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Self-Reported Prevalence of Endometriosis and its Symptoms in the United Arab Emirates (UAE)

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ABSTRACT

The true prevalence and risk factors for endometriosis among women in UAE are unknown. Objectives: To estimate the prevalence of endometriosis among women in UAE aged 18 to 55 years, risk factors and related health problems. A questionnaire-based cross-sectional study exploring information about reproductive events and gynecological problems including endometriosis. Among participants (n= 3572) confirmed endometriosis diagnosis was reported by 55 women. Hence, the estimated prevalence of endometriosis was 1.5 % (55/3572). Endometriosis was more prevalent among age 20-29 years. Endometriosis was more prevalent among those with cycle irregularity and long menses (≥7 days) (41.8% & 27.3 % vs 30.7% & 18.8%) respectively. Moreover, endometriosis was more prevalent among divorced women (26 (0.7%) vs 3 (5.5%), p-0,003) in control. Women with endometriosis were found to have more severe dysmenorrhea (49.1% (27) vs 17.6% (618)), infertility (12.7% (7) vs 0.9% (32), chronic pelvic pain (18.2% (10)) and dysuria (18.2% (10)) vs (2.5% (88) and 3.1% (108) respectively), p <0.001. Women with endometriosis more frequently experience abnormal uterine bleeding (20% (11) vs 4.3% (153), p<0.0001), uterine fibroids (10.9% (6) vs 0.7% (24), p<0.0001), and ovarian cysts (38.2% (21) vs 7.2% (252), p<0.0001). Ovarian cysts surgery was also strongly associated with endometriosis diagnosis (21.8% (12) vs 0.7% (23), p<0.0001. In our study, the estimate prevalence of endometriosis is 1.5 %. Irregular and prolonged periods, dysmenorrhea, chronic pelvic pain, dysuria, being divorced and infertility are associated with endometriosis.No funding was received and there are no competing interests.

Keywords: Endometriosis; Pelvic pain, Epidemiology; Prevalence.

INTRODUCTION

Endometriosis is an oestrogen-dependent gynaecological disorder that is characterized by the presence of endometrial-like tissue outside the uterus with an inflammatory background[1]. Various risk factors have been described to be associated with endometriosis. Menstrual and reproductive risk factors include early menarche (d" age 11), shorter cycle length (d" 27 days), longer duration of menses and nulli- or reduced parity[2, 3], environmental exposure to dioxins and dioxin-like compounds may be associated with an increased risk for developing endometriosis[4-6], disrupted and defective immune

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system and their associated growth factors and inflammatory markers may lead to an increased occurrence of endometriosis[7, 8]. Moreover, a strong underlying familial predisposition has been suggested, a young woman reported to have first-degree relatives with proven endometriosis will have approximately an eight-fold increased risk of developing the disease compared to a woman without a family history[9]. Concordance in monozygotic twins has also been described[10].

The basic epidemiology of endometriosis has been difficult to assess for many reasons, including that diagnosis can only be made definitively by direct visualization during invasive laparoscopy or laparotomy and critically depends on the clinical expertise of the surgeon; that a large proportion of women with the disease may be asymptomatic, which may lead to an underestimation in the number of cases; and that culturally, pain symptoms related to periods are perceived as a normal thing that women need to cope with without seeking medical care[11-13]. As a result, many affected women remain undiagnosed; and there is a significant diagnostic delay of 7 years in the USA, and 8 years in the UK[14, 15], therefore, the true prevalence rate of this disease in the general population is unknown. However, estimates of 5 – 15 % of women in their reproductive years within the general population suffer from endometriosis[2, 16, 17]. In addition, many of the foundational studies follow surgically confirmed endometriosis in highly selected patient populations in a clinical setting. The reported prevalence among women presenting for investigations of dysmenorrhoea is as high as 50 % and in women with infertility, it is estimated to be 40 – 50 % [17, 18]. In a recent study in Jordan, the prevalence of primary dysmenorrhea was around 28% and was found to negatively affect the quality of life[19].

The reported prevalence among those with chronic pelvic pain is estimated to be around 70%|[20]. In those with chronic pelvic pain refractory to treatment, the prevalence of endometriosis is reported to be as high as 71%[21]. Two third of young adult females with chronic pelvic pain or dysmenorrhea have evidence of endometriosis and about one-third of these adolescents with endometriosis have moderate–severe disease [22]. Although the majority of women with endometriosis are of child-bearing age, reports have also rarely described endometriosis in pre-menarchal girls and postmenopausal women[2, 23]. Prevalence of endometriosis in benign gynecologic diseases was reported as 30.5% (24), in fertile women undergoing tubal sterilization around 4%[25], and up to 50% in infertile women[26]. Self-reported prevalence of endometriosis has been reported by some studies; 4.0% in Puerto Rico[27] and 2.5 % in Jordan[28].

The present study aimed to determine the estimate prevalence of endometriosis, its symptoms and associated morbidities in non-clinical setup and an unselected population of Emirati women, a largely understudied population. In addition, we compared the results of our study with another Arabic study (Jordanian,[28]) to explore similarities and differences in endometriosis regionally.

METHODS

A self-administered, questionnaire was given to 3572 women aged between 18-55 years residents of UAE, who are working or studying at the United Arab Emirates University in Al-Ain city in November 2016. Participants were recruited via email generated system. The questionnaire inquired about demographics, gynaecologic history, menstrual cycle characteristics, endometriosis related symptoms. In the questionnaire, the participants were asked “Have you ever been diagnosed with endometriosis? if yes; the diagnosis of endometriosis needed to be confirmed by a history of surgical diagnosis report (laparoscopy and or laparotomy with histological confirmation). This study was approved by the Institutional Review Board of the Division of Research and Graduate Studies Ethics Committee at UAEU (N- ERH-2016_5438 (06/10/2016). Informed consent was obtained from participants.

To validate our methodology we defined the target population[29] to obtain information about a larger group. The target population must be defined by shared characteristics assessed and measured accurately. Some of these characteristics include age, sex, language, ethnicity and residency. Our study clearly defined the target group as Emirati; females in the reproductive age (18-55). Furthermore, we aimed to collect information for

purposes of estimation (in our study prevalence and features of endometriosis) and hypothesis testing (eg, association between endometriosis and other variables of interest)[29]. To achieve these purposes, identical methods of assessment and data collection was used with all respondents so that the information for analysis is completely comparable.

Sample size calculation was based on Kish formula ($n_0 = Z^2 p q / e^2$) (3.84*0.10*0.90/0.0009=384, Z=1.96, prevalence* (P=10%), e=margin of error = 3%. *prevalence of endometriosis worldwide = 4-10%. Considering a non–response rate of 10%, the desired sample size was (384/0.9) or 427 respondents. Therefore, a sample of 427 respondents' was required for the overall study. However, 3572 respondents were sampled for the entire study. Output: Critical χ^2 = 3.8414588 with a Power (1-â err prob) = 0.9877612[30].

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 ÷2 test or Fisher exact test, where appropriate. Continuous variables were compared using the t-test. The level of statistical significance was set at 0.05. We calculated descriptive information of endometriosis-related questions for participants with and without endometriosis as absolute numbers and percentages.

Table 1: Participants demographics (N = ~ 3572)

Characteristics	**General population (no endometriosis)**		**Endometriosis patients**		***P- value***
	n	**(%)**	**n**	***(%)***	***(X^2)***
Age group:					<0.0001
d" 19	1218	(34.60)	17	(30.90)	
20–29	2098	(59.60)	21	(38.20)	
30–39	147	(4.20)	2	(3.60)	
40–49	40	(1.10)	10	(18.20)	
e"50	17	(0.50)	5	(9.10)	
Nationality:					0.873
UAE	2909	(82.60)	45	(81.80)	
Non-UAE	611	(17.40)	10	(18.20)	
Education level:					
School Education	284	(8.10)	2	(3.60)	0.001*
University Education	3078	(87.40)	45	(81.80)	
Post Graduate Education	136	(9.10)	5	(3.90)	
Marital Status:					
Single	3077	(87.40)	35	(63.60)	0.003*
Married	411	(11.70)	17	(30.90)	
Divorced	26	(0.70)	3	(5.50)	
Widowed	6	(0.20)	0		
Medical Insurance:					
Private	325	(9.20)	4	(7.30)	0.217*
Public	2959	(84.10)	51	(92.70)	
Military	62	(1.80)	0	(0.00)	
No insurance	171	(4.90)	0	(0.00)	

* Fisher's Exact test

RESULTS

The total number of participants who completed the study questionnaire was 3572. Of these only 55 participants reported having confirmed endometriosis diagnosis, making the overall prevalence 1.5%. Among our study participants, the number with UAE nationality was 2954, of them 45 cases with endometriosis and non-Emirati 621, of them 10 cases with endometriosis. The estimated prevalence of endometriosis patients still 1.5%.

As shown in table 1; majority of the study population were between the ages of 20 – 29 years (59.6% vs 38.2% for those reporting no diagnosis of endometriosis vs those diagnosed with endometriosis respectively), whereas approximately one third of the participants were 19 years of age or under for both groups, making it the second largest age group. Among all the age groups, the group of women without endometriosis comprised of higher proportions when compared to those with the disease, except for the older age groups (40

Table 2: Age of menarche and menstrual cycle features (N = ~ 3572)

Menstrual cycle features	Women without endometriosis		Women with endometriosis		*P-value*
	n	(%)	n	(%)	*(X^2)*
Age at menarche:					0.341*
d” 9 years	81	(2.30)	3	(5.50)	
9–11 years	722	(20.50)	11	(20)	
12–13 years	1846	(52.50)	25	(45.50)	
e”14 years	870	(24.70)	16	(29.10)	
Cycle:					
Regular	2446	(65.90)	32	(58.20)	0.071
Irregular	1073	(30.70)	23	(41.80)	
Length of menses:					0.081
Short (<3 days)	679	(19.30)	14	(25.50)	
Average (3–6 days)	2181	(62.00)	26	(47.30)	
Long (e”7 days)	660	(18.80)	15	(27.30)	

* Fisher’s Exact test

Table 3: Pain symptoms and infertility among study participants (N = ~ 3572)

	Women without endometriosis		Women with endometriosis		*P-value*
	n	(%)	n	(%)	*(X^2)*
Menstrual cramps	1866	(53.00)	23	(41.80)	0.099
Severe Dysmenorrhea	618	(17.60)	27	(49.10)	<0.0001
Problems to conceive	32	(0.90)	7	(12.70)	<0.0001
Chronic pelvic pain	88	(2.50)	10	(18.20)	<0.0001
Pain during urination	108	(3.10)	10	(18.20)	<0.0001
Pain while defecating	192	(5.50)	5	(9.10)	0.241
Back pain during menses	1677	(47.60)	31	(56.40)	0.199
Use of pain killers regularly (N=3559)	1150	(32.8)	30	(55.6)	<0.0001
Constipation (N=3575)	939	(26.7)	22	(40.0)	0.027

years and above), where an inverse pattern is seen (p<0.0001). Similarly the two groups significantly differed in the rest of the demographic characteristics (except for medical insurance where no difference was seen); generally showing more of participants from the women without endometriosis group achieving higher levels of education and are single.

Though there was no statistically significant difference between the endometriosis group and those without the disease when it came to the age of menarche and menstrual cycle features, however, cycle irregularity and long menses (e"7 days) was more commonly reported by the endometriosis group (41.8% & 27.3 % vs 30.7% & 18.8%), as shown in Table 2.

Almost half of those with endometriosis reported symptoms of severe dysmenorrhea compared to only 17.6% of those without endometriosis (49.1% [n-27] vs 17.6% [n- 618]), p <0.0001) and interestingly, reported symptoms of menstrual cramps for this latter group appear to be more frequent then those reported from the endometriosis group (53% [n- 1866] vs 41.8% [n- 23]), however, this observation was not significant. Infertility was more frequently experienced by women with endometriosis, where 12.7% [n- 7] of them reported problems in conceiving compared to 0.9% [n- 32] of those without endometriosis. Also significant number of the endometriosis group reported chronic pelvic pain (18.2% [n- 10]) and pain during urination (18.2% [n- 10]) compared to those without the disease (2.5% [n- 88] and 3.1% [n- 108] respectively). A similar trend is seen with constipation with a significant number of affirmative responses from the endometriosis group with 939 (26.7%) women without endometriosis vs 22 (40.0%), p- 0.027) (Table 3). In addition, 28 (50.9%) women with endometriosis had endometrioma, 12 (21.8%) of them underwent surgery.

Comorbidities among study participants are given in Table 4, showing greater burden of morbidities among women reporting diagnosis of endometriosis compared to those without endometriosis, where we see women with endometriosis more frequently experience abnormal uterine bleeding (20% [n- 11] vs 4.3% [n- 153], p<0.0001), uterine fibroids (10.9% [n- 6] vs 0.7% [n- 24], p<0.0001), and ovarian cysts (38.2% [n- 21] vs 7.2% [252], p<0.0001). Ovarian cysts surgery was also strongly associated with endometriosis diagnosis (21.8% [n- 12] vs 0.7% [n- 23], p<0.0001]. Whilst none of the women in the endometriosis group reported abnormal PAP smear nor any cancers, however, reports of gynaecological infections were three times more common among the endometriosis group (p = 0.001). There appeared

Table 4: Comorbidities among study participants (N = ~ 3572)

Morbidities	Women without endometriosis		Women with endometriosis		*P-value*
	n	(%)	n	(%)	*(X^2)*
Abnormal uterine bleeding	153	(4.30)	11	(20.00)	<0.0001
Uterine fibroids	24	(0.70)	6	(10.90)	<0.0001
Ovarian cysts	252	(7.20)	21	(38.20)	<0.0001
Ovarian cysts surgery	23	(0.70)	12	(21.80)	<0.0001
Abnormal PAP smear	6	(0.20)	0	(0.00)	1.00*
Gynecological infections	264	(7.50)	12	(21.80)	<0.0001
Cancer	2	(0.10)	0	(0.00)	1.00*
Asthma	170	(4.80)	3	(5.50)	1.00*
Migraines	190	(5.40)	8	(14.50)	0.003
Allergies	398	(11.30)	8	(14.50)	0.453
Hypertension	56	(1.60)	2	(3.60)	0.224*

* Fisher's Exact test

Table 5: Comparison between UAE and Jordanian studies

Morbidities	UAE Study				*P-value*	Jordanian Study				*P-value*
	Women without endometriosis (n =~3572)		Endometriosis patients (n = 55)			Women without endometriosis (n = 1727)		Endometriosis patients (n = 45)		
	%	n	%	(n)		%	(n)	%	(n)	
Abnormal uterine bleeding	4.3%	*(153)*	20.0%	*(11)*	<0.0001	3.2%	*(56)*	4.4%	*(2)*	NS
Uterine fibroids	0.7%	*(24)*	10.9%	*(6)*	<0.0001	1.0%	*(18)*	4.4%	*(2)*	NS
Ovarian cysts	7.2%	*(252)*	38.2%	*(21)*	<0.0001	7.1%	*(122)*	20.0%	*(9)*	0.001
ovarian cysts surgery	0.7%	*(23)*	21.8%	*(12)*	<0.0001	1.4%	*(24)*	31.1%	*(14)*	0.001
Abnormal PAP smear	0.2%	*(6)*	0.0%	*(0)*	NS	0.1%	*(2)*	8.9%	*(4)*	0.001
Gynaecological infections	7.5%	*(264)*	21.8%	*(12)*	0.001	17.7%	*(306)*	13.3%	*(6)*	NS
Cancer	0.1%	*(2)*	0.0%	*(0)*	NS	0.3%	*(6)*	0.0%	*(0)*	NS
Asthma	4.8%	*(170)*	5.5%	*(3)*	NS	2.3%	*(39)*	6.7%	*(3)*	0.001
Migraines	5.4%	*(190)*	14.5%	*(8)*	0.01	2.6%	*(45)*	2.2%	*(1)*	NS
Allergies	11.3%	*(398)*	14.5%	*(8)*	NS	6.3%	*(109)*	2.2%	*(1)*	0.001
Hypertension	1.6%	*(56)*	3.6%	*(2)*	NS	0.6%	*(11)*	2.2%	*(1)*	NS

to be no associations between endometriosis and other morbidities as listed in table 4 except reports of migraines.

DISCUSSION

Our results showed that probable estimate of endometriosis prevalence is 1.5% among Emirati women between the age group 18-55y, this is the exact same result as other studies aimed to determine the prevalence in unselected populations (31, 32). In recent edition of BJOG, Eisenberg *et al*. (33) reports on a large population-based database study that found a point prevalence of endometriosis of 1% in women age 15–55 and 2% in the highest-prevalence age group. They also found a slight increase in the incidence of endometriosis, however, it's not clear if it is a true increase or simply due to an increased awareness of the disease and thus better diagnosis[34]. However, this number is lower than what has been reported worldwide - 4% (27, 28, 35). This is likely to be due to the differences in methodology or ethnic differences, with most studies drawing their samples in clinical setting, whereas our sample reflected the rates of diagnosed endometriosis within unselected population.

Our results show that associations were observed between a diagnosis of endometriosis and menstrual cycle characteristics. Our participants with endometriosis had more irregular periods and longer duration of menses which is in concordance with the widely accepted notion that having a longer length of menses and having shorter cycle length are risks factors for endometriosis[36], contrary to what has been shown in another report[27].

Significant associations were observed between endometriosis and dysmenorrhea, fertility problems, and chronic pelvic pain. Endometriosis usually causes pain symptoms which may start early in life. However, endometriosis can be asymptomatic, only coming to a clinician's attention during evaluation for infertility. In a recent study in Jordan, the prevalence of primary dysmenorrhea was around 28% and was found to negatively affects the quality of life [19].

Our results showed around 50% of women with endometriosis diagnosis had severe dysmenorrhea, this is in concordance with a recent study where dysmenorrhea was the chief complaint, reported by 62% of women with mainly peritoneal endometriosis[37].

Around 18% of women with endometriosis reported to have chronic pelvic pain. One recent review that included 27 publications based on estimation of prevalence of endometriosis showed that the average prevalence of endometriosis in women with self-reported chronic pelvic pain was 28.7%. [38]. Prevalence of endometriosis among those with chronic pelvic pains is estimated to be as high as 70%[20]. Two third of young adult females with chronic pelvic pain or dysmenorrhea have evidence of endometriosis and about one-third of these adolescents with endometriosis have moderate–severe disease[22].

Due to cultural sensitivity, we were not able to ask about dyspareunia. Interestingly we found that among those with endometriosis, divorced women were 5.5 % and this may be a reflection of difficult marital environment in which endometriosis may be negatively affecting relationships especially sex life[39,40, 41]. Women with endometriosis have a nine-fold increase risk of deep dyspareunia in comparison to the general female population of corresponding age[42, 43]. Dyspareunia affects mainly young women in their most sexually active years, which may compromise their fertility in addition to struggling with the painful symptoms of endometriosis|[44]

Ovarian endometriomas are present in 17–44% of patients with endometriosis, and may be associated with infertility, dysmenorrhea and chronic pelvic pain[45]. In our study 28 (50.9%) women with endometriosis had endometrioma, 12 (21.8%) of them underwent surgery. This means that one in every 5 women with endometriosis will have ovarian surgery for ovarian endometrioma. This is an alarming fact as there is substantial evidence that the possibility of damage to the ovarian reserve after excision of the endometrioma is high, as has been shown in two recent systematic reviews, reporting consistent evidence on the reduction of ovarian reserve, evaluated with serum anti-Mullerian hormone (AMH) levels, after excisional surgery for ovarian endometrioma[46, 47].

Our study showed a lower estimate of the prevalence of endometriosis than that in another

study on Arabic population; the Jordanian study (28) with a difference of 1% (1.5 vs 2.5%). This may be due to the larger sample size. However, when looking at the demographics of the two sites of the populations; they are almost the same. Moreover, the comorbidities showed different patterns with more abnormal uterine bleeding and fibroids among Emirati endometriosis patients. Women with endometriosis frequently suffer from autoimmune inflammatory diseases, hypothyroidism, fibromyalgia, chronic fatigue syndrome, allergies and asthma (48, 49). Our results show no association with allergies and asthma among those with endometriosis; this in concordance with other reports (50) this may be due to the environmental and climate factors as UAE is a desert area. However, Jordanian women with endometriosis showed more allergies and asthma; this may be due to the difference in environmental exposures between the two countries (Table 5).

A weak point in our study is that we don't have verified reports of medical records, only self-reported diagnosis. However, in a recent large study from Sweden; authors concluded that self-reported data on endometriosis are moderately accurate and may be useful in studies when register data are not available (51) and (52, 53)., which is the case with our study. Self-reported surveys had been validated in nonfatal myocardial infarction (54), self-reported cases of stroke and acute myocardial infarction (55), self-reported hypertension and/or proteinuria during past pregnancies and actual clinical findings (56) and self-reported cases of Type II diabetes (57). Despite its limitations, our approach allowed us to obtain important data in a relatively quick and economical way. Moreover, we were able to include women from all age groups, education levels and all socioeconomic strata in UAE.

In summary, this, the first—to our knowledge— and only study ever conducted on the epidemiology of endometriosis in the UAE, has obtained important data and insights about this significant women's health issue that will promote additional research in this area with larger sample size. We believe our study may encourage healthcare policy makers to have a national registry of all cases of endometriosis. Our reported endometriosis prevalence of 1.5%, while lower than the 8–10% prevalence widely reported from hospital-based studies, may reflect the estimate prevalence of diagnosed endometriosis in the UAE general population. Our findings are expected to impact public health campaigns geared towards early diagnosis/management of reproductive problems in the UAE and other Arabic populations. We hope that our study will help to establish endometriosis as an important reproductive public health problem in the UAE.

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