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OPINION

Self-management strategies to consider to combat endometriosis symptoms during the COVID-19 pandemic

Mathew Leonardi [1,2,3,*], Andrew W. Horne [4], Katy Vincent [5], Justin Sinclair [6], Kerry A. Sherman [7], Donna Ciccia[8], George Condous [1,2], Neil P. Johnson[9,10,11], and Mike Armour [6,12]

[1]Acute Gynaecology, Early Pregnancy, and Advanced Endoscopy Surgery Unit, Nepean Hospital, Kingswood, Australia [2]Sydney Medical School Nepean, University of Sydney, Sydney, Australia [3]Department of Obstetrics and Gynecology, McMaster University, Hamilton, Canada [4]MRC Centre for Reproductive Health, University of Edinburgh, Edinburgh, UK [5]Nuffield Department of Women's and Reproductive Health, University of Oxford, John Radcliffe Hospital, Oxford, UK [6]NICM Health Research Institute, Western Sydney University, Penrith, Australia [7]Department of Psychology, Centre for Emotional Health, Macquarie University, North Ryde, Australia [8]Endometriosis Australia, Sydney South, Australia [9]Robinson Research Institute, University of Adelaide, Adelaide, Australia [10]Department of Obstetrics and Gynaecology, University of Auckland, Auckland, New Zealand [11]Auckland Gynaecology Group and Reprimed Auckland, Auckland, New Zealand [12]Translational Health Research Institute (THRI); Western Sydney University, Penrith, Australia

*Correspondence address. Acute Gynaecology, Early Pregnancy, and Advanced Endoscopy Surgery Unit, Sydney Medical School Nepean, Nepean Hospital, University of Sydney, Sydney 2747 NSW, Australia. Tel: +61 2 4734 4777; Fax: +61 2 4734 4887;
E-mail: mathew.leonardi@sydney.edu.au https://orcid.org/0000-0001-5538-6906

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ABSTRACT: The care of patients with endometriosis has been complicated by the coronavirus disease 2019 (COVID-19) pandemic. Medical and allied healthcare appointments and surgeries are being temporarily postponed. Mandatory self-isolation has created new obstacles for individuals with endometriosis seeking pain relief and improvement in their quality of life. Anxieties may be heightened by concerns over whether endometriosis may be an underlying condition that could predispose to severe COVID-19 infection and what constitutes an appropriate indication for presentation for urgent treatment in the epidemic. Furthermore, the restrictions imposed due to COVID-19 can impose negative psychological effects, which patients with endometriosis may be more prone to already. In combination with medical therapies, or as an alternative, we encourage patients to consider self-management strategies to combat endometriosis symptoms during the COVID-19 pandemic. These self-management strategies are divided into problem-focused and emotion-focused strategies, with the former aiming to change the environment to alleviate pain, and the latter address the psychology of living with endometriosis. We put forward this guidance, which is based on evidence and expert opinion, for healthcare providers to utilize during their consultations with patients via telephone or video. Patients may also independently use this article as an educational resource. The strategies discussed are not exclusively restricted to consideration during the COVID-19 pandemic. Most have been researched before this period of time and all will continue to be a part of the biopsychological approach to endometriosis long after COVID-19 restrictions are lifted.

Key words: endometriosis / pelvic pain / COVID-19 / coronavirus / self-management / self-care / mind-body therapies / counseling / lifestyle management / psychology

Introduction

The coronavirus disease 2019 (COVID-19) pandemic, and the resultant required self-isolation, is having a huge impact on the care of patients with endometriosis worldwide. With the support of several gynecological associations (AAGL – Elevating Gynecologic Surgery, 2020), many medical centers have temporarily stopped offering surgical management for endometriosis. Similarly, many outpatient appointments for endometriosis with family physicians, gynecologists, fertility specialists and/or other allied healthcare

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WHAT DOES THIS MEAN FOR PATIENTS?

This is an article that aims to help patients with endometriosis-related pain symptoms through the difficult obstacles posed by coronavirus disease 2019 (COVID-19). Across the world, care for patients with endometriosis has changed dramatically: patients may be unable to visit their doctors or allied healthcare providers in person or obtain imaging tests, surgery or fertility treatments. Patients with endometriosis may be experiencing increased stress during this time.

In addition to the more typical treatments for endometriosis, such as drug treatments or surgery, it is widely accepted that complementary or alternative treatments should be used. We encourage patients and healthcare providers to more strongly consider using these strategies at this time. Some examples of those that aim to directly target the problem of endometriosis-related pain are improving sleep hygiene, low-intensity physical activity (including pelvic exercises, yoga), dietary changes, application of heat and medical cannabis. Other examples target the emotional aspect of endometriosis-related pain and these include relaxation/mindfulness, acceptance of chronic illness (e.g. via Acceptance and Commitment Therapy (ACT)) and improving a balance toward positive attitude.

Some patients may already be using these strategies during normal times, but many will not have been counseled on them or advised to use them. Some of these strategies could be implemented directly by patients whilst others may require the guidance of healthcare providers through telephone and online avenues. Initiating any of these strategies now to combat endometriosis symptoms may prove beneficial for patients and may encourage ongoing use once life gets back to normal.

professionals (e.g. physiotherapists, psychologists, dieticians) have been canceled or postponed. In addition, the International Society of Ultrasound in Obstetrics and Gynecology has recommended postponing ultrasound evaluation of non-acute pelvic pain (Bourne *et al.*, 2020). In addition to the effects of restrictions on healthcare services, patients with endometriosis, like everyone else, are at risk of negative psychological effects from mandated self-isolation (Brooks *et al.*, 2020). To offset the direct healthcare obstacles, we hope that as much as possible, patients are still able to connect with their healthcare providers by telephone or virtually online. We encourage healthcare providers and patients alike to consider medical management options that they have not yet trialed and that are within reach during this period of self-isolation despite the closure of services they may otherwise access. In combination with medical therapies or as an alternative, we encourage patients to consider self-management strategies that may be effective in combating the negative physical or psychological effects triggered by COVID-19 restrictions. The importance of integrating self-management strategies into the broad biopsychological approach to endometriosis is not novel (Buggio *et al.*, 2017) nor will it be exclusively relevant during this time. The necessity of long-term and multimodal treatments for endometriosis, including the self-management strategies described here, means the usefulness of the content of this article will extend beyond the current situation. We have therefore prepared the following expert opinion-based guidance on self-management strategies for patients to consider using during self-isolation and beyond (Table I).

Problem-focused strategies

Research in psychology provides a useful framework for understanding how an individual with endometriosis will respond to a serious health threat such as COVID-19. The transactional model of stress and coping (Lazarus and Folkman, 1987; Folkman and Moskowitz, 2004) indicates that the way any person adapts to this kind of stressor varies according to how they think about the stressor and the actions and behaviors they initiate to manage the demands of the situation; that is, the pain and challenges of living with endometriosis (Folkman and Moskowitz, 2004). If one adopts active, engagement coping strategies (Kvillemo and Bränström, 2014), such as problem-solving, information-seeking, acceptance, seeking support and planning, one is more likely to effectively cope with the ongoing stresses of living with endometriosis. On the other hand, disengagement coping strategies that focus attention away from thoughts and feelings about endometriosis, such as denial, substance use and self-blame, are likely to heighten feelings of being out of control and being distressed (Dijkstra and Homan, 2016). Women with endometriosis often use both problem- and emotion-based coping strategies (Roomaney and Kagee, 2016). Women with endometriosis who engage in positive, problem-focused coping strategies report lower stress levels and less depressive symptoms, which results in less non-cyclical pelvic pain and dysmenorrhea compared to those with maladaptive coping strategies (Donatti *et al.*, 2017). The key here is for individuals with endometriosis to adopt self-management and self-care strategies that will enhance feelings of being in control and minimize feelings of worry in the face of the additional serious health threat of COVID-19. While medical and/or surgical intervention in endometriosis may be effective (Leonardi *et al.*, 2020), they are not a 'magic bullet' and do not stand alone. Encouragement from healthcare providers to implement other self-management strategies should improve the confidence patients have in those strategies. Below, we review a series of active and self-directed strategies that may assist in coping with endometriosis in the face of COVID-19.

Education about endometriosis

Having a coherent understanding of endometriosis is an important step in being able to effectively self-manage this condition, as is the case with other chronic diseases such as diabetes and heart disease (Griva *et al.*, 2000; Weinman *et al.*, 2000). While awareness of endometriosis is building amongst the general population thanks to efforts by advocacy organizations and academics working in the field, endometriosis remains an enigmatic disease. Many patients learn of the word 'endometriosis' at the time of consultation with their healthcare provider as a possible explanation for their

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Table I Self-management strategies for patients with endometriosis to consider using during self-isolation and beyond, and recommendation statements.

Strategy	Recommendation
Problem-focused strategies	
Education about endometriosis	Patients could access information from reputable organizations that have demonstrated clear dedication to advancing the care of those with endometriosis.
Managing work and study	Patients could be honest with employers/educators about anticipated and possibly unanticipated episodes of pain.
	Patients could discuss modifications of work/school obligations during times of pain exacerbation, if appropriate.
Social activities	Patients should make a strong effort to maintain social activities (in the context of current isolation rules).
	Patients could use video conferencing applications, social media portals or websites to best replace their typical social activities.
Social support	Patients should consider connecting with their social supports by video link instead of messaging or the telephone.
	Patients could consider joining online endometriosis support groups.
Sleep	Patients should talk to their family physician/general practitioner about dysfunctional sleep or improving sleep before initiating over-the-counter treatments.
Physical exercise	Patients could initiate or maintain exercise based on their personal experiences and take a graduated approach to increase physical activity.
	Patients could access a large selection of online material to support exercise activities.
Yoga	Patients could initiate or maintain an at-home yoga program, guided by online material.
Pelvic exercise and physiotherapy	Patients could consider at-home pelvic exercises but should do so with caution and most ideally with the past/current guidance of a physiotherapist.
Diet	Patients could consider trialing modifications in their diet. Possible considerations include: anti-inflammatory diet; gluten-free diet; low FODMAP diet.
Heat	Patients could consider trialing stick-on heat patches that provide a stable temperature for long durations (8–12 h at a time).
Cannabis	Patients could consider medicinal cannabis as a potential option if they live in a location with legal access.
Emotion-focused strategies	
Relaxation and mindfulness	Patients should consider trialing relaxation, breathing exercises and mindfulness.
	Patients could access online material to support relaxation through websites or smartphone applications.
Acceptance and commitment therapy	Patients could consider self-initiating aspects of Acceptance and Commitment Therapy using online resources. Alternative methods to learn how to 'accept' endometriosis could be utilized.
Adopting a positive attitude	Patients could consider self-initiating the process of learning to adopt a positive attitude using online resources and social support (e.g. online endometriosis groups).

FODMAP, fermentable oligosaccharides, disaccharides, monosaccharides, and polyols.

symptoms. Patients may be given a diagnosis following clinical assessment (Agarwal *et al.*, 2019), imaging (Nisenblat *et al.*, 2016) or surgery (Wykes *et al.*, 2004). Depending on how they receive a diagnosis and by whom they are diagnosed, the information they receive may be inconsistent and ambiguous. Endometriosis education in schools has recently been introduced in some countries to raise awareness early and standardize messaging (Bush *et al.*, 2017), but this has not been successfully attempted with adults. The tangible nature of endometriosis means that education is often focused on what can be seen (i.e. endometriosis deposits, endometriomas) rather than on the invisible downstream effects like chronic pelvic pain and central sensitization.

Learning more about endometriosis independently has been useful for some individuals (Roomaney and Kagee, 2016). Education on the role of the nervous system in endometriosis would be helpful for patients to understand how the various non-medical and non-surgical treatments may be useful. Knowing how and where to access patient-friendly information can be challenging.

Recommendation

Beyond the education delivered to patients directly by healthcare providers, we recommend guiding patients to reputable organizations that have demonstrated clear dedication to advancing the care of individuals with endometriosis. For some during self-isolation due to COVID-19, there may be more opportunities to educate themselves and so this should be especially encouraged. Sources of education may include university websites, where 'Information for patients' can be found (EXPPECT, 2020a) or other reputable sources, such as regional or national advocacy organizations, which often involve collaboration between healthcare providers and patient representatives (Endometriosis Australia, 2020; Endometriosis New Zealand, 2020; Endometriosis UK, 2020; The Endometriosis Network Canada, 2020).

Work and study

During normal circumstances, episodes of escalated pain (frequently often associated with the menstrual cycle) lead to an inability to complete work/school obligations resulting in loss of productivity (Soliman

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et al., 2016). Working from home (WFH) or attending school virtually has become a new normal for many individuals. This may create unfamiliar challenges for reporting sickness that limits one's ability to complete work/school obligations. People may be sensing a change in attitude on what warrants a 'sick day' since WFH no longer requires commuting or the same degree of human interaction.

Recommendation

During this unprecedented time, we should endeavor to be empathetic of new obstacles (e.g. WFH with children, exacerbations of mental health issues, the necessity to devote extra time to ensuring financial stability) that may lead to difficulty fulfilling typical obligations. Honesty with employers and educators about anticipated and possibly unanticipated episodes of endometriosis-related pain may help to set expectations and decrease anxiety when it is necessary to request a sick day (Roomaney and Kagee, 2016). This period of time could also be an opportunity to discuss modifications of work/school obligations during times of pain exacerbation, if appropriate, and deemed possible by the person experiencing the troublesome symptoms. As a positive, it may demonstrate that removing the commute and having a comfortable environment allows the woman to be adequately productive, meaning a sick day is not required.

Social activities

During normal circumstances, episodes of escalated pain (or associated menstrual symptoms) or the development of chronic pelvic pain may necessitate social isolation (Mellado et al., 2016). In the past, social activities, such as going to the theatre, having coffee with friends or hosting a games night, might have been canceled or postponed due to pain. Now, during mandatory social isolation, these activities and others are no longer viable. While social isolation is being mandated broadly globally due to COVID-19 and this might seem advantageous to those with endometriosis, isolation is recognized as a contributor to psychosocial issues, especially amongst those who are vulnerable (Usher et al., 2020). A frequent strategy for those suffering from endometriosis is to schedule social events during more reliable periods of decreased or no pain.

Recommendation

More than ever, making a concerted effort to maintain social activities (in the context of current isolation rules) is vital. Using video conferencing applications and social media portals should be considered as a replacement for in-person gatherings. Many arts and culture organizations are providing access to material online. For those living with others, honesty about when and why they may be able or unable to socialize could be helpful. As a positive, this experience may teach us ways to connect that do not require leaving the house, which may facilitate a greater sense of social connectivity for women unable to leave the house in the future due to endometriosis-associated symptoms.

Social support

During the pandemic, social support networks will undoubtedly change in appearance, but their function and critical importance to help with coping with the dual stressors of endometriosis and COVID-19 should not be underestimated. The World Endometriosis Society has long espoused the value of endometriosis support groups in providing a valuable forum for mutual sharing of experiences and quality of life improvement through teaching coping mechanisms (Johnson and Hummelshoj, 2013). As noted above, utilizing technology to fill the void of in-person social interaction will be essential. However, there is an increasingly common belief that social media use is negatively associated with health-related outcomes (Shakya and Christakis, 2017). While there is certainly evidence for a concerning association, there is a suggestion that how one uses social media matters more than the quantity of use (Bekalu et al., 2019; Killam, 2020).

Recommendation

If possible, patients should consider connecting with their social supports by video instead of messaging or the telephone. This method of communication allows for the next best thing to in-person interaction. There is also a plethora of established online support through social media websites such as Twitter and Facebook. An example is the 'Endometriosis Australia' Facebook page, which is, in part, a social network for those living with endometriosis where they may get the emotional support they need from others who similarly suffer from endometriosis (Endometriosis Australia, 2020). Similar groups may exist locally and patients can be pointed in the direction of their local or national endometriosis advocacy organization.

Sleep

Sleep plays an important role in regulating an individual's quality of life and social, emotional and physical well-being. Dysfunction in the physiology of sleep is common in those suffering from chronic pain (Smith and Haythornthwaite, 2004). To face the COVID-19 pandemic, ensuring good sleep practices is even more important because sleep can modulate physical and mental health. Thinking and planning about sleep are relevant as our routines have changed, whereby some individuals may be WFH or studying from home, possibly even in their bedroom. Individuals with endometriosis are prone to issues with sleep (Nunes et al., 2015; Leone Roberti Maggiore et al., 2017). Arion et al. (2020) found that overall quality of sleep was poorer in those also reporting more severe pain, poorer functional quality of life on the Endometriosis Health Profile-30 questionnaire, and more depression symptoms. Thus far, the literature on sleep dysfunction in women with endometriosis is limited. However, one randomized controlled trial (RCT) implemented an administration of 10 mg of daily melatonin, which was found to improve the quality of sleep, reduce pain scores and reduce analgesia use (Schwertner et al., 2013).

Recommendation

Adult patients should attempt to obtain 7–9 h of sleep each night (Hirshkowitz et al., 2015). Mindfulness activities may be helpful in falling asleep. Since sleep can be affected by many factors, patients should try to assess what factors are immediately modifiable (e.g. surrounding noise, light, distractions in bed). For extra support, the National Sleep Foundation has produced ready-to-use patient guidelines, which can be found here: https://www.sleepfoundation.org/sleep-guidelines-covid-19-isolation#guidelines (National Sleep Foundation, 2020). Talking to one's family physician about dysfunctional sleep or improving sleep is recommended before initiating over-the-counter agents such as melatonin. Online sleep programs based on sound scientific approaches (cognitive behavioral therapy (CBT) for insomnia (Horsch

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et al., 2017)) are also available and may be of benefit to those women with significant sleep disruption.

Physical exercise

Exercise is increasingly being recommended to manage a range of chronic pain conditions (Geneen et al., 2017), including primary dysmenorrhea (Armour et al., 2019a) and endometriosis (Awad et al., 2017; Mira et al., 2018). A recent systematic review found that regular exercise in women with primary dysmenorrhea, irrespective of intensity, reduced menstrual pain severity (Armour et al., 2019a). Conversely, a focused systematic review on endometriosis and physical exercise found inconclusive results from only six studies (Bonocher et al., 2014). Armour et al. (2019b) have found in a survey of Australian women that exercise led to episodes of exacerbated pelvic pain, more 'flare-ups', and increased fatigue in approximately one-third of respondents.

Recommendation

The limited research on endometriosis and general physical activity makes formulating a recommendation difficult. However, during the COVID-19 pandemic, outdoor exercise remains one of the few reasons people can leave their homes, which undoubtedly will have an overall positive impact on well-being, for everyone (Fallon, 2020). For those with endometriosis, we suggest using previous and current personal experiences to judge what exercise is appropriate and to take a graduated approach to advance this exercise, setting achievable goals. There is a wide selection of exercise types that could be considered.

Yoga

In a survey of Australian women, Armour et al. (2019b) reported 35% of 372 participants used yoga/Pilates to self-manage their endometriosis symptoms. An RCT by Gonçalves et al. (2017) found that yoga was associated with a reduction in levels of chronic pelvic pain and an improvement in the quality of life in women with endometriosis. Similarly, yoga therapy in the forms of asanas, pranayama and relaxation has been shown to decrease pain intensity and improve the quality of life for women with chronic pelvic pain.

Recommendation

Patients should be aware that at-home yoga led by an online instructor may not replicate the formal 8-week program utilized by Gonçalves and colleagues, but may still be useful. A simple search of YouTube for 'yoga for endometriosis' identifies many videos and patients may wish to engage in a telehealth style consultation with a trained yoga therapist if they wish to have more personalized information.

Pelvic exercises and physiotherapy

Pelvic physiotherapy is increasingly being recognized as an important component of the multidisciplinary treatment approach to endometriosis (Ball and Khan, 2020; Findeklee et al., 2020), especially when there is coexisting chronic pelvic pain. The British Pain Society (2013) considers a physiotherapist an essential member of the multidisciplinary team for patients with chronic pain. While evidence on the efficacy for endometriosis specifically is scarce (Fuentes-Márquez et al., 2019; Klotz et al., 2019), there is evidence that patients are seeking this intervention (Schwartz et al., 2019).

Recommendation

Pelvic physiotherapy is not something a patient can initiate on their own at home while in isolation. However, if patients have established relationships with pelvic physiotherapists, they could consider connecting with that individual to receive advice on what they may achieve at home while in isolation. In some cases, often due to funding limitations for the services of physiotherapy, patients are given instructions or lessons to perform at home, minimizing the number of in-person appointments necessary. Patients should consider implementing these strategies whilst at home. Patients can be directed to this simple pelvic exercise program recommended by the patient organization 'Endometriosis UK' (Supplementary Data S1). Besides this document, which has been approved by experts in physiotherapy and contains important instructions on safety, patients should be cautious about using videos without previous consultation with a physiotherapist. In some cases, the pelvic floor muscles can already be hypertonic or non-relaxed, requiring relaxation and coordination of pelvic floor muscles rather than strengthening (Faubion et al., 2012). Hence, Kegel-based programs should be avoided unless otherwise specified by one's physiotherapist.

Diet

A recent review of the complex relationship between diet and endometriosis highlights many of the studies that have evaluated this concept (Saguyod et al., 2018). Though often limited by bias intrinsic in the data collected from observational studies and the complexity of the subject being evaluated, there is evidence that there may be an increase in endometriosis risk with increased red meat consumption (Yamamoto et al., 2018) and a decrease in risk with increased consumption of fish oils, green vegetables, fruits (especially citrus fruits) (Harris et al., 2018) and dairy products (Missmer et al., 2010; Harris et al., 2013; Nodler et al., 2020). However, we do not currently have evidence that altering the consumption of these potential risk factors once endometriosis has occurred leads to any symptomatic improvements. There is some evidence for the following dietary modifications that may improve symptoms:

- dietary factors (e.g. green tea, resveratrol, fish oil, soy isoflavones) with known anti-inflammatory effects have been shown to mitigate disease progression, assessed as lesion size in mouse models;
- there may be a decreased risk for advanced endometriosis stage and/or reduction in pain symptoms in afflicted patients who use an anti-inflammatory diet;
- a gluten-free diet showed a significant positive effect in reducing pain symptoms in endometriosis patients (Marziali et al., 2012).

In addition, a low fermentable oligosaccharides, disaccharides, monosaccharides and polyols (known as FODMAP) diet may reduce the gastrointestinal symptoms, such as bloating, that many women with endometriosis report (Moore et al., 2017). Armour et al. (2019b) found that 18% of survey respondents who used a specific diet reported being able to reduce their endometriosis-related medication by 50% or more. In some cases, it is unclear if there are confounding reasons for improvements (e.g. coexisting celiac disease in the case of a gluten-free diet). There is increasing evidence that visceral pain comorbidities (e.g. bowel or bladder conditions) can exacerbate chronic pain conditions and vice-versa (Costantini et al., 2017). As

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such, mitigating visceral pain triggers may have a positive downstream effect on endometriosis-associated pain. While these findings are interesting, and in some cases promising, there is no strong evidence for dietary interventions improving endometriosis symptoms.

There is some preliminary evidence that dietary supplements may be beneficial in the treatment of endometriosis. A small observational cohort study found that, compared to no treatment, daily consumption of 1800 mg of N-acetylcysteine for 3 months was associated with a greater likelihood of canceling planned laparoscopic surgery compared to the no treatment group (Porpora *et al.*, 2013). Similarly, a small RCT of melatonin (10 mg per day) for 8 weeks improved non-cyclical pelvic pain and dysmenorrhea while reducing analgesic consumption (Schwertner *et al.*, 2013). Resveratrol, commonly found in significant quantities in grapes, wine and berries, may also assist in the reduction of endometriosis-related pain, however, the results from clinical trials in humans are mixed (Dull *et al.*, 2019). Finally, palmitoylethanolamide, in combination with a fatty acid and myrrh, taken twice daily for 6 months resulted in a reduction of non-cyclical pelvic pain and dysmenorrhea, however, there was no placebo group so caution is advised (De Leo *et al.*, 2019).

Recommendation

It is too early to make formal recommendations on dietary changes that will improve the lives of those living with endometriosis. Nevertheless, simple advice like ensuring adequate fiber and fluid intake to avoid constipation and avoiding known triggers of bladder symptoms (personal to the individual but may include alcohol, acidic fruits, etc.) may be useful. The potential positive impact of dietary improvements extends far beyond endometriosis. Therefore, patients may consider experimenting as the risk of adverse events is low and there may be a potential benefit, especially during COVID-19 where spending more time eating at home may allow more opportunities to modify dietary intake. New practices that one may initiate during COVID-19 self-isolation to combat endometriosis-pain could lead to longer-lasting positive health effects.

Heat

There are no RCTs directly looking at the effectiveness of heat in endometriosis. Despite this, heat is commonly used and rated as effective for endometriosis-related pain (Armour *et al.*, 2019b). Heat therapy has been shown to be effective in primary dysmenorrhea, where heat therapy using adhesive heat patches on the lower abdomen showed a moderate improvement in pain intensity compared to placebo patches, placebo pills or no treatment and a small to moderate improvement compared to ibuprofen (Armour *et al.*, 2019c). While these are promising findings, several caveats may reduce heat's effectiveness in real-world use compared to clinical trials. Most women in the community are unlikely to be able to maintain constant heat at 38–40°C for 8–12 h using heat packs or hot water bottles, which are the most common forms used (O'Connell *et al.*, 2006). Stick-on heat patches that provide stable temperatures for long periods of time may be the safest and most effective form of sustained heat.

Recommendation

More evidence is necessary at this time, but patients can consider trialing adhesive heat patches that provide a stable temperature for long durations (8–12 h at a time).

Medicinal cannabis

Similar to heat, there are currently no RCTs that have investigated the efficacy of medicinal cannabis for endometriosis; however, emergent evidence for its use in managing chronic pain has been reported (Klimkiewicz and Jasinska, 2018). There exists a plausible rationale for the use of medicinal cannabis in endometriosis-associated pain and concurrent symptoms via modulation of the endocannabinoid system, which can impact neuropathic and inflammatory pain, along with the psychological experience of the pain (Bouaziz *et al.*, 2017). A recent survey of Australian women with confirmed endometriosis noted that 1 in 10 respondents was utilizing cannabis, for symptom management, with cannabis rated as the highest self-management strategy for the pain of all those assessed (Armour *et al.*, 2019b). Furthermore, significant improvements in sleep, nausea, gastrointestinal upset, anxiety and depression were self-reported, along with 56% of women in the cannabis-using cohort being able to reduce their pharmaceutical usage by 50% or more (Sinclair *et al.*, 2020). Medicinal cannabis is not risk-free but the majority of reported adverse events tend to be mild and self-limiting (Lintzeris *et al.*, 2018). Potential cannabis dependence (reported in 4–9% of users) (Anthony *et al.*, 1994; Volkow *et al.*, 2014) and possible psychosis must also be considered in heavy, chronic users, although whether this applies to medicinal products, as it is in illicit use, is unclear at this time.

Recommendation

Whilst more evidence is required for its use in the endometriosis population, women who are not able to access their normal medical or surgical treatment during this time may wish to consider medicinal cannabis as a potential option if they live in a location with legal access. Ideally, the use of medicinal cannabis should be discussed with one's family physician or pain specialist through telephone or video consultation before initiation.

Emotion-focused strategies

Health anxiety that interferes with everyday life can be heightened in individuals with pre-existing chronic conditions, such as endometriosis. Along with the problem-based self-management strategies, individuals with endometriosis must adopt strategies to manage negative emotional responses to these threats posed by COVID-19. These strategies are always important, but there is a heightened need for adopting these strategies during this time. There are many self-help options to assist with managing these concerns, along with readily available support from psychologists and counselors. Consequently, several strategies that address the negative psychological effects of living with endometriosis exist and may be helpful for patients (Roomaney and Kagee, 2016). It is the responsibility of healthcare providers to guide patients through these emotion-focused, non-medical and non-surgical strategies. Some of these approaches are outlined below.

Relaxation and mindfulness

A systematic review of psychological and mind–body interventions for endometriosis highlighted several studies that identified a significant reduction in pain when patients were exposed to physical therapy with CBT, yoga, biofeedback, mindfulness and psychotherapy,

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psychotherapy combined with acupuncture and progressive muscle relaxation (Evans *et al.*, 2019). Not all of these interventions are relevant to self-management at home during isolation, but some are within reach of patients. Moreover, this category of treatment is included and encouraged by The British Pain Society (2013) guidelines on pain management for adults. In a survey of Australian women, 47% of 372 participants used meditation/breathing to self-manage their endometriosis symptoms (Armour *et al.*, 2019b).

Performing mindfulness meditation is not a skill most people naturally have so it must be learned and practiced. From YouTube (San Bruno, CA, USA) to smartphone applications, to innumerable websites, the resources necessary are accessible and sometimes free. A Danish research group has published two studies on mindfulness, the second being a 6-year follow-up study (Kold *et al.*, 2012; Hansen *et al.*, 2017). While only 10 participants were recruited, they found significant improvements in participants' pain level, well-being and ability to function in daily life after the first study (Kold *et al.*, 2012). Six years later, 9 out of the 10 women were still using the mindfulness-techniques and other mental techniques learned during the original study, and seven of these nine women experienced benefits from these techniques to a great or very great extent (Hansen *et al.*, 2017).

Recommendation

During self-isolation, relaxation, breathing exercises and mindfulness seem to be helpful to patients with endometriosis. Progressive muscle relaxation and breathing exercises can be undertaken at home using a variety of websites and/or audio downloads. One example can be found at (Beyond Blue, 2020): https://www.beyondblue.org.au/get-support/staying-well/relaxation-exercises.

More evidence is needed to support this as an effective intervention in the context of endometriosis, however, there is a body of evidence in chronic pain more generally (Ball *et al.*, 2017; Hilton *et al.*, 2017), but in the absence of harmful side effects, these strategies could be safely trialed by patients. Patients can access online material through websites or smartphone applications. If health-related anxiety and worries are interfering with a patient's everyday life, then it is critical that they are referred for professional support from a health professional trained in appropriate psychotherapy (i.e. psychologist). There are telehealth options in many jurisdictions providing high-quality psychological support, using therapeutic techniques such as CBT (focusing on identifying and changing unhelpful thought patterns, and thereby changing behaviors) and ACT (discussed below) that can be effective at managing health-related negative emotions.

Acceptance

The concept of accepting chronic illness goes well beyond the sphere of endometriosis. ACT is a form of evidence-based psychotherapy that aims to increase psychological flexibility (Wetherell *et al.*, 2011). In other words, the goal is to give patients the knowledge to recognize internal and external triggering events or experiences (e.g. pain) and equipping them with appropriate and useful thoughts and behaviors (Kuba and Weißflog, 2017). ACT aims to provide the following skills (Hayes *et al.*, 2012):

- accept automatic thoughts, sensations and urges;
- defuse from thinking (i.e. observe thoughts without believing them or following their directions);
- experience self as context (i.e. a continuous, stable sense of self as an observer of psychological experiences);
- attend to the present moment with self-awareness;
- clearly articulate values (i.e. self-chosen, desirable ways of behaving);
- engage in committed action (i.e. participating in values-consistent activities, even when psychologically challenging).

Recommendation

Telephone and video consultation options will enable individuals with endometriosis to access support from psychologists and counselors trained in these techniques, and basic information about this therapeutic approach is freely available in the first two chapters of '*ACT made simple*' by Dr Harris (2009). As with CBT, it is important to stress that these therapies are not designed as self-help approaches, and should be utilized only in consultation with a trained health professional (e.g. psychologist). Moreover, freely available online therapy delivered and supported by psychologists for managing general anxiety and depression may be available. For example, in Australia support can be accessed online through the MindSpot Clinic (2020). While the literature on ACT for endometriosis is currently scarce (Hållstam *et al.*, 2018), there is an ongoing RCT that includes therapy based on ACT as intervention (Forman *et al.*, 2016), and some evidence that ACT may be of some help in managing chronic pain, generally (Öst, 2014).

Adopting a positive attitude

Some patients report needing to make a conscious effort to positively adjusting their attitude, almost as a last resort (Roomaney and Kagee, 2016). The concept of attitude in chronic illness is not new: correlation between optimism and well-being in patients with chronic illness has been investigated with findings suggestive that optimism improves well-being (Gustavsson-Lilius *et al.*, 2012; Hurt *et al.*, 2014). Though no studies have been completed assessing how a change in attitude in patients with endometriosis impacts outcomes, there has been a study that found a lower level of optimism in women with endometriosis compared to those without (Morán-Sánchez *et al.*, 2020). Recently, the Survey of Pain Attitudes (SOPA) was tested and demonstrated reliability and validity in a sample of women with chronic pain due to endometriosis (Ferreira-Valente *et al.*, 2019). This is important as the SOPA tool could be used to measure pain-related beliefs in future studies. It would be ideal to have scientific evidence to support or refute the suggestion to adopt a positive attitude to improve well-being. However, in the absence of this evidence, the default advice will surely be 'adopt a positive attitude'. Similar to the concept of *accepting the disease*, trying to adopt a positive attitude may not be so straightforward without guidance. Maintaining a remote relationship with established psychological healthcare providers may allow this to be a focus, but establishing new connections and building a rapport may not be possible.

Recommendation

Like the other self-management strategies, it may be within reach of patients to self-initiate this process by finding and reading resources online. Utilizing social supports, particularly online endometriosis community groups, may also aid in motivating patients to achieve this goal (EXPPECT, 2020b).

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Discussion

Our review article briefly touches on the various problem-focused and emotions-focused strategies that are non-medication and non-surgical, which patients with endometriosis and their healthcare providers could discuss and consider implementing during the pandemic of COVID-19. These strategies could be attempted in combination with medical management strategies that may still be prescribed via telephone or video consultations. In addition, regardless of whether exacerbated by endometriosis or not, the COVID-19 restrictions may trigger negative psychological effects (Brooks *et al.*, 2020) in patients with endometriosis, which require diverse and multimodal strategies. The strategies discussed here may have merit not necessarily because they specifically target endometriosis, but because they target overall well-being. In relation to endometriosis, the literature on these self-management strategies is scarce and/or limited by lower methodological quality. In many cases, no RCTs have been completed within endometriosis populations to test the efficacy or safety of the strategies. For some (e.g. diet, sleep, mindfulness), the likelihood and severity of possible adverse events are low enough that the potential benefits would outweigh the risk. These may be more reasonable to attempt as novel strategies and patients could use their judgment and independent research to guide their decisions. For other strategies (e.g. pelvic floor exercises, cannabis), the risks are greater or they require guidance by healthcare providers. As such, greater caution should be used in initiating these strategies, though maintenance may be easier if the patient had initiated them before COVID-19 and had a period of adequate supervision or training.

For many of the problem-focused strategies, access to electricity, technological devices and the internet is required. Not all individuals may have access or the knowledge to navigate online resources. Some individuals may also experience difficulty accessing other necessities such as food to fulfill new diet trials or exercise equipment to complete at-home exercises. Unfortunately, providing solutions to this larger-scale disparity is beyond the aim of the article, which hopes to guide those who may read this article themselves or via their healthcare providers whom they may still be seeing through the telephone/virtual consultations.

While the postponement of surgeries and the limits to visiting healthcare providers for diagnosis and management of endometriosis are tragic, this is a time to seek alternative solutions. While they may be initiated as 'temporary bandages' until the traditional options resurface, some individuals may find the lessons learned and outcomes experienced valuable, resulting in long-lasting changes to how their endometriosis is managed. Besides, in many ways, the strategies laid out here have possible benefits for general well-being and non-endometriosis conditions that may be useful during the present global scenario of COVID-19, which is undoubtedly eliciting new stressors.

It should be noted that this article is not meant to prescribe specific self-management strategies to patients, but rather provide education so patients may discuss options with their healthcare providers or make independent decisions that might be right for them. Healthcare providers may also direct their patients to the following article lay summary on 'Medical and self-care advice for women with endometriosis during the COVID-19 pandemic', which has been recently published by Endometriosis UK (Supplementary Data S2).

Supplementary data

Supplementary data are available at *Human Reproduction Open* online.

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Authors' roles

All authors meet justification criteria of authorship as per ICMJE that is they all provided substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data, were involved in drafting the article or revising it critically for important intellectual content, gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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