

# Endometriosis-associated Symptoms and Diagnostic Delay: An Online Survey

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## ABSTRACT

**Background & Objective:** The aim of this study was to determine the endometriosis-associated symptoms and diagnostic delay through an online survey.

**Materials & Methods:** A cross-sectional study was conducted in Australia using an online web-based survey. All data were entered into and analyzed using the STATA software (version 14.1). A total of 903 respondents completed an online survey from September 2013 to October 2015.

**Results:** Out of 903, 71.10% were Australians and 28.90% were Non-Australian, with a self-reported diagnosis of endometriosis confirmed by surgery. Out of the participants, 86.5% completed the online survey. Delay in diagnosis was 8.1±6.2 years. There was no difference in the age range ( $P = 0.35$ ), mean age of onset of the first symptoms ( $P = 0.93$ ), and delay in diagnosis ( $P = 0.11$ ) between both groups. Most common endometriosis-related symptoms that all respondents had experienced in their lifetime were period pain (98.1%), fatigue (94%), bloating (90.7%), ovulation pain (88.7%), pelvic pain (87.3%), pain during and before/after sexual activity (82.7%), and heavy bleeding (82.2%). Treatments used by affected women included: pain killers (96%), hormonal medication (84.7%), surgical treatments (84.5%), and delayed fertility (37.1%).

**Conclusion:** Vast similarities in demographics and endometriosis-associated symptoms among the Australian and non-Australian women with endometriosis support the universality of the disease characteristics. Delay in diagnosis of endometriosis is a problem and the reasons for delayed diagnosis must be understood to try to shorten this delay. Besides pain, patients with endometriosis suffer from a variety of other symptoms; hence, any treatment must take into account the most prominent symptoms.

**Keywords:** Diagnosis, Diagnostic Delay, Endometriosis, Symptoms



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## Introduction

Endometriosis is a debilitating gynecologic disease characterized by the presence of uterine epithelial and stromal tissue outside of the uterine cavity. It affects about 10-15% of women at reproductive age (1). Around 1 in 9 women born during 1973–78 were diagnosed with endometriosis by age 40–44, based on the Australian Longitudinal Study on Women's Health and there were around 34,200 endometriosis-related hospitalizations in Australia during 2016–17 (2).

Women with endometriosis experience a variety of pain symptoms. Up to 80% of women with endometriosis suffer from chronic pains such as

dysmenorrhea, dyspareunia, persistent pelvic pain, non-menstrual pelvic pain, and dyschezia (3), and it has been revealed that 47% of infertile women have endometriosis (4).

Previous research has found the negative effects of endometriosis are significant and extensive (3). The physical and psychological impacts of symptoms, often severe and unpredictable (5), at a time in life when self-esteem, social involvement, school attendance, and performance are critical for this patient population, can lead to the development of serious emotional issues and

cause long-term effects on their psychological well-being (6-8).

The basic epidemiology of endometriosis has been difficult to be assessed for many reasons (9); for instance, diagnosis can only be made definitely by direct visualization during invasive laparoscopy or laparotomy, and critically depends on the clinical expertise of the surgeon. Pain symptoms related to periods can also be perceived culturally by the women as a normal event without seeking medical care (10).

As a result, many affected women remain such undiagnosed that a significant diagnostic delay of  $11.7 \pm 9.05$  years was reported in the USA, and  $8.0 \pm 7.92$  years in the UK (11). In a cross-sectional study conducted between 2008 and 2010 on women aged 18 to 45 years recruited from 10 countries, 745 were consequently diagnosed with endometriosis, and diagnostic delay was  $6.7 \pm 6.3$  years in the affected women (12).

Studies have described the characteristics of women with endometriosis in two different populations, however only a few have investigated the demographics as well as symptomatology of endometriosis in different geographic regions or ethnicities. One study with similar demographics and characteristics of women with endometriosis in the USA and the UK reported significant differences including early age at diagnosis and less frequency of contraceptive use (13). Ballweg (14) reported that the delay between the onset of symptoms and the actual diagnosis of disease in over 7020 women with confirmed endometriosis in the USA was 9.28 years. Data from over 7000 confirmed endometriosis cases clearly show that delay in diagnosis (the average time for diagnosis is 9 years) is a major problem and that current treatments are far from satisfactory (14). Reid *et al.* (15) through a cross-sectional survey of Australian adults over 18 years found that the prevalence of self-reported diagnosed endometriosis in the Australian women of reproductive age (18-49 years) was 3.4% (22 out of 652) (15), which corroborates a previous Australian research on this issue; however, the prevalence rate from this data set was lower than the estimated prevalence from the Global Burden of Disease Study. Lack of awareness and lack of communication about this condition contribute to a delayed diagnosis of endometriosis (16).

With regards to endometriosis-associated symptoms, Fuldeore *et al.* (17) found that more women had menstrual pelvic pain/cramping. However a study conducted by Apostolopoulos *et al.* (18) in the UK showed that no difference in pain including dysmenorrhoea, dyspareunia, and dyschezia was found between the women with and without endometriosis. The profile of endometriosis as a chronic condition is needed to provide informed and accurate understanding of endometriosis by individuals, education and health professionals, and the community more broadly. This will enable early recognition of

symptoms, greater awareness of treatment options, and understanding of the impact of the condition (17). The aim of this study was to determine the endometriosis-associated symptoms and diagnostic delay through an online survey.

## Methods

The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) was used to report the study results (19).

A cross-sectional study was conducted using a self-report online survey in Australia. This article is part of a larger study related to the development and validation of the Endometriosis Impact Questionnaire (EIQ) (20).

An online questionnaire including the demographic and medical questions was created using the Polling Online system. Demographic and medical information form (Appendix 1), designed by the main researcher through an extensive literature review, and revised and finalized by the research team, was used to collect data. The form included such data as demographics, diagnosis of endometriosis, educational level, employment status, obstetrics history including history of pregnancy and having children, and history of delayed fertility, endometriosis-associated lifetime symptoms, diagnostic delay, treatments, and having hysterectomy because of endometriosis. The online web-based survey was designed as 'survey- open', which means there was no need to log in to complete the questionnaire, making it anonymous. Respondents were able to go back to the previous completed pages and review or edit their responses. Questions on the physical, psychosocial, and lifestyle dimensions were mandatory, while remaining dimensions were optional, and there was also the option of "Not applicable" if the question or non-mandatory dimensions were not relevant to the respondents.

The target group in this survey was women with self-reported diagnosis of endometriosis and ability to understand English, from secondary or tertiary care levels as well as from the general community, with an emphasis on those residing in Australia. However, it had been predicted that patients with endometriosis from outside Australia might also complete the questionnaire as the questionnaire went online. For this reason, questions relating to the current location and country of origin were included in the demographic questions.

To recruit a sufficiently large number of accessible participants, convenience sampling and snowball sampling of women meeting the inclusion criteria were used. The invitation email stated that "If you know any women with endometriosis who might like to participate in this study, please help us by sending this email to them."

The study subjects were all 903 participants who completed the online questionnaire of a larger study

related to the development of Endometriosis Impact Questionnaire (EIQ) consisting 642 Australian (born in Australia) and 261 non-Australian (not born in Australia) women with confirmed endometriosis.

Recruitment began in October 2013 by sending an invitation email with an embedded link to the online questionnaire and an information form to 40 email addresses obtained from the dedicated Canberra Endometriosis Centre based at the Canberra hospital, Australia, to test technical functionality of the online questionnaire and flow of questions. From the responses received, questions and answers were assessed to ensure that everything was satisfactory, and thereafter the online questionnaire was released widely to the public.

The first page of the online survey included a brief information form including the aim of the study, and the estimated length of time to complete the questionnaire, and it was stated that "Completing this questionnaire is voluntary". The online survey was an anonymous web-based survey, and could be completed without being logged in.

Many groups/organizations and people were asked to assist with disseminating the study link through different strategies. These strategies included dissemination to a range of local-to-national governmental and private health facilities and specialized women's health services, and leading endometriosis and women's health organizations.

All data were entered into and analyzed using the Stata software (version 14.1). Data were reported by descriptive statistics including means, standard deviations (SD), proportions, and ranges. Data were also analyzed using Mann-Whitney U test, Chi-square test, and Fisher's exact test. A probability value of  $P < 0.05$  was considered as statistically significant.

## Results

Demographic and clinical characteristics of participants are provided in [Table 1](#).

Response rate was not calculated in the current study as it was not technically available through the used Polling Online system. Most items were compulsory in this online survey and submission was possible only by completing all pages, so there were no missing data in this survey.

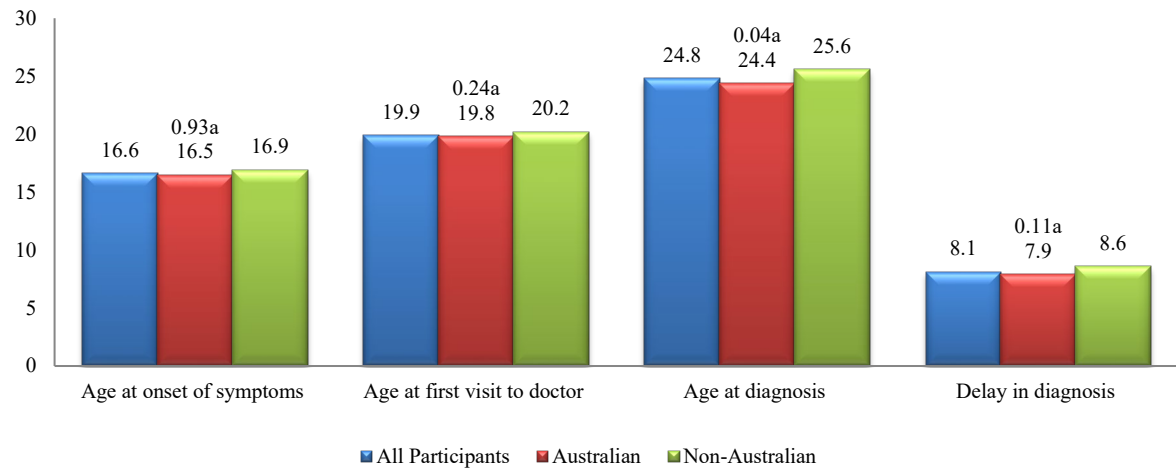
Of the 903 participants, 71.10% ( $n=642$ ) were born in Australia and 28.90% ( $n=261$ ) were born outside

Australia, in countries including the USA (82), the UK (29), New Zealand (34), England (21), Ireland (17), Canada (14), Scotland (7), Republic of South Africa (7), Scotland (7), Germany (5), Netherlands (3), Korea (3), Italy (3), Japan (2), Poland(3), Malaysia (2), Indonesia (2), Wales (1), Slovakia (1), Tanzania (1), Greece (1), Mexico (1), Nigeria (1), Chile (1), Slovenia (1), Trinidad (1), Singapore (1), Bulgaria (1), Barbados (1), Malaya (1), Namibia (1), Honduras (1), Philippines (1), Macedonia (1), South Switzerland (1), Sweden (1) and Norway (1).

Participants were aged 16-68 years with self-reported confirmed diagnosis of endometriosis by surgery (86.5%) and the rest had a provisional diagnosis mostly based on ultrasound or symptoms. Mean age at onset of the symptoms was  $16.61 \pm 5.7$  years, at first visit to doctor was  $19.98 \pm 7.2$  years, and at diagnosis was  $24.81 \pm 6.9$  years, making a delay in diagnosis of  $8.1 \pm 6.2$  years from the onset of symptoms.

The Australian and non-Australian participants were within the age ranges of 16-66 ( $33.46 \pm 8.4$ ) and 18-68 ( $32.38 \pm 9.4$ ) years, respectively, and there was no statistically significant difference between the two groups ( $P=0.35$ ) in this regard. The predominant language in both groups was English ( $P < 0.001$ ). In addition, 39.1% and 43.3% of Australian and non-Australian patients were married, respectively. Approximately 30% and 34.5% of Australian and non-Australian participants had tertiary education, respectively. Additionally, 90.5% and 81.6% of Australian and non-Australian women were employed, respectively. There was no significant difference between the two groups in terms of full-time and part-time employment, education level, retirement, and home duties ( $P > 0.05$ ; [Table 1](#)).

Mean ages of Australian and non-Australian women at the onset of the first symptoms were  $16.5 \pm 5.5$  (within the age range of 9-46) and  $16.9 \pm 6.3$  (within the age range of 8-42), respectively. There was no statistically significant difference between the two groups in this regard ( $P=0.93$ ). The mean age of Australian and non-Australian women at the time of diagnosis of symptoms were  $24.4 \pm 6.9$  (within the age range of 12-46) with a delay of  $7.9 \pm 6.3$  years and  $25.6 \pm 7.1$  (within the age range of 14-48) with a delay of  $8.6 \pm 6$ , respectively. Although the Australian women were diagnosed at a marginally younger age, the results did not indicate a significant difference between the two groups ( $P=0.11$ ; [Figure 1](#)).



**Figure 1.** Age at onset of endometriosis-associated symptoms, first visit to doctor and diagnosis; delay in diagnosis in participants (all participants (n=903), Australian (n=642) and Non-Australian participants (n=261))

P-value<sup>a</sup>: Mann-Whitney

Participants with delayed fertility, never pregnant, miscarriage or stillbirth, and hysterectomy because of endometriosis were respectively 37.1%, 54.8%, 13.4%, and 9.6%.

Furthermore, 54.4% of Australian and 55.9% of non-Australian participants had never been pregnant. In addition, 37.5% and 36.0% of Australian and non-

Australian women with endometriosis were infertile, respectively.

About 13% of people in both groups had a history of miscarriage and stillbirth and more than 30% of them had a history of infertility. Prevalence of hysterectomy due to endometriosis was not significantly different between the two groups ( $P>0.05$ ; [Table 1](#)).

**Table 1.** Demographic and clinical characteristics of participants (All participants (n=903), Australian (n=642) and Non-Australian participants (n=261))

		Total participants	Australian N (%)	Non-Australian N (%)	P-value
Age groups	Australia	642(71)			
			Range =16-66, mean=33.46±8.4 16-24 N(%) 135(21) 25-34 N(%) 372(45.5) 35and above years N(%) 135(33.5)		
Age groups	Non-Australian	261(28.9)			
			Range=18-68, mean=32.38±9.4 16-24 N(%) 44(16.9) 25-34 N(%) 103(39.4) 35and above years N(%) 114(43.7)		
Language spoken at home	English	884(97.8)	640(99.7)	244(93.5)	$X^2=34.65$ P-value <sup>b</sup> <0.001
	Non- English	19(2.1)	2(0.3)	17(6.5)	
Marital status	In a relationship	296(32.7)	215(33.5)	81(31.0)	$X^2=2.24$ P-value <sup>b</sup> =0.81
	Married	364(40.3)	251(39.1)	113(43.3)	
	Never married	89(9.8)	63(9.8)	26(10.0)	
	Separated/Divorced	44(4.8)	32(5.0)	12(4.6)	
	Single	108(11.9)	79(12.3)	29(11.1)	
	Widow	2(0.2)	2(0.3)	0(0.0)	

		Total participants	Australian N (%)	Non-Australian N (%)	P-value
<b>Highest educational level</b>	Primary school or high school without certificate/completion	26(2.9)	16(2/5)	10(3.8)	X <sup>2</sup> =55.91 value <sup>b*</sup> <0.000
	lower secondary school (up to age 16 years, year 10 certificate)	48(5.3)	35(5.5)	13(5)	
	Upper secondary school (up to age 17/18years, year 12 certificate)	114(12.6)	86(13.4)	28(10.7)	
	Vocational (e.g. TAFE, apprenticeship)	150(16.6)	134(20.9)	16(6.1)	
	Some college/university, did not graduate	106(11.7)	58(9)	48(18.4)	
	Tertiary education: undergraduate (e.g. Bachelor's degree)	283(31.3)	193(30.1)	90(34.5)	
	Tertiary education: postgraduate (e.g. Master's or PhD degree)	141(15.6)	105(16.4)	36(13.8)	
Other	35(3.9)	15(23)	20(7.7)		
<b>Employment status</b>					
<b>Not employed</b>	no	794(71)	581(90.5)	213(81.6)	X <sup>2</sup> =13.81 value <sup>b*</sup> <0.001
	yes	109(12)	61(9.5)	48(18.4)	
<b>Paid work, full time</b>	no	520(57.5)	369(57.5)	151(57.9)	X <sup>2</sup> =0.01 P-value <sup>b</sup> =0.91
	yes	383(42.4)	273(42.5)	110(42.1)	
<b>Paid work, part time</b>	no	667(73.8)	458(71.3)	209(80.1)	X <sup>2</sup> =7.33 value <sup>b*</sup> =0.007
	yes	236(26.1)	184(28.7)	52(19.9)	
<b>Student, full time</b>	no	826(91.4)	589(91.70)	237(90.8)	X <sup>2</sup> =0.21 P-value <sup>b</sup> =0.64
	yes	77(8.5)	53(8.3)	24(9.2)	
<b>Student, part time</b>	no	848(93.9)	598(93.1)	250(95.8)	X <sup>2</sup> =2.25 P-value <sup>b</sup> =0.13
	yes	55(6)	44(6.9)	11(4.2)	
<b>Retired</b>	no	896(99.2)	636(99.1)	260(99.6)	fisher=0.73 P-value <sup>c</sup> =0.68
	yes	7(0.7)	6(0.9)	1(0.4)	
<b>Home duties</b>	no	790(87.4)	566(88.2)	224(85.8)	X <sup>2</sup> =0.92 P-value <sup>b</sup> =0.33
	yes	113(12.5)	76(11.8)	37(14.2)	
<b>Other</b>	no	816(90.3)	579(90.2)	237(90.8)	X <sup>2</sup> =0.08 P-value <sup>b</sup> =0.77
	yes	87(9.6)	63(9.8)	24(9.2)	

Self-reported diagnosis of endometriosis was confirmed by surgery in 86.5% of participants, including 87.9% of Australians and 83.1% of non-Australians, and no significant difference was observed between the two groups ( $P=0.06$ ). Australians (48.6%) and non-Australians (64.2%) were referred to the emergency department at least once for endometriosis symptoms and there was a statistically significant

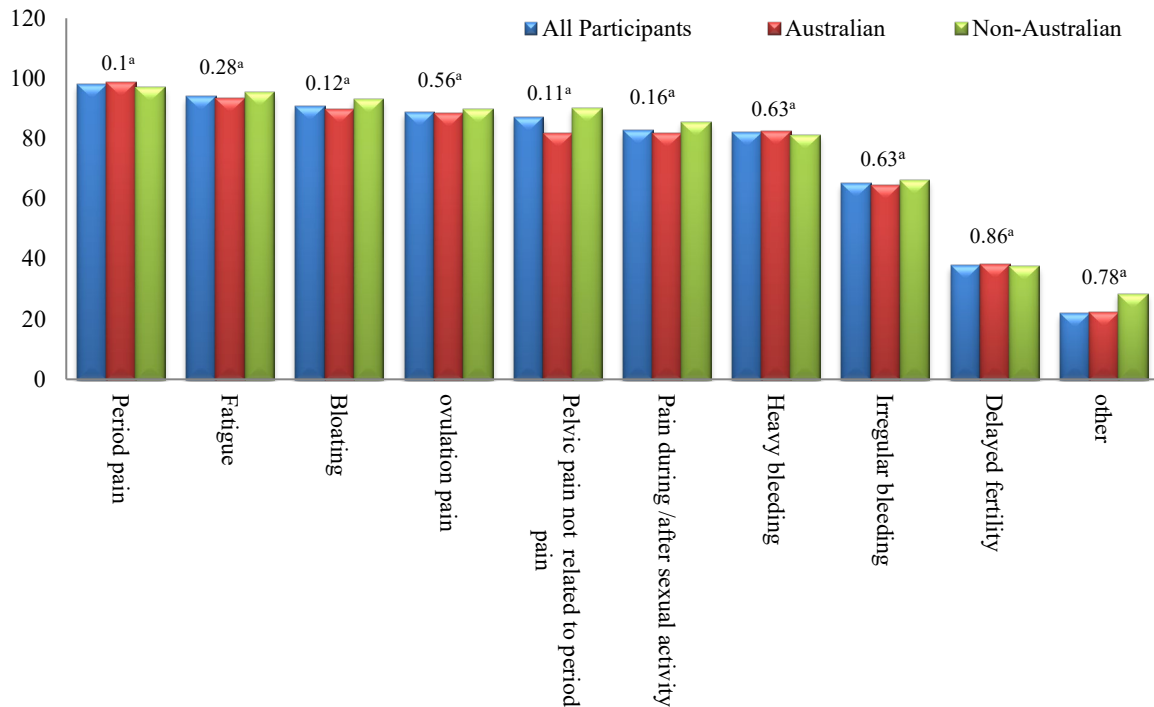
difference between the two groups in this regard ( $P<0.001$ ).

Endometriosis-related symptoms that Australian participants experienced in their lifetime were period pain 98.6% ( $n=633$ ), fatigue 93.5% ( $n=600$ ), bloating 89.7% ( $n=576$ ), ovulation pain 88.3% ( $n=567$ ), heavy bleeding 82.6% ( $n=530$ ), pelvic pain 81.6% ( $n=553$ ),



pain during/before/after sexual activity 81.6% (n=524), irregular bleeding 64.6% (n=415), delayed fertility 38.2% (n=245), and other 22.3% (n=143). For the Non-Australian participants symptoms were period pain 96.9% (n=253), fatigue 95.4% (n=249), bloating 93.1% (n=243), pelvic pain 90% (n=235), ovulation

pain 89.7% (n=234), pain during/before/after sexual activity 85.4% (n=223), heavy bleeding 81.2% (n=212), irregular bleeding 66.3% (n=173), delayed fertility 37.5% (n=98), and other 21.5% (n=56). The prevalence of symptoms had no significant difference between the two groups ( $P>0.05$ ) (Figure 2).



**Figure 2.** Lifetime endometriosis related symptoms in participants in percentage (all participants (n=903), Australian (n=642) and Non-Australian participants (n=261))

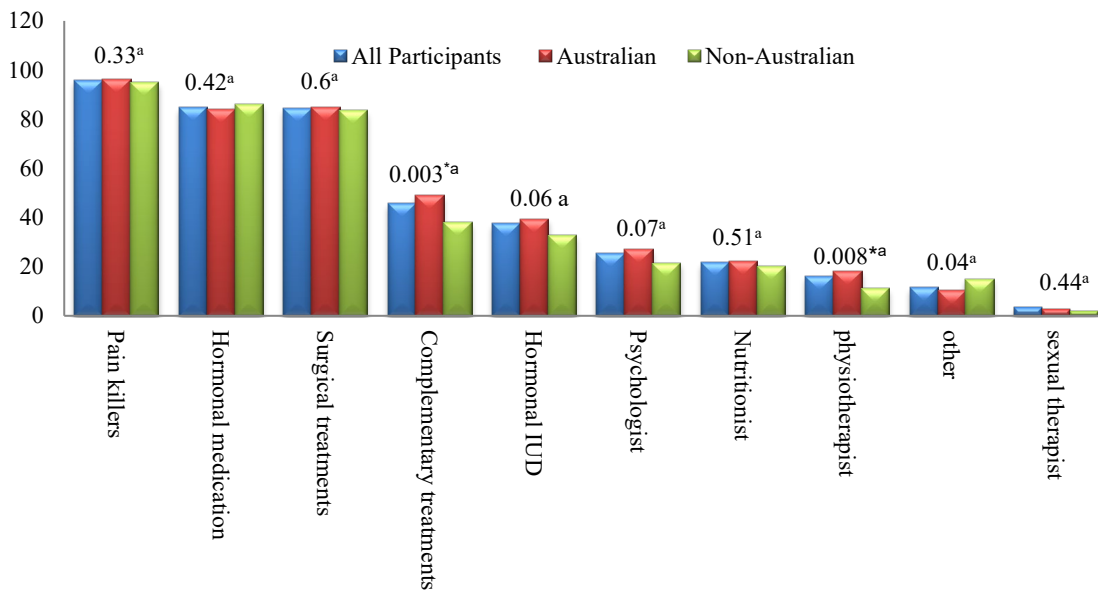
P-value<sup>a</sup>: Chi-square

Exact percentage of lifetime endometriosis related symptoms in All participants, Australian and Non-Australian participants: Period pain (98.11%, 98.6%, 96.9%), Fatigue (94.01%, 93.5%, 95.4%), Bloating (90.69%, 89.7%, 93.1%), Ovulation pain/mid-cycle pain (88.70%, 88.3%, 89.7%), Pelvic pain not related to period pain (87.26%, 81.6%, 90%), Pain during/after sexual activity (82.72%, 81.6%, 85.4%), Heavy bleeding (82.17%, 82.6%, 81.2%), Irregular bleeding (65.11%, 64.6%, 66.3%), Delayed fertility (37.98%, 38.2%, 37.5%), and Other (22.03%, 22.3%, 25.45%).

Lifetime treatments used for endometriosis by Australian participants included: Pain killers 96.4% (n=619), surgical treatments 84.9% (n=545), hormonal medication 84.1% (n=540), complementary treatments 48.8% (n=313), hormonal IUD 39.4% (n=253), psychologist 27.1% (n=174), nutritionist 22.3% (n=143), physiotherapist 18.2% (n=117), sexual therapist 2.8% (n=18) and other 10.3% (n=66). For the Non- Australian participants, lifetime treatments used were Pain killers 95% (n=248), hormonal medication 86.2% (n=225), surgical treatments 83.5% (n=218), complementary treatments 37.9% (n=99), hormonal

IUD 33% (n=86), psychologist 21.5% (n=56), nutritionist 20.3% (n=53), physiotherapist 11.1% (n=29), sexual therapist 1.9% (n=5) and other 14.9% (n=39).

There was no difference between the two groups in terms of the consumption of analgesics, hormone medications, and surgical treatments ( $P>0.05$ ). However, the use of complementary treatments ( $P=0.003$ ) and referral to a physiotherapist ( $P=0.008$ ) was significantly higher in Australian women (Figure 3).



**Figure 3.** Lifetime treatments used for endometriosis in participants in percentage (all participants (n=903), Australian (n=642) and Non-Australian participants (n=261))

P-value<sup>a</sup>: Chi-square test

## Discussion

The present study aimed to determine endometriosis-associated symptoms and diagnostic delay through an online survey.

The mean age of Australian and non-Australian participants and mean diagnostic delay were not significantly different between the two groups. Reid *et al.* (15) identified that women self-reporting a diagnosis of endometriosis mostly were between 40–49 years of age, with a higher proportion living in South Australia (18.2%). In a study by Bernuit *et al.* (21) the prevalence of the different diagnoses was comparable in eight countries (Brazil, Canada, France, Germany, Italy, South Korea, UK, and the USA). The mean age at diagnosis was 28 years, and the estimated time to diagnosis was 6.1 years (21). This rate is close to that found in previous studies, which have identified delays of  $6.7 \pm 6.3$  years in a cross of ten-country study (12). In a study by Khong *et al.* (2010) mean age of the respondents was  $34.6 \pm 7.6$  years, and the average time from onset of symptoms to the first consultation was 9.8 years. However, the average time from symptom onset to the first diagnosis of endometriosis was 4.5 years (22).

In a study by Hudelist *et al.* (23) in Austria and Germany with 171 participants, the mean age at the time of diagnosis was  $32 \pm 6$  years. The diagnostic delay for women with pelvic pain was 10.5 years and 9.8 years for patients with subfertility (23). This period lies above the upper range in European countries, reporting a median delay time of 8 years in the UK and Spain (12, 22–24), 6.7 years in Norway (24) 8.9 years in Puerto Rico (8) 7–10 years in Italy and 4–5 years in Ireland and Belgium (12). The mean age and delay in diagnosis in the above studies are similar to the present study, thus confirms patients with endometriosis endure symptoms for years without being diagnosed.

Fatigue is an underestimated symptom of endometriosis, yet it affects most women with endometriosis. Fatigue can cause major distress, impacting the daily activities and quality of life of women with endometriosis. A multicenter cross-sectional study of women with endometriosis in Switzerland, Germany, and Austria found that they suffered significantly from chronic pain and fatigue (25).

Symptoms such as dysmenorrhea, fatigue, pelvic pain, dyspareunia, and heavy bleeding were more common in Australian women with endometriosis. Nevertheless, these symptoms were also reported by most non-Australian respondents, and there was no statistically significant difference between the two groups. The results of a study by Kuohung *et al.* (13) concluded the many similarities in demographics, symptoms, and behaviors among women with endometriosis in the US and the UK support the universality of the disease process (13). Similarly, in the present study between both groups of Australian and non-Australian women, there were slight differences in the frequency of endometriosis-associated symptoms, but those were not statistically significant. In contrast to the present study, Fourquet *et al.* (26) compared characteristics of women with endometriosis from the USA and Puerto Rico and showed that endometriosis patients from two ethnically and geographically dissimilar populations vary in their reporting of symptoms associated with endometriosis and co-morbid conditions, and concluded that clinical scenarios and history differ, likely due to genetics, access to care, cultural issues, and years dealing with the symptoms.

Medical and surgical approaches are dominated in treating endometriosis; however, there are some non-

pharmacological therapies, including complementary and alternative medicine (27). In the present study, analgesia, hormone therapy, and surgery were among the majority of treatment modalities reported by patients, but no statistically significant difference between Australian and non-Australian women was found. Long-term painkillers and hormone medication use are risky due to the potential side effects and the high probability of recurrence (27).

In a study by Schwartz *et al.* (25), 62.5% of women with a confirmed diagnosis of endometriosis used some form of complementary health approaches/home remedies, and women suffering from fatigue often selected alternative therapies. In the present study, 48.8% of Australian women had resorted to complementary medicine to relieve endometriosis-associated symptoms, which was significantly higher than Non- Australian participants.

In the present study, more than 13% of women in both groups had a history of abortion. Luteal phase insufficiency combined with decreased estrogen and progesterone levels decreased circulating estradiol levels during the pre-ovulatory phase. Endometrial changes have been reported as causes of abortion in endometriosis patients. Based on the results of a systematic review, in spontaneous pregnancies, endometriosis increases the risk of miscarriage by about 80% (28).

Previous studies have indicated that 30-50% of women with endometriosis are infertile. Ovarian involvement, adhesions, and decreased mobility of the fallopian tubes can lead to reduced fertility. Several mechanisms have been suggested, including ovulatory dysfunction, luteal phase defect, luteinized unruptured follicle syndrome, immunosuppression, and peritonitis (29).

The history of delayed fertility among Australian and non-Australian participants in the present study was consistent with the infertility rate among endometriosis patients reported in the USA (19).

### Limitations of this Study

There are some limitations in the present study, which decrease the ability to generalize the results. Limitations related to self-reporting and recall errors may apply. A web-based survey was used in the current study; therefore, the generalizability of the results is limited to those who are keyboard and Internet literate. The online EIQ was designed as 'survey- open'. This means there was no need to log in to complete the questionnaire, making it anonymous. Van Gelder *et al.* (30) point out that calculating a response rate is difficult in that case, and multiple completions from one participant cannot be prevented. However, some strategies, such as recording Internet protocol addresses and personal data, may detect multiple submissions (30). Data were assessed for duplication in this study based on demographics during data cleaning,

and no duplications were found. Dissemination of the study link was focused inside Australia, and 71.10% of responders to the online survey were born in Australia. Therefore, the applicability to Australian women with different characteristics to the participants and non-Australians might be limited. In addition, it is not clear whether some of the respondents from outside Australia were actually Australians living in another country then this is a limitation. Finally, this study did not collect clinical information such as the severity of endometriosis lesions or the existence of comorbidities that could also contribute to symptoms. It is acknowledged that not knowing these clinical characteristics of the sample could limit the generalizability of the findings.

### Conclusion

Similarities in demographics and endometriosis-associated symptoms among the Australian and non-Australian women with endometriosis were identified, which supports the universality of the disease characteristics. Delay in diagnosis of endometriosis is a problem, and the reasons for delayed diagnosis must be better understood to try to shorten this delay and improve the quality of their lives. Except for pain, endometriosis patients suffer from various symptoms, and treatment must take into account the most prominent symptoms.

### Acknowledgments

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An online questionnaire including the demographic and medical questions was created using the Australian National University Polling Online system called 'APOLLO' (Link: <https://apollo.anu.edu.au/default.asp?pid=7700>).

### Availability of Data and Materials

The datasets generated and analyzed during the current study will be available from the corresponding author on reasonable request.

### Ethics Approval and Consent to Participate

Approvals were obtained from the ACT Health Human Research Ethics Committee (ETH.6.13.155), and the ANU Human Research Ethics Committee. The online survey's first page stated, "By completing the questionnaire, you are indicating your consent to participate in the study".

### Conflict of Interest

The authors declared no competing interests.



## References

- Burkman RT. Berek & Novak's Gynecology. JAMA. 2012;308(5):516-7. [DOI:10.1001/jama.308.5.516]
- hospitalizations AEiApa. 2019 [Available from: <https://www.ihw.gov.au/getmedia/a4ba101d-cd6d-4567-a44f-f825047187b8/aihw-phe-247pdf.aspx?inline=true>].
- Bulletti C, Coccia M, Battistoni S, Borini A. Endometriosis and infertility. J Assist Reprod Genet. 2010;27(8):441-7. [DOI:10.1007/s10815-010-9436-1] [PMID] [PMCID]
- Meuleman C, Vandenabeele B, Fieuws S, Spiessens C, Timmerman D, D'Hooghe T. High prevalence of endometriosis in infertile women with normal ovulation and normospermic partners. Fertil Steril. 2009;92(1):68-74. [DOI:10.1016/j.fertnstert.2008.04.056] [PMID]
- Laganà AS, La Rosa VL, Rapisarda AMC, Valenti G, Sapia F, Chiofalo B, et al. Anxiety and depression in patients with endometriosis: impact and management challenges. Int J Women's Health. 2017;9:323. [DOI:10.2147/IJWH.S119729] [PMID] [PMCID]
- Friedl F, Riedl D, Fessler S, Wildt L, Walter M, Richter R, et al. Impact of endometriosis on quality of life, anxiety, and depression: an Austrian perspective. Arch Gynecol Obstet. 2015;292(6):1393-9. [DOI:10.1007/s00404-015-3789-8] [PMID]
- Matasariu RD, Mihaila A, Iacob M, Dumitrascu I, Onofriescu M, Tanasa IC, et al. Psycho-social aspects of quality of life in women with endometriosis. Acta Endocrinol. 2017;13(3):334. [DOI:10.4183/aeb.2017.334] [PMID] [PMCID]
- Fourquet J, Gao X, Zavala D, Orengo JC, Abac S, Ruiz A, et al. Patients' report on how endometriosis affects health, work, and daily life. Fertil Steril. 2010;93(7):2424-8. [PMCID] [DOI:10.1016/j.fertnstert.2009.09.017] [PMID]
- Cicinelli E, Trojano G, Mastromauro M, Vimercati A, Marinaccio M, Mitola PC, et al. Higher prevalence of chronic endometritis in women with endometriosis: a possible etiopathogenetic link. Fertil Steril. 2017;108(2):289-95. [DOI:10.1016/j.fertnstert.2017.05.016] [PMID]
- Vercellini P, Trespidi L, De Giorgi O, Cortesi I, Parazzini F, Crosignani PG. Endometriosis and pelvic pain: relation to disease stage and localization. Fertility and sterility. 1996;65(2):299-304. [DOI:10.1016/S0015-0282(16)58089-3]
- Hadfield R, Mardon H, Barlow D, Kennedy S. Delay in the diagnosis of endometriosis: a survey of women from the USA and the UK. Hum Reprod. 1996;11(4):878-80. [DOI:10.1093/oxfordjournals.humrep.a019270] [PMID]
- Nnoaham KE, Hummelshoj L, Fau - Webster P, Webster P, Fau - d'Hooghe T, d'Hooghe T, Fau - de Cicco Nardone F, de Cicco Nardone F, Fau - de Cicco Nardone C, de Cicco Nardone C, Fau - Jenkinson C, et al. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. Fertil Steril. 2011;96(2):336-73. [DOI:10.1016/j.fertnstert.2011.05.090] [PMID] [PMCID]
- Kuohung W, Jones GL, Vitonis AF, Cramer DW, Kennedy SH, Thomas D, et al. Characteristics of patients with endometriosis in the United States and the United Kingdom. Fertility and sterility. 2002;78(4):767-72. [DOI:10.1016/S0015-0282(02)03342-3]
- Ballweg ML. Impact of endometriosis on women's health: comparative historical data show that the earlier the onset, the more severe the disease. Best Pract Res Clin Obstet Gynaecol. 2004;18(2):201-18. [DOI:10.1016/j.bpobgyn.2004.01.003] [PMID]
- Reid R, Steel A, Wardle J, McIntyre E, Harnett J, Foley H, et al. The prevalence of self-reported diagnosed endometriosis in the Australian population: results from a nationally-representative survey. BMC Res Notes. 2019;12(1):1-6. [DOI:10.1186/s13104-019-4114-6] [PMID] [PMCID]
- Cox H, Ski CF, Wood R, Sheahan M. Endometriosis, an unknown entity: the consumer's perspective. Int J Consum Stud. 2003;27(3):200-9. [DOI:10.1046/j.1470-6431.2003.t01-1-00302.x]
- Fuldeore MJ, Soliman AM. Prevalence and symptomatic burden of diagnosed endometriosis in the United States: national estimates from a cross-sectional survey of 59,411 women. Gynecol Obstet Invest. 2017;82(5):453-61. [DOI:10.1159/000452660] [PMID]
- Apostolopoulos NV, Alexandraki KI, Gorry A, Coker A. Association between chronic pelvic pain symptoms and the presence of endometriosis. Arch Gynecol Obstet. 2016;293(2):439-45. [DOI:10.1007/s00404-015-3855-2] [PMID]
- Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res. 2004;6(3):e132. [DOI:10.2196/jmir.6.3.e34] [PMID] [PMCID]

20. Moradi M, Parker M, Sneddon A, Lopez V, Ellwood D. The Endometriosis Impact Questionnaire (EIQ): a tool to measure the long-term impact of endometriosis on different aspects of women's lives. *BMC Women's Health*. 2019;19(1):1-11. [DOI:10.1186/s12905-019-0762-x] [PMID] [PMCID]
21. Bernuit D, Ebert AD, Halis G, Strothmann A, Gerlinger C, Geppert K, et al. Female perspectives on endometriosis: findings from the uterine bleeding and pain women's research study. *J Endometr*. 2011;3(2):73-85. [DOI:10.5301/JE.2011.8525]
22. Khong S-Y, Lam A, Luscombe G. Is the 30-item Endometriosis Health Profile (EHP-30) suitable as a self-report health status instrument for clinical trials? *Fertil Steril*. 2010;94(5):1928-32. [DOI:10.1016/j.fertnstert.2010.01.047] [PMID]
23. Hudelist G, Fritzer N, Thomas A, Niehues C, Oppelt P, Haas D, et al. Diagnostic delay for endometriosis in Austria and Germany: causes and possible consequences. *Hum Reproduc*. 2012;27(12):3412-6. [DOI:10.1093/humrep/des316] [PMID]
24. Ballard K, Lowton K, Wright J. What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertil Steril*. 2006;86(5):1296-301. [DOI:10.1016/j.fertnstert.2006.04.054] [PMID]
25. Schwartz ASK, Gross E, Geraedts K, Rauchfuss M, Wölfler MM, Häberlin F, et al. The use of home remedies and complementary health approaches in endometriosis. *Reprod Biomed Online*. 2019;38(2):260-71. [DOI:10.1016/j.rbmo.2018.10.009] [PMID]
26. Fourquet J, Sinaii N, Stratton P, Khayel F, Alvarez-Garriga C, Bayona M, et al. Characteristics of Women with Endometriosis from the USA and Puerto Rico. *J Endometr Pelvic Pain Disord*. 2015;7(4):129-35. [DOI:10.5301/je.5000224] [PMID] [PMCID]
27. Marqui ABTd. Non-pharmacological approach to pain in endometriosis. *Revista Dor*. 2014;15:3003. [DOI:10.5935/1806-0013.20140065]
28. Minebois H, De Souza A, Mezan de Malartic C, Agopianz M, Guillet May F, Morel O, et al. Endométriose et fausse couche spontanée. Méta-analyse et revue systématique de la littérature. *Gynecol Obstetr Fertil Senol*. 2017;45(7):393-9. [DOI:10.1016/j.gofs.2017.06.003] [PMID]
29. Boujenah J, Salakos E, Pinto M, Shore J, Sifer C, Poncelet C, et al. Endometriosis and uterine malformations: infertility may increase severity of endometriosis. *Acta Obstet Gynecol Scand*. 2017;96(6):702-6. [DOI:10.1111/aogs.13040] [PMID]
30. Van Gelder MMHJ, Bretveld RW, Roeleveld N. Web-based Questionnaires: The Future in Epidemiology? *Am J Epidemiol*. 2010;172-(11):1292-8. [DOI:10.1093/aje/kwq291] [PMID]

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