. Logistic regressions revealed that fear of COVID-19 significantly predicted impact themes (healthcare odds ratio = 0.93, 95% confidence interval: 0.87–0.98; symptoms odds ratio = 0.88, 95% confidence interval: 0.82–0.95; functioning odds ratio = 0.92, 95% confidence interval: 0.85–0.99). **Conclusion:** Our findings indicate the need to provide patients with supportive care during pandemic restrictions that leverage self-management strategies.

1. Introduction

COVID-19 has swept the world, resulting in lockdowns and unprecedented fear about health. The Australian government regimes of social distancing have slowed the rate of infection, but presented risks, including to mental health [1] and reduced access to routine healthcare [2,3]. The pandemic and associated restrictions may particularly impact those with chronic health conditions, such as endometriosis, due to their reliance on frequent medical and allied health consultations, pain and fertility-related surgery, and regular use of painkillers [4]. During the strictest stages of Australia’s restrictions, outpatient appointments were reduced, cancelled or moved to telehealth, non-urgent surgery was halted, and worldwide medication shortages may have created anxiety around access to painkillers [4]. In addition, patients may be concerned about whether endometriosis, a chronic inflammatory condition, places them at high-risk of COVID-19 complications [5]. Consequently, COVID-19 may have substantially impacted the wellbeing of those with

endometriosis, over and above the negative effect of restrictions and isolation faced by the general community.

Fear of COVID-19 is an emerging concept that encapsulates the fears, worries and anxieties that people may have related to the pandemic [6]. A recent online survey in Turkey ($n = 261$) reported over 80% of people with endometriosis are afraid of endometriosis-related problems during the pandemic, and more than half felt the management of their endometriosis was negatively impacted during the pandemic [5]. Given the link between increased stress and endometriosis symptoms, especially pain [7,8], there is an urgent need to understand the experiences of those with endometriosis during COVID-19, including fear of COVID-19. The Australian perspective is as yet unexplored in this context, and particularly worthy of focus. Much of the population was primed for stress before the onset of the pandemic, having endured bushfires, and then experiencing one of the strictest COVID-19 lockdowns in the world.

Even before the emergence of bushfires and a pandemic, people with endometriosis endure substantial hardship, often experiencing years of

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pain, stigma and challenges in diagnosing and managing their condition. Affecting one in nine girls, women and non-binary people [9], the condition is both common and debilitating, associated with complex symptoms, such as pain, fatigue, and infertility that substantially compromise quality of life [10]. Delays in diagnosis, which can take as long as 10 years [11], and the lack of a cure, mean that people with endometriosis already live with considerable physical, psychological and social burden [12].

The aim of the present exploratory study was to understand the impact of COVID-19 on Australian women with endometriosis, including how the pandemic and associated restrictions had affected healthcare, symptoms and functioning. Given the unprecedented demands of COVID-19, qualitative work is necessary to explore the impacts upon health and functioning by giving voice to those directly impacted. A qualitative approach allows for the inclusion of unexpected findings and a broad range of experiences. Although it is likely that COVID-19 represents additional risk to wellbeing [4], we sought to remain open to a range of experiences and therefore explored people's experiences without restricting our inquiry to testing specific hypotheses. Employing an inductive approach, which allows data to speak for themselves, the present study therefore aimed to document the potentially myriad ways that COVID-19 impacted access to healthcare, symptoms and daily functioning. Using a mixed methods design, we also aimed to examine the role of COVID-19 fear in women's experiences.

2. Method

2.1. Design

This study was part of a longitudinal examination of women with dysmenorrhea and endometriosis [13]. The present study is focused on the qualitative data obtained during the second wave of data collection during 29th June- 12 August 2020. Given the emergence of COVID-19 during 2020, we added COVID-19 questions to understand how the pandemic and associated restrictions were impacting women. The study was approved by the University Human Ethics Advisory Group (HEAG-H 10_2019).

A critical realist approach was applied. This approach argues that research is not independent of the researchers' perspective but there is a reality to observe and describe [14,15]. Within this approach, a descriptive theoretical framework, which aims to "summarize events in the everyday terms of those events" was employed [16,17]. An inductive approach was taken, where we allowed the data to guide the emergence of themes.

The data for the present study were derived from three open ended questions that required a short-answer text response: "What impact, if any, does COVID-19 have on your access to healthcare?"; "What impact, if any, does COVID-19 have on your symptoms?"; "How does COVID-19 impact your daily functioning?"

2.2. Recruitment

An online link to the initial survey conducted in 2019 was distributed via University forums, social media sites (e.g. Facebook), and e-mails to members of women's gyms using a study advertisement flyer. Women who agreed to be contacted for a longitudinal survey were sent a link via email for the 12-month survey in June 2020, a time when many individuals were navigating social restrictions/isolation restrictions and lockdown measures. The online link directed participants to a web-based survey created using Qualtrics (www.qualtrics.com). Participants were offered the chance to win 1 of 10 \$50 vouchers.

2.3. Participants

Eligible participants were women aged 18–50 living in Australia, who self-reported experiencing a period in the past 12 months. In the

baseline survey, which has been described previously [13], 532 women self-reported as having endometriosis. Over 90% reported their diagnosis via laparoscopy ($n = 148$; 91%); 5% via pelvic exam ($n = 8$), and 2.5% via ultrasound ($n = 4$); 2 participants did not specify. This approach is consistent with methods used in previous cross-sectional surveys [19]. Of the 532 women who completed the baseline survey, 423 gave consent for the 12-month survey and were contacted via email to complete the 12-month survey. A total of 162 women responded to the open-ended COVID-19 questions and were included in the present study.

2.4. Measures

2.4.1. Demographics

A demographic questionnaire was used at baseline and 12-month follow-up. Some variables were only collected at baseline, including resident state, age, marital status and ethnicity. Data on employment and parous status were collected at the 12-month follow-up survey.

2.4.2. Menstrual pain severity

A single-item Numerical Rating Scale (NRS) was used to assess menstrual pain severity [20]. Participants were asked to rate on an 11-point scale from 0 (no pain) to 10 (worst pain possible) 'what is your usual level of pain during your period (without any pain medicine)?' The NRS has good construct validity and extensive use in women with menstrual pain [20,21]. Consistent with previous approaches, dysmenorrhea can be considered mild (scores 1–4), moderate (scores 5–7) and severe (scores 8–10) [22].

2.4.3. Fear of COVID scale

A self-report 7-item measure of pandemic fear [6]. Participants responded on a five-item scale ranging from 1 (strongly disagree) to 5 (strongly agree). Example items: 'It makes me uncomfortable to think about coronavirus-19'; 'I am afraid of losing my life because of coronavirus-19.' The total score ranges between 7 and 35, with a higher score indicating more fear. A cutoff of 16.5 points predicts anxiety, health anxiety, and posttraumatic stress symptoms; with scores below 16.5 indicating normal fear reactions [23]. The scale has good reliability and validity [6,24,25]. The scale was found to have a high reliability index (7 items; Cronbach's $\alpha = 0.90$) in the present study.

2.5. Data analysis

For the qualitative data, template thematic analysis was used to understand patterns of meaning across the texts [26]. This technique allows for structure early in the analysis, including the development of a coding book before detailed analysis and the development of early themes. Template thematic analysis involves a series of six steps including: 1) familiarization with the data (SE, AMW, CD); 2) preliminary hand coding (SE); 3) organization of emerging themes into clusters; 4) the development of a coding template; 5) the iterative modification of the coding template, which was achieved by hand coding 20% of the data; a final template was produced to capture all relevant sections of the text; 6) and finalization of the template to code the entire dataset. The entire dataset was then hand coded in excel (SE). Double coding of 20% of the data was then undertaken (AMW, CD), with any discrepancies discussed and resolved. The final list of themes was generated via discussion with the research team. Frequency counts for the main themes related to impact on healthcare, symptoms, and daily functioning were computed. Sub-themes were illustrated with quotes to provide context to themes. The responses of even one or two patients can hold key insights for improving clinical care [27], and experience in words, rather than numbers, was prioritized in sub-themes.

Quantitative and qualitative data were combined to undertake a mixed methods analysis to understand predictors (sociodemographic and endometriosis variables, and fear of COVID-19) of themes, using

binary logistic regression. Categorical variables were recoded into dummy variables (e.g, given that Victoria -unlike other Australian states- had just entered into a second lockdown, resident of Victoria = 1, resident of other states = 0).

3. Results

Demographic information is presented in Table 1. Participants represented a relatively wide range of sociodemographic backgrounds, had lived with pain for many years ($m = 16.1$ years, $SD = 6.8$), with moderate pain ($m = 7.18$, $SD = 1.89$). The majority (76%) did not have children, and were relatively young (mean age = 30 years old).

Notably, 43% lived in Victoria, which was entering its second lockdown at the time of the survey. Despite 25% having been tested for COVID-19, no participants had tested positive to the virus. Participants' fear of COVID-19 scores was relatively high ($m = 16.23$, $SD = 5.83$). Seventy-three participants (45%) scored higher than the cut point of 16.5, demonstrating clinically concerning levels of COVID-19-related fear.

3.1. Themes

We derived four themes, relating to healthcare, symptoms, daily functioning, and hidden benefits. A number of sub-themes were also identified, demonstrating distinct aspects of impact. Supporting quotes for each sub-theme are summarised in Table 2. Participants are

Table 1
Demographic data, menstrual pain and fear of COVID-19 in women with endometriosis.

| | Women with Endometriosis (n = 162) |
|---|------------------------------------|
| Mean ± SD (range); number (%) | |
| Age | 30.8 ± 7.1 (18–50) |
| Menstrual pain duration (years) | 16.1 ± 6.8 (2–35) |
| Parous | 38 (24%) |
| Tested for COVID-19 | 41 (25%) |
| Tested positive for COVID-19 | 0 (0%) |
| Employment status | |
| Full time | 67 (41%) |
| Part time | 40 (25%) |
| Student | 17 (11%) |
| Home-maker | 8 (5%) |
| Self-employed | 5 (3%) |
| Unemployed | 15 (9%) |
| Ethnicity ^a | |
| English | 135 (83%) |
| European | 42 (26%) |
| Chinese | 1 (1%) |
| Indian | 3 (2%) |
| Other Asian | 3 (2%) |
| Other | 3 (2%) |
| Marital status ^a | |
| Single | 65 (40%) |
| Married | 86 (53%) |
| Divorced | 4 (3%) |
| Separated | 1 (1%) |
| Other | 3 (2%) |
| Menstrual pain severity | 7.18 ± 1.89 (1–10) |
| COVID-19 Fear | 16.23 ± 5.83 (7–35) |
| Location of main residence ^a | |
| NSW | 45 (28%) |
| ACT | 0 (0%) |
| VIC | 69 (43%) |
| QLD | 21 (13%) |
| SA | 11 (7%) |
| WA | 7 (4%) |
| TAS | 4 (4%) |
| NT | 0 (0%) |

^a Data collected at baseline.

Table 2
Themes, sub-themes and illustrative quotes.

| Theme | Sub-theme | Illustrative Quotes |
|---|---|--|
| Healthcare: interrupted but not for all | No impact: 40% | |
| | Treatment (fertility, surgery, tests, medication) | <i>It delayed my IVF treatment a few months. 45 year old with severe pain</i> |
| | | <i>I had one appointment over the phone, one of my medications I usually get two repeats of but can only get one but its not a big issue. 34 year old with severe pain</i> |
| | | <i>Surgery postponed adding 6 months to the wait list on top of 365 days Can only treat symptoms until surgery happens 26 year old with severe pain</i> |
| | Doctor's appointments | <i>I'm afraid that the hospital will just discharge me instead of taking me seriously when I need medical attention. A lot of endo patients have experienced this. 42 year old with severe pain</i> <i>My appointment has been pushed back 6 months so I will be waiting 1 year to see a gynaecologist 27 year old with moderate pain</i> |
| | Allied health | <i>There are less apps and my apps were transferred to phone appointments and no one ever called me and they have not made contact. So I am falling through the cracks of the public system again. 27 year old with severe pain</i> <i>Lack of in person appointments which was an issue when I had a problem with my IUD. 28 year old with moderate pain</i> <i>Have had to reduce pelvic physio sessions. 38 year old with moderate pain</i> |
| | COVID barriers | <i>Could not do pilates classes which were to help strengthen muscles to help reduce associated pain. 21 year old with moderate pain</i> <i>Telehealth appts are hard when you need a physical exam. I was also nervous to attend clinic. 38 year old with moderate pain</i> |
| | | <i>Prevented me from wanting to visit my doctor for a check up as I felt it wasn't important enough to risk getting myself sick or anyone else sick. 27 year old with moderate pain</i> |

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Table 2 (continued)

| Theme | Sub-theme | Illustrative Quotes |
|---|-----------------------------------|---|
| | | <i>I see my specialist in Melbourne. I live in regional Victoria so the current lockdown makes it hard, more so mentally with stress of possibly not being able to attend/being turned away. 23 year old with mild pain</i> |
| | | <i>I lost my job due to COVID-19. so, if I did want to go back to accessing healthcare right now, I wouldn't be able to afford it. 27 year old with severe pain</i> |
| | Telehealth: love it or hate it | <i>I love telehealth. It means I don't need to drag myself to a doctors office when I'm full of pain and anxious, and when I'm in the calm of my home I feel less anxious, and better able to discuss my problems with the doctor as my mind is clearer. 27 year old with severe pain.</i> |
| | | <i>Cancelled appointments. Phone appointments only and less extensive investigations than normal. 30 year old with moderate pain</i> |
| | | <i>It's actually easier for regular stuff like scripts as can do telehealth so don't need time off work. It was problematic for an issue I had a few months back where I was misdiagnosed with migraine and repeatedly only offered telehealth despite ongoing and unusual symptoms. Eventually paid privately to see a neurologist who diagnosed vestibular Neuronitis she believed which would have been picked up had someone physically assessed me. 38 year old with moderate pain</i> |
| Symptoms as usual for most | No impact: 77% | <i>I'm in iso anyway all the time anyway. My life is iso and I'm only in my thirties. 37 year old with moderate pain</i> |
| | | <i>Stress obviously causes more pain. 31 year old with severe pain</i> |
| | | <i>Greater pain due to isolation. 27 year old with severe pain</i> |
| Daily Functioning: 'Same as everyone else.' | No impact: 24% | |
| | Missing social and community life | <i>Well I cant see my family or friends so that makes it much harder. 42 year old with mild pain</i> |

Table 2 (continued)

| Theme | Sub-theme | Illustrative Quotes |
|-----------------|-----------------------|---|
| | | <i>I see less people and definitely do not go out much at all now. It's a bit depressing. 40 year old with moderate pain</i> |
| | | <i>Apart from 3 social visits in February, I have not seen any friends. Zoom is not the same - walls are thin and our catch ups are public to our households (so I'm not going to talk about period pain). 33 year old with moderate pain</i> |
| | Reduced/ loss of work | <i>It has impacted every aspect of my life - I can't see friend, I lost my job, I can't see my family as they are interstate. 38 year old with severe pain</i> |
| | | <i>Employment directly effected, but thankfully now back at work. 31 year old with moderate pain</i> |
| | Less healthy living | <i>Took away my only source of relief by taking away my sport. Woman with severe pain.</i> |
| | | <i>Working from home has decreased my physical activity and mood. 32 year old with moderate pain</i> |
| | Psychological burden | <i>It's impacted it a lot. I've felt very socially isolated. My daughter was born in February via emergency c section and stage 3 restrictions came in when I got my driving privileges back. So I was isolated with a baby for 16 weeks. It was really tough. 35 year old with mild pain</i> |
| Hidden benefits | Working from home | <i>Isolation is hard on mental health. 31 year old with severe pain</i> <i>Working from home - allows me to better-manage pain and be much more productive and comfortable. 33 year old with moderate pain</i> |
| | | <i>I have spent a lot of time at home which has allowed me to be less stressed and always have a heat pack. 21 year old with moderate pain.</i> |
| | Healthier living | <i>It's actually made things better. I've been working from home so feel much less stress and anxiety about needing to take time off & the judgement/questioning that follows as I can just work from the couch. Its also given me more time to focus on healthy eating, exercise and relaxation 28 year old with severe pain</i> |

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Table 2 (continued)

| Theme | Sub-theme | Illustrative Quotes |
|-------|-----------|--|
| | | <i>It has impacted me positively to workout more by doing online yoga and going to the gym and walks which i am proud of as motivation has always been hard for me. 24 year old with moderate pain</i> |

identified with their age and pain severity to contextualize their responses.

3.2. Healthcare: interrupted, but not for all

Almost half of participants ($n = 64$; 40%) reported that the pandemic and associated restrictions had not impacted their healthcare. However, for the 60% of participants who were affected, a range of providers and treatments were unavailable or had been compromised.

3.2.1. Treatment, tests, and appointments impacted

The main ways in which healthcare was impacted are shown in Table 1. These included fertility treatments such as IVF, reduced surgery/laparoscopy, and medication shortages (including contraception). Most responses about healthcare described reduced GP and specialist appointment availability, which was especially challenging for those already on lengthy waiting lists. Access to allied health was also compromised, including pelvic physiotherapists.

3.2.2. COVID-19 barriers

Some participants indicated that they were reluctant to seek treatment due to anxiety over catching the virus or wished to reduce non-urgent outings and/or leave appointments for more urgent cases. Direct barriers as a result of restrictions included state border closures and difficulty travelling from regional to metro areas, and barriers due to COVID-19 job loss.

3.2.3. Telehealth: love it or hate it

Telehealth elicited opposing reactions. For some, telehealth was associated with convenience. Others felt it substantially compromised their healthcare, resulting in their care 'falling through the cracks', less thorough exams, missed diagnoses, and discomfort in discussing symptoms over the phone - especially with an unfamiliar practitioner or specialist. Telehealth suited some needs (eg, prescriptions), but was a poor substitute when physical interaction was necessary. It is unknown whether telehealth with or without video was offered to women.

3.3. Symptoms as usual for most

Many participants ($n = 125$; 77%) reported that COVID-19 had not impacted their symptoms. Common responses were 'none' or 'no impact'. However, one participant wrote about isolation being her usual state, even before COVID-19. Perhaps life was relatively 'normal' during the restrictions, with challenge and isolation commonplace for some women. In that sense, COVID-19 may have highlighted the everyday disadvantage of people with endometriosis. For those reporting worsening of symptoms, stress and reduced coping strategies (such as sport, and less access to healthcare) was linked to flares in pain and other symptoms.

3.4. Daily functioning: 'Same as everyone else'

Approximately one quarter of participants ($n = 35$; 22%) reported that COVID-19 had not impacted their daily functioning - with the

majority feeling that life was now harder. There was a sense that women with endometriosis were experiencing similar hardships as 'everyone else', including missing social and community connections, reduced work and financial concerns. There was an associated impact on psychological functioning, with stress, fatigue, and symptoms of anxiety and depression reported. However, not everyone reported poorer daily functioning, as noted in the final theme on benefits.

3.5. Hidden benefits

Despite the difficulties experienced by some women with endometriosis, COVID-19 was also associated with silver linings. Twenty women (12%) wrote about positive outcomes, most notably the convenience of telehealth, and the benefits of working from home, where women could pace their working day to accommodate symptoms. The restrictions also allowed for more opportunities to rest, which women appreciated, with one participant reporting that the reduced social gatherings suited her lifestyle. Despite the pandemic resulting in unhealthy choices for some, women who reported benefits also wrote about increased opportunities to engage in healthier habits, including time to cook nutritious meals, and exercise.

3.6. Predictors of themes: mixed methods analysis

Correlations between quantitative variables (sociodemographic factors, pain duration and severity, fear of COVID-19) and the themes are shown in Table 3. Only fear of COVID-19 was significantly associated with all themes. Victorian residence was also associated with the functioning impact theme. There were no significant associations between the benefits theme and quantitative data. Therefore, only fear of COVID-19 and Victorian residence were entered as predictors of the impact themes in logistic regressions. (See Table 4.)

Results of the logistic regression examining predictors of impact themes ('no impact' coded as 0, + 'impact' coded as 1) are shown in Table 3. For the healthcare impact theme, fear of COVID-19 emerged as a significant predictor of impact, such that higher fear of COVID-19 predicted greater likelihood that women's healthcare was impacted (OR = 0.93, 95% CI = 0.87–0.98, $p = .01$). For the symptoms impact theme, fear of COVID-19 emerged as a significant predictor of impact, such that higher fear of COVID-19 predicted greater likelihood that women's symptoms were impacted (OR = 0.88, 95% CI = 0.82–0.95, $p = .001$). For the daily functioning impact theme, fear of COVID-19 emerged as a significant predictor of impact, such that higher fear of COVID-19 predicted greater likelihood that women reported their daily functioning was impacted (OR = 0.92, 95% CI = 0.85–0.99, $p = .03$). Victorian resident status was also a significant predictor of daily functioning impact, with living in Victoria significantly more likely to predict impact on daily functioning than living in other Australian states (OR = 0.31, 95% CI = 0.13–0.76, $p = .01$).

4. Discussion

The qualitative data showed that a substantial number of women with endometriosis felt their healthcare and daily functioning had been adversely impacted by COVID-19 while endometriosis symptoms were less affected. Our mixed methods analysis revealed that fear of COVID-19 predicted themes related to negative impact on healthcare, symptoms and daily functioning, while residing in Victoria - which experienced one of the strictest and longest lockdowns worldwide - predicted negative impact on functioning.

The themes related to impact provide a descriptive overview of the way in which endometriosis has been affected by COVID-19. Healthcare was negatively impacted by reduced access to appointments and pain and fertility treatment, which is consistent with worldwide disruptions to endometriosis care [4]. Women conveyed distress at what this would mean, including increased waiting times. Given the historic delays in

Table 3
Correlations between demographic and endometriosis variables, fear of COVID-19, and themes.

| | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. | 11. | 12. | 13. |
|--------------------------|---------|---------|---------|-------|---------|-------|---------|--------|--------|-------|-------|-------|-----|
| 1. Healthcare impact | 1 | - | - | - | - | - | - | - | - | - | - | - | - |
| 2. Symptom impact | 0.24** | 1 | - | - | - | - | - | - | - | - | - | - | - |
| 3. Functioning impact | 0.20* | 0.20* | 1 | - | - | - | - | - | - | - | - | - | - |
| 4. Hidden benefits | 0.00 | -0.01 | -0.06 | 1 | - | - | - | - | - | - | - | - | - |
| 5. Age | -0.02 | 0.11 | -0.01 | -0.00 | 1 | - | - | - | - | - | - | - | - |
| 6. Ethnicity (= English) | 0.03 | -0.02 | 0.07 | -0.04 | -0.14 | 1 | - | - | - | - | - | - | - |
| 7. Employed | 0.02 | 0.00 | 0.03 | -0.06 | 0.18* | -0.09 | 1 | - | - | - | - | - | - |
| 8. Married/Partner | -0.03 | 0.13 | -0.03 | -0.06 | 0.28** | 0.02 | 0.12 | 1 | - | - | - | - | - |
| 9. Children (1 = Yes) | -0.01 | 0.09 | -0.04 | -0.07 | 0.35** | -0.03 | -0.11 | 0.36** | 1 | - | - | - | - |
| 10. Postcode (1 = VIC) | -0.11 | -0.06 | -0.23** | 0.05 | -0.14 | 0.07 | -0.25** | 0.04 | 0.12 | 1 | - | - | - |
| 11. Pain severity | 0.10 | -0.07 | -0.03 | 0.02 | -0.30** | -0.00 | -0.10 | -0.20* | -0.11 | 0.03 | 1 | - | - |
| 12. Pain duration | -0.11 | 0.04 | -0.01 | 0.04 | 0.81** | -0.01 | 0.13 | 0.21* | 0.25** | -0.12 | -0.12 | 1 | - |
| 13. COVID-19 fear | -0.21** | -0.29** | -0.20* | 0.12 | -0.10 | -0.03 | -0.10 | -0.08 | 0.04 | 0.10 | 0.08 | -0.02 | 1 |

Table 4
Predictors of impact themes.

| | Healthcare impact | | | Symptoms impact | | | Daily functioning impact | | |
|--------------------|-------------------|------|-------------------|-----------------|------|--------------------|--------------------------|------|--------------------|
| | B | SE B | OR (95% CI) | B | SE B | OR (95% CI) | B | SE B | OR (95% CI) |
| Victorian resident | -0.38 | 0.34 | 0.69 (0.35–1.33) | -0.24 | 0.45 | 0.79 (0.32–1.92) | -1.16 | 0.45 | 0.31 (0.13–0.76)** |
| Fear of COVID-19 | -0.08 | 0.03 | 0.93 (0.87–0.98)* | -0.13 | 0.04 | 0.88 (0.82–0.95)** | -0.09 | 0.04 | 0.92 (0.85–0.99)* |

* $p < .05$.

** $p < .01$.

endometriosis diagnosis and treatment [11], it is likely that further delays will lead to elevated suffering, with an urgent need to address waiting lists. Telehealth was an acceptable stop-gap for some women – especially those with direct requests such as prescriptions – but many reported inadequacies, including a lack of physical exams. Of interest, prior studies on telehealth during COVID-19 have shown general patient satisfaction, with health professionals being more critical than patients [28]. It was reassuring that despite problems accessing healthcare, most women reported that their symptoms were unaffected. Some did note that stress had exacerbated symptoms, including pain, consistent with research documenting the role of stress in worsening endometriosis [7,8].

Our qualitative findings related to daily functioning suggest women with endometriosis experienced similar disruptions to life tasks as the general community, including loss of work, social connections, healthy lifestyle habits, and associated feelings of worry, depression, and isolation [3]. We found an important theme related to benefit finding; notably, working from home enhanced well-being. Women could continue working when they might ordinarily need to call in sick, by taking rest breaks, not needing to ‘hide’ their pain, and using pain relieving strategies in the privacy of their own home. The benefit of working from home in managing a chronic health condition is perhaps an unexpected outcome. Some women also reported COVID-19 had prompted healthier lifestyles, including exercising, which has been shown to boost mental health during COVID-19 [29]. In addition to outdoor exercise as permitted, appropriate home-based exercise has been recommended during lockdowns, including exergaming, dancing and yoga, with app-based technology supporting training [30].

Research with Australian parents and families during the pandemic has similarly found a range of experiences, from considerable hardship to the emergence of silver linings [3]. These mixed findings highlight the importance of remaining open to a range of experience, and using qualitative work to understand such an unprecedented event. Overall, our qualitative data indicate that people with endometriosis are facing the same hardships as the rest of the community, in addition to specific hardships related to managing their chronic health condition. Underlying many responses was a sense of worry and hesitance, including reluctance to seek care.

Our use of a quantitative measure, the fear of COVID-19 scale,

triangulates these worries. Women displayed high levels of worry about the virus, with almost half reporting clinically elevated fear. We did not include a comparison group, so it is difficult to gauge whether this is representative of the Australian population, or specific to people with a chronic health condition. Given that endometriosis is associated with mental health issues, such as anxiety and depression [10], it is possible that baseline levels of distress – compounded with concerns over whether endometriosis as an inflammatory condition may be a risk factor for COVID-19 complications - resulted in heightened worry.

Australia has handled the COVID-19 pandemic relatively well, with new cases generally in managed quarantine from overseas travellers. Perhaps that is why Australians with endometriosis reported minimal impact on symptoms, with almost half also feeling their healthcare was not adversely affected. However, fear of COVID-19 scores were high, indicating lingering worry. Given Australia’s strict lockdowns, paired with paused healthcare and minimal support during a stressful time, fear of COVID-19 may be a natural response. Interestingly, residing in Victoria (the only state in Australia to experience a second lockdown, which occurred during data collection) predicted adverse impact on daily functioning, but not healthcare or symptom impact.

Our mixed methods findings demonstrate a relationship between fear of COVID-19 and women’s perceptions of their healthcare, symptoms and daily functioning, such that high levels of fear were associated with perceived difficulties. Women who have faced barriers in their healthcare, worsening symptoms and lost work and social connections may have come to fear the virus. One important limitation, however, is our cross-sectional design, which precludes definitive conclusions about whether such barriers lead to fear of the virus, or whether feeling anxious about COVID-19 leads to poor perceptions of healthcare, symptoms and function. Other limitations include lack of healthcare provider data, and lack of inclusion of transgender and non binary people with endometriosis. It is also possible that data collected at baseline (eg Victorian residence) may have changed within the last 12 months.

5. Conclusions

Our findings have implications for clinical care, including addressing waiting lists, which women reported as being 12-months or longer pre

pandemic. Telehealth seems to be beneficial for shorter and less complex appointments and may continue to be used alongside face-to-face appointments according to patient preference. Telehealth appointments with general practitioners may be used to support physical and mental health, such as by helping patients to problem solve how they can fulfil their physical activity needs despite restrictions. Upskilling patients about the importance of self-care including exercise, nutrition and stress reduction early in care would help to promote patient self-efficacy, which could be leveraged during lockdowns such that patients feel less reliant on healthcare providers for relief. Promoting endometriosis guidelines, as well as key publications addressing evidence-based self-management strategies [4], are critical to supporting the holistic care of patients with endometriosis, during and after COVID-19. Working from home emerged as a substantial benefit, and people with endometriosis should be able to continue working from home post COVID-19 to support their workplace functioning. Finally, ensuring the delivery of high quality telehealth, clear dissemination of evidence-based self-management strategies [4], and quick resumption of care should help to alleviate patients' fear of COVID-19.

Conflicts of Interest

None.

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