Aust N Z J Obstet Gynaecol 2022; 62: 164–167

ANZJOG

DOI: 10.1111/ajo.13458

SHORT COMMUNICATION

Endometriosis and the workplace: Lessons from Australia's response to COVID-19

Mike Armour[1,2,3], **Donna Ciccia**[1,4], **Chelsea Stoikos**[4] and **Jon Wardle**[5]

[1]NICM Health Research Institute, Western Sydney University, Sydney, New South Wales, Australia
[2]Medical Research Institute of New Zealand (MRINZ), Wellington, New Zealand
[3]Translational Health Research Institute, Western Sydney University, Sydney, New South Wales, Australia
[4]Endometriosis Australia, Sydney, New South Wales, Australia
[5]National Centre for Naturopathic Medicine, Southern Cross University, Lismore, New South Wales, Australia

Correspondence: Dr Mike Armour, NICM Health Research Institute, Western Sydney University, Locked Bag 1797 Penrith, NSW 2751 Australia.
Email: m.armour@westernsydney.edu.au

Conflict of Interest: MA and DC: NICM Health Research Institute receives research grants and donations from foundations, universities, government agencies and industry. Sponsors and donors provide untied and tied funding for work to advance the vision and mission of the Institute. This survey was not specifically supported by donor or sponsor funding to NICM. MA is a clinical advisory board member for Endometriosis Australia and the chair of their research committee. DC is the co-founder and Director of Endometriosis Australia and until recently their CEO. CS and JW report no conflict of interest.

Received: 18 July 2021;
Accepted: 1 November 2021

Endometriosis is known to impact work productivity. The COVID-19 pandemic resulted in a shift in working practices for many, with an increase in working from home and/or flexible working hours. The aim of this online cross-sectional study was to determine if these changes resulted in changes in symptom management and productivity in Australian people with endometriosis. Three hundred and eighty-nine people responded to the survey. The majority of respondents found that their endometriosis symptoms were much easier to manage, and they were more productive. A key factor was flexibility in work hours and the increased ability to self-manage their time.

KEYWORDS
endometriosis, productivity, workplace, covid, disability

INTRODUCTION

Endometriosis has been associated with a loss of productivity in the workplace.[1] Australian research has shown that over half of those with endometriosis have had issues with their workplace due to their symptoms, most commonly having to work reduced hours, while over one in ten people reported losing their job.[2] In Australia, endometriosis is associated with both absenteeism from work, along with significant reductions in productivity when at work (presenteeism), leading to a cost of illness burden of approximately $9.7B AUD per year, with the majority of the costs due to productivity loss.[3] As part of the national action plan for endometriosis, released in 2018,[4] there are a number of recommendations supporting women with endometriosis in the workplace, namely the legal obligations by employers with respect to the potential disability caused by the disease.[5] Unlike the United Kingdom where an Endometriosis Friendly Employer Scheme[6] exists, Australia currently has no formal, evidence-based recommendations on specific factors that may improve the quality of life and ability to work productively for those with endometriosis.

The workplace changes associated with the government's COVID-19 policy response, including state-wide lockdowns that have often meant non-essential workers are able to work partially or completely from home, have provided a unique opportunity to examine the impact of flexible working arrangements on endometriosis symptom management. The aim of this cross-sectional survey was to explore how endometriosis affected people's work prior to the pandemic, what changes (if any) occurred due to COVID-19, and how these changes (positively or negatively) affected people's abilities to work and manage their symptoms.

MATERIALS AND METHODS

In order to understand how workplace changes during the COVID-19 pandemic affected women with endometriosis, an online questionnaire comprising 32 items and one free-text open qualitative question was developed by the authors. The questionnaire was hosted on the Qualtrics platform and had a completion time of 15–30 minutes. Questions included demographics, nature of endometriosis diagnosis, symptoms and treatments, employment arrangements and the impact of employment arrangements and initiatives on their endometriosis management. The questionnaire also included the validated Endometriosis Health Profile-30 (EHP-30)[7] and Fatigue Severity Scale (FSS).[8] Women were eligible to participate in the study if they were between 18 and 55 years of age, were able to speak English, had a diagnosis of endometriosis from a health professional, were currently living in Australia, and were working in a workplace setting separate from their home prior to the COVID-19 pandemic. Recruitment occurred primarily through email distribution to Endometriosis Australia members, as well as via social media and university media promotions. In order to preserve anonymity, a direct link was provided for distribution. Informed consent was obtained from all participants, with the questionnaire introduction and participant information sheet outlining that completion of the questionnaire implied consent. The questionnaire link was active for 6 weeks between 7 September, 2020 and 16 November, 2020. The study was approved by the Southern Cross University Human Research Ethics Committee (approval 2020/131). Data were exported from the Qualtrics platform into SPSS, and descriptive statistics, including frequencies and percentages, were calculated for variables of interest.

RESULTS

Three hundred and eighty-nine people with a self-reported diagnosis of endometriosis responded to the survey and were included in the analysis.

Negative impact of endometriosis at work before COVID-19

When asked how having endometriosis has impacted their employment, nearly two-thirds (65.0%) of respondents reported taking unpaid leave to manage their endometriosis, including annual or long service, as they had exceeded sick leave allowance. In open comments, respondents reported fatigue, pain or other symptoms impacting their capacity to work productively. A similar proportion of respondents (64.0%) reported feeling judged when trying to manage symptoms, while others commented on the burden of 'hiding' symptom management from fellow employees or employers. Nearly one-third (31.18%) reported missing out on a promotion during their career as a consequence of their endometriosis symptoms, while 15.93% reported being passed over for projects due to their endometriosis. One in seven (14.71%) respondents even reported being fired as a result of managing their endometriosis.

Workplace hardships impacting endometriosis

Women with endometriosis reported several hardships experienced at work. Approximately half of the respondents highlighted the inability to manage work schedules (55.27%), not being able to have work hour flexibility (50.89%) and feelings of judgement or stigma (47.56%) as workplace hardships they had faced. Over one-third (39.85%) of women feared job loss or firing due to their endometriosis, and a similar proportion of respondents (35.22%) indicated they perceived their employer to be unknowledgeable of the impact of the workplace environment on management of endometriosis symptoms. More than two-thirds (71.97%) of respondents had spoken with their employer about how their endometriosis was affecting their work, of which two-thirds (69.91%) received a positive response, and approximately one in eight (13.28%) received a negative response. Nearly one in ten (9.24%) respondents did not disclose their endometriosis at work because they did not feel comfortable to do so.

COVID-19-related workplace changes

Prior to COVID-19, over two-thirds of respondents (68.6%) were in full-time employment, with just over one in five (22.0%) in part-time employment and one in 14 (7.1%) in casual employment. The remainder were in other employment relationships (eg freelance or student). During COVID-19, more than two-thirds (68.57%) of respondents indicated their workplace or employment arrangements had changed, most commonly working from home for at least some of their normal work hours (72%). Table 1 outlines the changes in wellbeing and productivity reported due to changes in working environment due to COVID-19.

Table 2 outlines the relative importance of changes in the workplace that may improve their working environment.

When asked what novel workplace initiatives would be beneficial in managing endometriosis at work, healthcare benefits (72.64%) and rest periods (70.44%) were rated as extremely or very important by over two-thirds of respondents. Psychology and counselling programs (50%), mindfulness programs (46.54%) and assisted exercise programs (46.23%) were also identified as being extremely or very important by half of respondents, with only minority support for coaching or mentoring programs. Qualitative comments indicated that flexible working arrangements, in terms of hours and working from home, were the most useful workplace initiatives to assist in management of endometriosis.

DISCUSSION

Nearly all people with endometriosis had identified that prior to the changes that occurred due to COVID-19 the need to manage their endometriosis symptoms had significant impact on their work life, with nearly two-thirds of women having to take unpaid time off work to manage their endometriosis symptoms. The major factor impacting work productivity, as identified by more than half of respondents, was the inability to undertake flexible working arrangements, in relation to work hours or locations. Given that fatigue and non-cyclical pelvic pain are common symptoms presenting in those with endometriosis,[2] and these symptoms are strongly associated with lost productivity (including presenteeism and absenteeism),[9] it is unsurprising that workplace inflexibility would have a significant effect on symptom management and productivity.

While COVID-induced workplace changes have been challenging for many in the community, for our respondents with endometriosis many of these changes were beneficial, with eight out of ten reporting that COVID workplace changes had made management of their endometriosis symptoms easier. As a result of easier endometriosis management and flexible working arrangements, they also felt more productive, with more than half indicating they were more productive as a result of COVID workplace changes. This is in line with previous qualitative research in Australia which found that while COVID-19 negatively impacted many aspects of the lives of those with endometriosis, a 'hidden benefit' from the pandemic was the ability to work from home, allowing them to better manage their symptoms.[10]

Workplace flexibility in relation to time management and working from home were identified by women with endometriosis as the most important factors which could improve management of endometriosis in the workplace. Other important interventions included the introduction of 20-minute rest periods, access to healthcare benefits, to healthcare services such as counselling, mindfulness or assisted exercise and to physical aids (ergonomic chairs, heat packs, props). There are pre-existing legal provisions for this kind of workplace flexibility as part of the flexible work arrangements provided by the Australian Government under the Fair Work Act (2009).[11] However, currently these are linked to disability, and many of those with endometriosis would not necessarily self-identify as having a disability and both they, and their employers, may not be aware of the workplace flexibility requirements.

There are several limitations to this study. Firstly, all endometriosis diagnoses were self-reported and could not be confirmed due to the anonymous nature of the survey. However, a self-reported diagnosis of endometriosis is accurate in most cases.[12] Secondly, recruitment via social media and support organisations tends to recruit those with more severe impacts on quality of life[13] and therefore caution must be taken extrapolating these results to the entire endometriosis population.

TABLE 1 Reported changes in wellbeing and productivity

	%
Management of endometriosis symptoms during COVID-19	
Much easier	55.59
Somewhat easier	23.82
About the same	18.53
Somewhat harder	1.47
Much harder	0.59
Changes in productivity during COVID-19	
Much more productive	29.29
Somewhat more productive	33.73
About the same	26.92
Somewhat less productive	7.40
Much less productive	2.66

TABLE 2 Suggested workplace changes to improve endometriosis management

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Flexibility and some level of freedom in time management in working from home	63.69%	23.38%	9.23%	1.85%	1.85%
Childcare support, eg assistance for childcare and child minding	11.38%	14.77%	14.15%	8.00%	51.69%
Healthcare support, eg having access to healthcare services, healthcare team	35.69%	32.23%	19.08%	7.08%	4.92%
Physical aids, eg ergonomic chair/heat packs/props for aiding sitting comfort	48.00%	32.00%	12.62%	6.46%	0.92%
Practical support, eg assistance with homecare duties	16.62%	21.54%	22.15%	20.00%	19.69%

CONCLUSION

COVID-19 restrictions have demonstrated that for those with endometriosis, changes in working arrangements mostly around the ability to self-manage working hours and rest breaks, improved both their own quality of life and also their productivity. Given the potential benefits to both employees and employers, a series of guidelines to help accommodate the needs of those with endometriosis should be developed for an Australian context.

FUNDING

No external funding was provided.

ACKNOWLEDGEMENTS

Thank you to Endometriosis Australia for their support in the promotion of this survey.

REFERENCES

1. Simoens S, Dunselman G, Dirksen C *et al*. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012; **27**(5): 1292–1299. Epub 2012/03/17. https://doi.org/10.1093/humrep/des073. PubMed PMID: 22422778.
2. Armour M, Sinclair J, Ng CHM *et al*. Endometriosis and chronic pelvic pain have similar impact on women, but time to diagnosis is decreasing: an Australian survey. *Sci Rep* 2020; **10**(1): 16253. Epub 2020/10/03. https://doi.org/10.1038/s41598-020-73389-2. PubMed PMID: 33004965; PubMed Central PMCID: PMCPMC7529759.
3. Armour M, Lawson K, Wood A *et al*. The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australia: a national online survey. *PLoS One*. 2019; **14**(10): e0223316. Epub 2019/10/11. https://doi.org/10.1371/journal.pone.0223316. PubMed PMID: 31600241; PubMed Central PMCID: PMCPMC6786587.
4. Australian Government Department of Health. National action plan for endometriosis 2018 [12/1/19]. Available from: http://www.health.gov.au/internet/main/publishing.nsf/Content/endometriosis
5. Safe Work Australia. Supporting workers with endometriosis in the workplace 2019 [updated March 20201st July 2021]. Available from: https://www.safeworkaustralia.gov.au/doc/supporting-workers-endometriosis-workplace
6. Endometriosis UK. Endometriosis friendly employer scheme N.D. Available from: https://www.endometriosis-uk.org/endometriosis-friendly-employer-scheme
7. Jones G, Kennedy S, Barnard A *et al*. Development of an endometriosis quality-of-life instrument: the Endometriosis Health Profile-30. *Obstet Gynecol* 2001; **98**(2): 258–264. Epub 2001/08/17. https://doi.org/10.1016/s0029-7844(01)01433-8. PubMed PMID: 11506842.
8. Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD. The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. *Arch Neurol* 1989; **46**(10): 1121. Epub 1989/10/01. https://doi.org/10.1001/archneur.1989.00520460115022. PubMed PMID: 2803071.
9. Soliman AM, Coyne KS, Gries KS *et al*. The effect of endometriosis symptoms on absenteeism and presenteeism in the workplace and at home. *J Manag Care Spec Pharm* 2017; **23**(7): 745–754.
10. Evans S, Dowding C, Druitt M, Mikocka-Walus A. "I'm in iso all the time anyway": a mixed methods study on the impact of COVID-19 on women with endometriosis. *J Psychosom Res* 2021; **146**: 110508. https://doi.org/10.1016/j.jpsychores.2021.110508.
11. Australian Government. Fair Work Act 2009 [1st July 2021]. Available from: https://www.legislation.gov.au/Series/C2009A00028
12. Shafrir AL, Wise LA, Palmer JR *et al*. Validity of self-reported endometriosis: a comparison across four cohorts. *Hum Reprod* 2021; **36**(5): 1268–1278. Epub 2021/02/18. https://doi.org/10.1093/humrep/deab012. PubMed PMID: 33595055; PubMed Central PMCID: PMCPMC8366297.
13. De Graaff AA, Dirksen CD, Simoens S *et al*. Quality of life outcomes in women with endometriosis are highly influenced by recruitment strategies. *Hum Reprod.* 2015; **30**(6): 1331–1341. Epub 2015/04/25. https://doi.org/10.1093/humrep/dev084. PubMed PMID: 25908657.