

Questionnaire-Based Prevalence of Endometriosis and its Symptoms in Jordanian Women

MOAMAR AL-JEFOUT,^{1,5*} ADEL NESHEIWAT¹, BUSHRA ODAINAT²,
RAWAN SAMI³ and NEDAL ALNAWASEH⁴

¹Department of Obstetrics and Gynecology, Mutah Medical Faculty,
Mutah University, Karak Governorate, Jordan.

²Jordan University Hospital, Amman, Jordan.

³Specialty Hospital, Amman, Jordan.

⁴Department of Public Health, Mutah Medical Faculty, Mutah University, Karak Governorate, Jordan.

⁵Department of Obstetrics and Gynecology, United Arab University,
College of Medicine & Health Sciences, United Arab Emirates.

*Corresponding author E-mail: drmoamar@yahoo.co.uk

<http://dx.doi.org/10.13005/bpj/1158>

(Received: April 20, 2017; accepted: May 06, 2017)

ABSTRACT

The true prevalence and risk factors for endometriosis in Jordanian women are not known. To estimate the prevalence of endometriosis, risk factors and related health problems in Jordanian women aged 15–55 years. A questionnaire-based cross-sectional study. Among the all-female participants (n=1772) endometriosis diagnosis was reported in 45 participants. Hence, the prevalence of endometriosis was 2.5% (45/1772). Endometriosis was more prevalent in those with long menstrual cycle (eⁿ7 days; n=18; 40%) and with frequent menstrual cycles (dⁿ 21 days; n=14; 31.1%; p<0.001). Moreover, endometriosis was more prevalent in those with university education (23/45) and in divorced women (23/45). In participants with endometriosis, dyspareunia was more prevalent than in those without endometriosis (n=15; 48.4% and n=105; 27.8%, respectively; p=0.015). Women with endometriosis are more likely to have ovarian cysts (n=9; 20% vs n=122; 7.1%), a history of ovarian cystectomy (n=14; 31.1% vs n=24; 1.4%), an abnormal Pap smear (n=4; 8.9% vs n=2; 0.1%), and asthma (n=3; 6.7% vs n=39; 2.3%), with an overall p-value of <0.001. In our study, the prevalence of endometriosis was 2.5%. Frequent and prolonged periods, dysmenorrhea, dyspareunia and infertility are associated with endometriosis in Jordanian women.

Keywords: Endometriosis; Pelvic pains, Epidemiology; Prevalence; Jordan.

INTRODUCTION

Endometriosis is a benign gynaecological disease defined as an inflammatory condition characterized by lesions of endometrial-like tissue outside of the uterus, and it is associated with pelvic pain and infertility¹. The basic epidemiology of endometriosis has been difficult to assess for many reasons, including the following: (i) diagnosis can be definitively made only by direct visualization during laparoscopy or laparotomy and critically

depends on the clinical expertise of the surgeon; (ii) a large proportion of women with the disease may be asymptomatic, which may lead to an underestimation in the number of cases; and (iii) culturally, pain symptoms related to periods are usually considered natural where women are often misguidedly taught to view severe pain during menses as normal, so that they do not seek medical care²⁻⁴. Consequently, many affected women remain undiagnosed; therefore, the true prevalence rate of this disease in the general population is unknown.

However, the prevalence in women of reproductive age is estimated to range between 10% and 15%⁵. The prevalence of endometriosis was 30.5% in women with benign gynaecologic diseases⁶, 4% in fertile women undergoing tubal sterilization⁷, and 50% in infertile women⁸. One questionnaire-based study reported 4.0% prevalence of endometriosis⁹.

A significant diagnostic delay is often reported with an estimated average delay of 7 years in the USA and 8 years in the UK^{10, 11}. A high index of suspicion is important to diagnose endometriosis. Currently, the diagnostic gold standard is laparoscopy and peritoneal biopsy for histological confirmation or exclusion. The advantage of such procedures is that they allow direct visualization of the interior of the abdominal and pelvic cavities and can be used for both diagnostic and therapeutic purposes.

The present study aimed to determine the prevalence of endometriosis and its symptoms in an unselected population of Jordanian women – a largely understudied population.

MATERIALS AND METHODS

A self-administered, anonymous questionnaire was given to 1772 Jordanian women aged between 15 and 55 years. Participants were recruited during endometriosis awareness campaigns at universities, schools and shopping centres in Amman, Karak and Tafila during the period between March and July 2015. Participants were asked to fill the questionnaire before the awareness campaign. The questionnaire inquired about demographics, gynaecologic history, menstrual cycle characteristics and endometriosis-related symptoms. The diagnosis of endometriosis needed to be confirmed by a history of surgical diagnosis reports (laparoscopy and or laparotomy with histological confirmation). This study was approved by the Institutional Review Board of the Mutah Medical Faculty Ethics Committee (Reference Number: 20142). All participants gave their written informed formal consent.

The sample size calculation was based on the Kish formula ($n_0 = Z^2 p q / e^2$) ($3.84^2 \cdot 0.10 \cdot 0.90 / 0.0009 = 384$, $Z = 1.96$; prevalence*¹ (p) = 10%; margin of error (e) = 3%). Considering a

non-response rate of 10%, the desired sample size will be (384/0.9) or 427 respondents. Therefore, a minimum sample size of 427 respondents will be required for the overall study. However, 1772 respondents were sampled for the entire study. Output: Critical $\chi^2 = 3.8414588$ with a Power (1- α err prob) = 0.9877612¹².

Statistical analysis was performed using SPSS version 20 (SPSS Inc., Chicago, IL, USA). Univariate statistical analyses were performed to describe the study population. Frequencies and proportions of categorical variables of those with and without disease were compared using either Pearson's χ^2 test or Fisher's exact test, where appropriate. Continuous variables were compared using the t test. The level of statistical significance was set at 0.05.

RESULTS

We distributed 2250 questionnaires; we only managed to get 1772 completed ones (response rate is 79%). Initially we identified 54 cases of endometriosis from a total of 1772 participants. However, we did not include nine cases: four participants did not provide any evidence of surgical proof of endometriosis diagnosis, and five participants did not complete the questionnaire for unknown reasons, leading to a final total number of cases of 45 surgically confirmed cases of endometriosis; therefore, the estimated point prevalence of endometriosis in our study is 2.5% (45/1772).

We then compared the demographic and gynaecologic profile of patients with endometriosis with those of the general female population surveyed (i.e. women without a diagnosis of endometriosis). The majority of participants with endometriosis [18/45 (40%)] were between 20 and 29 years old; half of the participants with endometriosis had university education with at least 1 year of college (51.1%). Half of the participants with endometriosis were divorced (51.1%). Most participants (33.3%) had private medical insurance. In patients with endometriosis, we found a statistically significant association with: (i) age, where the age group (20–29 years) had the highest prevalence of endometriosis ($n=18$; 40%; $p < 0.001$); (ii) university education ($n=23$; 51.1%;

Table 1: Demographic features of study subjects

Characteristics	General population (no endometriosis) (n= 1727)	Endometriosis patients (n=45)	P value
Age group, n (%)	0.000		
d ⁿ 19	442 (25.6)	4 (8.9)	
20–29	1026 (59.4)	18 (40.0)	
30–39	136 (7.9)	14 (31.1)	
40–49	97 (5.6)	8 (17.8)	
e ⁿ 50	26 (1.5)	1 (2.2)	
Education level, %			
School Education	566 (32.8)	14 (31.1)	0.002
University Education	1067 (61.8)	23 (51.1)	
Post Graduate Education	94 (5.4)	8 (17.8)	
Marital Status, %			
Single	1355 (78.5)	14 (31.1)	0.000
Married	191 (11.1)	8 (17.7)	
Divorced	172 (9.96)	23 (51.1)	
Widowed	9 (0.52)	0 (0.0)	
Medical Insurance, %			
Private	471 (27.3)	15 (33.3)	0.856
Public	527 (30.5)	14 (31.1)	
Military	344 (19.9)	5 (11.1)	
No insurance	385 (22.3)	11 (24.4)	

Table 2: Menstrual cycle characteristics of participants

Characteristics N (%)	General population (no endometriosis) (n=1727)	Endometriosis patients (n=45)	P value
Age at menarche, (n=1621)	0.284		
d ⁿ 9 years	32 (1.9)	0 (0.0)	
9–11 years	242 (14.0)	11 (24.4)	
12–13 years	718 (41.6)	18 (40.0)	
e ⁿ 14 years	629 (36.4)	16 (35.6)	
Cycle, n (%)			
Regular	1207 (69.5)	32 (71.1)	0.895
Irregular	520 (30.1)	13 (28.9)	
Menstrual cycle length, n (%)			
d ⁿ 21 days	4 (0.2)	14 (31.1)	0.000
21–34 days	1428 (82.7)	25 (55.6)	
>35 days	295 (17.1)	6 (13.3)	
Length of menses, n (%)	0.000		
Short (<3 days)	403 (23.3)	2 (4.4)	
Average (3–6 days)	1040 (60.0)	25 (55.6)	
Long (e ⁿ 7 days)	284 (16.4)	18 (40.0)	

p=0.002); and (iii) marital status, where the highest proportion was divorced (n=23; 51.1%; p<0.001) (Table 1).

Regarding the menstrual cycle characteristics of patients with endometriosis, the age at menarche and the regularity of menstrual cycle were not significantly associated with the presence of endometriosis with p-values of 0.284, and 0.895, respectively. However, menstrual cycle frequency (dⁿ 21 days; n=14; 31.1%) and length of menses (long: eⁿ7 days; n=18; 40%) were significantly associated (p<0.001) with the presence of endometriosis (Table 2). Moreover, women with endometriosis had higher rates of oral contraceptive use (n=13; 28.9%) than women without endometriosis (n=155; 9.0%), with

a chi-square of 20.26 and p<0.001. The results also show that women with endometriosis were more prone to have dysmenorrhea (24.4% vs 16.9%), infertility (4.4% vs 0.4%) and chronic pelvic pain (2.2% vs 0.4%) with p=0.001 (Table 3).

About half of the study participants with endometriosis (who are or were sexually active), suffered from dyspareunia (n=15; 48.45%) compared to participants without endometriosis (n=105; 27.8%). This difference was statistically significant (p=0.015) (Table 4).

Participants with endometriosis had higher rates of a family history of dysmenorrhea among first-degree relatives (elder sister, and/or mother); (n=32;

Table 3: Endometriosis-related symptoms among subjects

	General population (no endometriosis) (n=1727)	Endometriosis patients (n=45)	P value
Menstrual cramps	953 (55.2)	23 (51.1)	0.001*
Dysmenorrhea	291 (16.9)	11 (24.4)	
Problems to conceive	7 (0.4)	2 (4.4)	
Chronic pelvic pain	7 (0.4)	1 (2.2)	
*chi-square=20.55			

Table 4: Prevalence of dyspareunia among sexually active participants

		Endometriosis		P-Value
		Yes	No	
Dyspareunia	Yes	15 (48.4%)	105 (27.8%)	0.015
	No	16 (51.6%)	273 (72.2%)	

Table 5: The relationship between the history of dysmenorrhea among first degree relatives and severity of dysmenorrhea in all participants

Endometriosis	Severity of dysmenorrhea(VAS)	History of dysmenorrhea among first degree relatives (elder sister, or mother)		p-value
		Yes	No	
Yes n (%)	< 7	16(51.6%)	3(23.1%)	0.081
	> 7	15(48.4%)	10(76.9%)	
No n (%)	< 7	609(52.7%)	355(65.3%)	0.001
	> 7	547(47.3%)	189(34.7%)	

Table 6: Prevalence of gynecological and non-gynecological diseases in patients with and without endometriosis

Disease, n (%)	Without endometriosis (n=1727)	With endometriosis (n=45)	p-value
Abnormal Uterine Bleeding	56 (3.2)	2 (4.4)	NS
History of Ovarian Cyst	122 (7.1)	9 (20.0)	0.001
History of ovarian cystectomy	24 (1.4)	14 (31.1)	0.001
Abnormal Pap Smear	2 (0.1)	4 (8.9)	0.001
Cancer	6 (0.3)	0 (0.0)	NS
Gynecological Infections	306 (17.7)	6 (13.3)	NS
Allergy	109 (6.3)	1 (2.2)	0.001
Uterine Fibroid	18 (1.0)	2 (4.4)	NS
Asthma	39 (2.3)	3 (6.7)	0.001
Hypertension	11 (0.6)	1 (2.2)	NS
Migraines	45 (2.6)	1 (2.2)	NS
None	1013 (57.4)	16 (35.6)	NS

71.1%) than those without endometriosis (n=1174; 68.0%), but this difference was not statistically significant (chi-square=0.867; p=0.656). Participants (regardless of the presence of endometriosis diagnosis) with severe dysmenorrhea (VAS score e"7), had a strong association with a history of painful menstrual periods among first-degree relatives (elder sister, and/or mother) (n=611; 50.7%) compared to those without a history of painful menstrual periods among first-degree relatives (n=224; 39.6%; chi-square=19.05; p<0.001). The severity of dysmenorrhea (VAS e"7) in those with endometriosis had no statistically significant association with the presence of dysmenorrhea in first-degree relatives (elder sister, and/or mother; p=0.081). Surprisingly, the severity of dysmenorrhea in participants without endometriosis had a statistically significant association with the presence of dysmenorrhea in first-degree relatives (elder sister, and/or mother; p=0.001) (Table 5).

Finally, we estimated the prevalence of gynaecological and non-gynaecological diseases in all the study participants. We found that women with endometriosis had significantly higher rates of ovarian cysts (n=9; 20% vs n=122; 7.1%), ovarian cystectomy (n=14; 31.1% vs n=24; 1.4%), abnormal Pap smears (n=4; 8.9% vs n=2; 0.1%), asthma (n=3; 6.7% vs n=39; 2.3%) and abnormal uterine bleeding

(n=2; 4.4% vs n=56; 3.2%) with an overall p-value of <0.001 (Table 6).

DISCUSSION

This study represents the first assessment of the basic epidemiology of endometriosis in Jordan, a representative of the general Arabic population. We found that the prevalence of endometriosis in this study was 2.5%. This number is close to that reported in the UK by Ballard *et al*¹³: 1.5%, and Pugsley (2007):¹⁴1.44% . However, this number is lower than that reported worldwide: 4%^{9, 15}. This is likely to be due to the methodological differences, with most studies drawing their samples from women attending gynaecological clinics, whereas our sample reflected the rates of endometriosis diagnosed within the population at large. However, this may be an underestimation as many women with endometriosis have few symptoms, and therefore never receive a clinical diagnosis or are unable or unwilling to seek medical care that would lead to a diagnosis of endometriosis.

Our results show that associations were observed between a diagnosis of endometriosis and any of the menstrual cycle characteristics surveyed, including menstrual cycle length and duration of menses, which is in concordance with the widely

accepted notion that having a longer length of menses and a shorter cycle length are risks factors for endometriosis¹⁶. This is contrary to that shown in other report⁹.

Significant associations were observed between endometriosis and dysmenorrhea, dyspareunia, fertility problems and chronic pelvic pain. Endometriosis usually causes pain symptoms that may start early in life. In a recent study in Jordan, the prevalence of primary dysmenorrhea was around 28% and was found to negatively affect quality of life¹⁷. The prevalence of endometriosis among those with chronic pelvic pain is estimated to be as high as 70%¹⁸. Two-thirds of young adult females with chronic pelvic pain or dysmenorrhea had evidence of endometriosis, and approximately one-third of them had moderate to severe disease¹⁹.

There is good evidence to suggest that women reporting multiple pain symptoms should undergo further appropriate investigation to exclude or confirm a diagnosis of endometriosis. The fact that divorced women had the highest prevalence of reported endometriosis may point out the possible negative effect of endometriosis on relationships, especially the sex life²⁰. Women with endometriosis have a nine-fold increase in the risk of deep dyspareunia compared to the general female population of corresponding age^{13, 21}. Dyspareunia mainly affects young women in their most sexually active years, which may compromise their fertility in addition to their struggle with the painful symptoms of endometriosis²². Our findings, which demonstrate that dyspareunia as a common complaint in patients with endometriosis, have already been shown by other reports^{23, 24}.

Women with endometriosis frequently suffer from autoimmune inflammatory diseases, hypothyroidism, fibromyalgia, chronic fatigue syndrome, allergies and asthma²⁵. Our study shows that women with endometriosis have a higher prevalence of bronchial asthma; however, one study reported no association²⁶. We also found that women with endometriosis have higher rates of abnormal uterine bleeding; this association was also reported in one old study from 1956²⁷.

Our data indicate that women with a surgical diagnosis of endometriosis have higher rates of the historical use of oral contraceptive pills, which has been confirmed in a previous report²⁸. This finding may be due to the fact that dysmenorrhea is more prevalent in endometriosis patients, and the higher rates of past use of oral contraceptive pills is because this is the treatment commonly offered to young adult females with severe dysmenorrhea who have not responded well to non-steroidal anti-inflammatory drugs²⁹.

It is well known that first-degree relatives of patients with endometriosis have a higher chance (four- to seven-fold) of developing endometriosis than that of the general population³⁰. We found that women with endometriosis show a positive and statistically significant difference in terms of family history (mothers and sisters) of severe dysmenorrhea compared with those without endometriosis. It is possible that these mothers and sisters also had endometriosis, which was not diagnosed. This points out the importance of obtaining good family history when dealing with women with suggestive symptoms of endometriosis.

The present study was limited by the fact that the self-reported status of being a patient with endometriosis was not verified by a review of medical records. It is likely that women who approached us and answered the questionnaire were those most interested in the topic, who knew someone with the disease or were themselves patients with endometriosis. Despite its limitations, our approach allowed us to obtain important data in a relatively quick and economical way. We could include women from all age groups and all socioeconomic strata in Jordan.

In summary, to our knowledge, this is the first and only study ever conducted on the epidemiology of endometriosis in the Jordanian and Arabic populations. It provided important data and insights on this significant women's health issue, which will promote additional research in this area. Our reported endometriosis prevalence of 2.5% in Jordanian women, which is lower than the 8–10% prevalence widely reported from hospital-based studies, reflects the prevalence of endometriosis

diagnosed in the general female population of Jordan. Our findings are expected to impact public health campaigns geared towards early diagnosis and management of reproductive problems in the Jordanian and other Arabic populations. We hope that our study will help to establish endometriosis as an important reproductive public health problem in Jordan.

ACKNOWLEDGMENT

We thank all medical students of the Mutah Medical Faculty who were involved in awareness endometriosis campaigns and all study participants. We also declare any form of conflict of interest.

REFERENCES

- Giudice, L.C., *Endometriosis. New England Journal of Medicine*, **362**(25): p. 2389-2398 (2010).
- Vercellini, P., *et al.*, *Endometriosis and pelvic pain: relation to disease stage and localization. Fertil Steril*, **65**(2): p. 299-304 (1996).
- Vigano, P., *et al.*, *Endometriosis: epidemiology and aetiological factors. Best Pract Res Clin Obstet Gynaecol*, **18**(2): p. 177-200 (2004).
- Missmer, S.A. and D.W. Cramer, *The epidemiology of endometriosis. Obstet Gynecol Clin North Am*, **30**(1): p. 1-19, vii (2003).
- Lebovic, D.I., M.D. Mueller, and R.N. Taylor, *Immunobiology of endometriosis. Fertility and sterility*, **75**(1): p. 1-10 (2001).
- Tanmahasamut, P., *et al.*, *Prevalence of endometriosis in women undergoing surgery for benign gynecologic diseases. Journal of the Medical Association of Thailand= Chotmaihet thangphaet*, **97**(2): p. 147-152 (2014).
- Fuentes, A., *et al.*, *[Prevalence of endometriosis in 287 women undergoing surgical sterilization in Santiago Chile]. Revista medica de Chile*, **142**(1): p. 16-19 (2014).
- Ozkan, S., W. Murk, and A. Arici, *Endometriosis and infertility. Ann NY Acad Sci*, **1127**(1): p. 92-100 (2008).
- Flores, I., *et al.*, *Self-reported prevalence of endometriosis and its symptoms among Puerto Rican women. International Journal of Gynaecology & Obstetrics*, **100**(3): p. 257-61 (2008).
- Jan, H., *et al.*, *Diagnostic Delay for Superficial and Deep Endometriosis in the United Kingdom: A First Quantitative Study. Journal of Minimally Invasive Gynecology*, **21**(6): p. S127 (2014).
- Hadfield, R., *et al.*, *Delay in the diagnosis of endometriosis: a survey of women from the USA and the UK. Human Reproduction*, **11**(4): p. 878-880 (1996).
- Kish, L., *Survey sampling* 1965, New York John Wiley & Sons, Inc. 664.
- Ballard, K.D., *et al.*, *Can symptomatology help in the diagnosis of endometriosis? Findings from a national case-control study—part 1. BJOG: An International Journal of Obstetrics & Gynaecology*, **115**(11): p. 1382-1391 (2008).
- Pugsley, Z. and K. Ballard, *Management of endometriosis in general practice: the pathway to diagnosis. Br J Gen Pract*, **57**(539): p. 470-476 (2007).
- Eskenazi, B. and M.L. Warner, *Epidemiology of endometriosis. Obstet Gynecol Clin North Am*, **24**(2): p. 235-58 (1997).
- Cramer, D.W. and S.A. Missmer, *The epidemiology of endometriosis. Ann NY Acad Sci*, **955**: p. 11-22; discussion 34-6, 396-406 (2002).
- Al-Jefout, M., *et al.*, *Dysmenorrhea: Prevalence & Impact on Quality of Life among Young Adult Jordanian Females. Journal of Pediatric and Adolescent Gynecology*, (2014).
- Louis, G.M.B., *et al.*, *Incidence of endometriosis by study population and diagnostic method: the ENDO study. Fertil Steril*, **96**(2): p. 360-365 (2011).
- Suvitie, P.A., *et al.*, *Prevalence of Pain Symptoms Suggestive of Endometriosis Among Finnish Adolescent Girls (TEENMAPS Study). Journal of Pediatric and Adolescent*

- Gynecology*, (2015).
20. Ferrero, S., *et al.*, *Quality of sex life in women with endometriosis and deep dyspareunia. Fertil Steril*, **83**(3): p. 573-579 (2005).
 21. Vercellini, P., *et al.*, "I Can't Get No Satisfaction": *deep dyspareunia and sexual functioning in women with rectovaginal endometriosis. Fertil Steril*, **98**(6): p. 1503-1511. e1 (2012).
 22. Hummelshoj, L., *et al.*, *Let's talk about sex and endometriosis. Journal of Family Planning and Reproductive Health Care*, p. jfprhc-2012-100530 (2013).
 23. Fritzer, N., *et al.*, *More than just bad sex: sexual dysfunction and distress in patients with endometriosis. European Journal of Obstetrics & Gynecology and Reproductive Biology*, **169**(2): p. 392-396 (2013).
 24. Gupta, S., *et al.*, *Endometriosis: Impact on Patient Quality of Life*, in *Endometriosis2015*, Springer. p. 75-78.
 25. Sinaii, N., *et al.*, *High rates of autoimmune and endocrine disorders, fibromyalgia, chronic fatigue syndrome and atopic diseases among women with endometriosis: a survey analysis. Hum Reprod*, **17**(10): p. 2715-2724 (2002).
 26. Ferrero, S., *et al.*, *Asthma in women with endometriosis. Hum Reprod*, **20**(12): p. 3514-3517 (2005).
 27. Bayly MA, G.L., *External endometriosis and abnormal uterine bleeding. Am J Obstet Gynecol.*, **72**(1): p. 147-50 (1956).
 28. Chapron, C., *et al.*, *Oral contraceptives and endometriosis: the past use of oral contraceptives for treating severe primary dysmenorrhea is associated with endometriosis, especially deep infiltrating endometriosis. Hum Reprod*, **26**(8): p. 2028-2035 (2011).
 29. Al-Jefout, M. and N. Nawaiseh, *Continuous Norethisterone Acetate versus Cyclical Drospirenone 3 mg/Ethinyl Estradiol 20 ig for the Management of Primary Dysmenorrhea in Young Adult Women. Journal of Pediatric and Adolescent Gynecology*, (2015).
 30. Eskenazi, B. and M.L. Warner, *Epidemiology of endometriosis. Obstet Gynecol Clin North Am*, **24**(2): p. 235-258 (1997).