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ORIGINAL RESEARCH ARTICLE

Comprehensive evaluation of the incidence and prevalence of surgically diagnosed pelvic endometriosis in a complete population

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Abstract

Introduction: The incidence and prevalence of pelvic endometriosis is still being debated. Population-based studies have shown annual incidences between 0.1% and 0.3%, which translates to a prevalence of symptom-giving disease of between 2% and 6% over a 20-year span in the reproductive years. However, a prevalence of 10% or higher is often assumed. We used Iceland's extensive record linkage possibilities, secure access to patient data and personal identification numbers to search for all cases with a surgical and/or histological first diagnosis over a 15-year study period.

Material and methods: Information was obtained from all healthcare facilities where an operative and/or histological diagnosis of pelvic endometriosis might have been made during 2001–2015. Hospital discharge diagnostic data and private clinic data sources were scrutinized and double-checked through a central register. Individual medical records, operation notes and pathology records were inspected. Visually and pathologically diagnosed cases were included. The data covered women aged 15–69 years, but the age range 15–49 (reproductive years) was specifically considered. Annual incidence was estimated per 10 000 person-years and prevalence possibilities calculated for varying disease durations. Disease severity was staged (revised American Society for Reproductive Medicine classification) and main lesion sites determined.

Results: A total of 1634 women 15–69 years old were diagnosed; 1487 of them between 15 and 49 years old. Histological verification was obtained for 57.1%. The age-standardized annual incidence for all confirmed endometriosis diagnoses was 12.5/10000 person-years among women in their reproductive years. The overall estimate of prevalence was 0.6%–3.6%, dependent on duration of symptoms from 5 up to 30 years. The most common sites by order of frequency were ovaries, deep pelvis, central pelvis, vesicouterine pouch and uterine appendages. Of the women, 1080 (66.1%) had minimal/mild and 553 (33.8%) moderate/severe disease.

Abbreviations: ICD, International Classification of Diseases; MRI, magnetic resonance imaging; rASRM, revised American Society for Reproductive Medicine.

Conclusions: We have in a comprehensive study covering a recent 15-year period confirmed an annual incidence of pelvic endometriosis of between 0.1% and 0.15% in the female population of reproductive age. Endometriosis is variably severe but, depending on the duration of symptomatic disease, the approximated prevalence during women's reproductive years could range from 1% to 4%.

KEYWORDS
endometriosis, histology, incidence, operative, population, surgical procedures

1 | INTRODUCTION

Endometriosis must preferably be verified surgically if the diagnosis is to be reasonably secure.[1,2] Even with the magnification offered by modern laparoscopy, identification of the disease can be difficult, as diagnosis depends on recognition of varying and often subtle lesions. If the surgeon is not sufficiently aware of endometriosis manifestations, these may be overlooked. Visual operative diagnosis should ideally be confirmed through biopsy, although this is often not done.[1–3] Recently, diagnostic criteria have been widened to include clinical situations, magnetic resonance imaging (MRI) and transvaginal or transrectal ultrasound findings,[1] but the surgical diagnostic gold standard is still valid. Biomarkers for the disease do not exist.[1–3]

In a considerable proportion of affected women, pelvic endometriosis gives rise to relatively typical but diverse clinical symptoms; in others, infertility may be the main problem. Endometriosis also exists with minimal or no symptoms.[1,2] It can be an incidental finding in a histopathological investigation. As a clinical disease it is prevalent during women's reproductive years. At that time, women seek medical attention for physical symptoms or because of infertility associated with endometriotic implants. Operative diagnosis may for many women not be readily available or desired, or may be inadequately covered by health insurance, which limits the diagnostic opportunities.[1,2] Therefore it is often problematic to investigate the real extent of endometriotic disease. It may even be questioned whether the condition should be termed a disease when it is symptomless.

Incidences and prevalence are easily under- or overestimated. In the case of endometriosis, they are likely to be overestimated when risk groups are studied, such as infertile women or women with abdominal pain syndromes. Conversely, insufficient attention to the possibility of endometriosis and inadequate diagnostic facilities may lead to underestimation, as recently discussed.[2] There is a well-known delay of at least 5–8 years from first symptoms to diagnosis,[4,5] which also affects assessments of incidence and prevalence. Population-based patient registers coupled to accessible surgical diagnoses have until recently mostly been accessible in high-resource countries with a mainly white ethnic background. The first and classic study stems from Rochester, Minnesota,[6] where the overall surgically verified and/or histologically confirmed annual incidence was reported as 0.3% for women aged 15–49 years. This study was followed by variable but similarly designed studies based on specific populations where the annual incidence ranged from 0.1% to 0.3%.[7–15] This included the Nurses' Health Study II cohort, a questionnaire survey in a specific socioeconomic group which yielded information on endometriosis incidence and was laparoscopically confirmed according to the patients' own reports,[16] but which may not provide a fully representative background view.

Key message

In a complete population with good diagnostic possibilities and data access all surgical and/or histological diagnoses of pelvic endometriosis were obtained. The annual incidence was just over 0.1%, counting all cases. Based on this, the prevalence was lower than often stated.

Icelanders, a small, homogeneous, Nordic-white population, show genetic diversity that is comparable to larger populations in Western Europe.[17] Two-thirds of the population live in the capital area of Reykjavik, where there is one average-size university hospital with wide-ranging diagnostic facilities and specialized staff. A few smaller public and private facilities with gynecologists/surgeons exist in the capital and other areas in the country. The population is well educated, living standards are good and a state social security scheme covers visits to general practitioners and specialists at a relatively low patient-fee. Hospital admissions and operative procedures are free of charge or low-cost. Every inhabitant receives a personal identification number at birth or immigration. These numbers are used in various societal aspects/situations and in all population registers, including those of public and privately run healthcare.

We aimed to use this advantageous and systematic setting to investigate anew visually diagnosed and histologically verified endometriosis in the pelvic cavity during a time when video-laparoscopy became established, and from this to re-estimate the incidence and prevalence of endometriosis. We also assigned disease location in the pelvic cavity and staged severity at the time of diagnosis.

2 | MATERIAL AND METHODS

Cases were obtained from all healthcare facilities in Iceland where an operative diagnosis of endometriosis might have been made during January 1, 2001 to December 31, 2015. The sources of data were:

- computerized files of the Discharge Diagnosis Register for Landspitali University Hospital through which access to individual case records (electronic or paper-based) was possible, and comparable access to data from another hospital in the capital area that had been merged with Landspitali University Hospital;
- data from district hospitals in the country with gynecology and surgical services;
- double-checks with diagnosis lists from the Icelandic Directorate of Health;
- local paper or electronic databases with diagnostic codes and operation registers at two private clinics not providing patient information to the centralized registers;
- the centralized and computerized pathology register at Landspitali University Hospital and one smaller allied but privately run pathology laboratory.

The International Classification of Diseases (ICD), version ICD-10 codes N80.0-N80.9, was used for searching the electronic hospital record-keeping of diagnoses, from where descriptions of operative procedures were also available for inspection. Paper-based record files were hand-searched. The Systematized Nomenclature of Medicine system (SNOMED; code 76500) was used for pathology records. All relevant records could be obtained for potential cases. All laparoscopic and other surgical descriptions were scrutinized by (at the time) two medical students (AK, KA) for visually confirmed and histologically verified information compatible with the relevant ICD-10 codes, under the supervision of a senior gynecology specialist (RTG). We excluded women with uterine adenomyosis only (though not women with endometriosis on the peritoneal uterine surface), endometriosis of the vagina and extrapelvic endometriosis. Women who had a first diagnosis before and up to the end of the year 2000 were excluded, as they were covered in a previous Icelandic study.[9] Each woman was only counted once, as the personal identification number enabled us to identify the first occurrence of the diagnosis in the records, thereby excluding double or multiple counting. We report on the age at which endometriosis was visually and/or histologically confirmed, but age at symptom onset was not investigated.

The data thus covered female residents with the diagnosis of pelvic endometriosis obtained in Iceland for ages 15–69 years during the study period. Women with a diagnosis in the age range 15–49 (reproductive life-span) were specifically considered. During the study period, diagnosis was primarily based on up-to-date video-laparoscopic equipment in units staffed by gynecologists, with a proportion being obtained at open abdominal surgery. Clinical diagnoses and diagnoses made with imaging methods only were not included. Magnetic resonance imaging and expert ultrasound diagnostics were not universally available during the study, but if endometriosis was suspected by these methods or clinically, there would be easy recourse to laparoscopy.

The type of operation(s) undergone by the women (laparoscopy/laparotomy/other) was recorded. Operation notes provided information on location and spread of the disease in the pelvis/abdomen, although the accuracy of the description was variable. The operative descriptions were used when possible to stage the endometriotic lesions according to the revised American Society for Reproductive Medicine classification (rASRM),[18] simplified to either stage I–II (minimal/mild; 1–15 points) or stage III–IV (moderate/severe; 16 to >40 points), as in the previous Icelandic study.[9] Staging was based on both operative notes and/or pathology records as relevant. Location of the described lesions was assigned where possible to five groups: vesicouterine (bladder peritoneum, peritoneum anterior on the uterus, vesicouterine pouch), deep pelvis (rectovaginal septum, rectouterine pouch of Douglas, uterosacral ligaments), central pelvis (pelvic peritoneal walls above uterosacral ligaments, peritoneum posterior on the uterus, inside parametrial tissues), appendages (broad ligaments, ovarian ligaments, Fallopian tubes, meso-salpinx) and ovarian. No other distinction could be made retrospectively of "deep" vs "superficial" endometriosis. Often, lesions were seen in more than one of these locations, thus giving a total number of locations greater than the number of women. In each location, more than one lesion could be seen. Incidental histopathological diagnoses and findings were classified in the same manner and their number noted. Definite histopathological diagnoses were included, not those where endometriosis was only suspected.

2.1 | Statistical analyses

To estimate incidence rates, the numerator was the yearly number of women with a laparoscopic or other surgical procedure leading to either visually confirmed and/or histologically verified diagnosis. The denominator was the mid-year number of different age-groups of women in the Icelandic population during 2001–2015, obtained from Statistics Iceland (https://statice.is/). It was not possible to exclude from the denominator, prevalent cases of women with endometriosis who had been diagnosed before the study period. We had no resources to identify, and thus exclude from the denominator, women who had undergone hysterectomy or oophorectomy or to take into consideration whether women had used hormone therapy before or after menopause. Thus, these factors could not be adjusted for. Age-specific rates for 5-year age-groups from 15 to 69 years were calculated using age at first diagnosis. Rates were standardized with the World Standard[19] and the annual incidence estimated per 10 000 person-years. We analyzed incidence using the whole group including the incidental histological data, but also without these, to obtain an indication on the incidence of clinical disease.

Prevalence odds were estimated from incidence rates and disease duration, assuming that these are stable over time using the equation $P/1-P = ID$, where P is the prevalence proportion, I the incidence rate and D the average duration of the disease (ie endometriosis).[20] The equation can be solved for the prevalence proportion, $P = ID/1+ID$. The average duration of endometriosis is unknown. However, taking into consideration that endometriosis is foremost a disease of women during fertile years and declines in clinical importance after the reproductive age (menopause), we decided in this

crude estimation of prevalence to test in the equation a duration spanning 5 years up to 30 years.

2.2 | Ethics statement

The study was approved by the Icelandic National Bioethics Committee (12-013-V1, approved January 12, 2012, updated December 13, 2017), by the Data Protection Commission (ref. 2012010079HGK7-, dated April 27, 2012), by the Directorate of Health (ref. 1803 146/5.6.1/gkg, updated June 21, 2018) and by the respective hospital and clinic authorities.

3 | RESULTS

A total of 1744 women were diagnosed with endometriosis. Of these, 110 were excluded; for 96 the location was outside the pelvic cavity (5.5%), ie in the cervix, vagina, colon, intra-rectal, ileum, appendix, diaphragm, ureter, omentum, umbilicus and cesarean scar tissue. Fourteen cases (0.8%) were diagnosed after age 69 years. The study group for the ages 15–69 years was therefore 1634 women (Figure 1). Primary diagnosis was by laparoscopy for 1240 women (75.9%), by laparotomy for 371 (some commenced as laparoscopy) and for 23 women at or after vaginal hysterectomy. Histological verification was available for 933 (57.1%) women, whereas 701 were only confirmed visually.

In the age range 15–49 years, 1487 women met the inclusion criteria; 793 of these (53.3%) were histologically verified (Table 1). The crude incidence of all endometriosis diagnoses in this group was 13.1/10000 person-years; for histologically verified endometriosis, the incidence was 7.0/10000 person-years (Table 1). The respective age-standardized annual incidence for all endometriosis diagnoses for ages 15–49 years was 12.5/10000 person-years; for histologically verified endometriosis, the incidence was 6.6/10 000 person-years.

For age 15–69 years, the crude incidence of all endometriosis diagnoses was 10.2/10000 person-years; for histologically verified endometriosis the incidence was 5.8/10000 person-years (Table 2). The age-standardized annual incidence for all endometriosis diagnoses among women aged 15–69 was 10.2/10000 person-years and for histologically verified endometriosis 5.7/10000 person-years.

There were 216 (13.2%) incidental findings, mostly histopathological. These comprised mainly endometriotic foci under or on

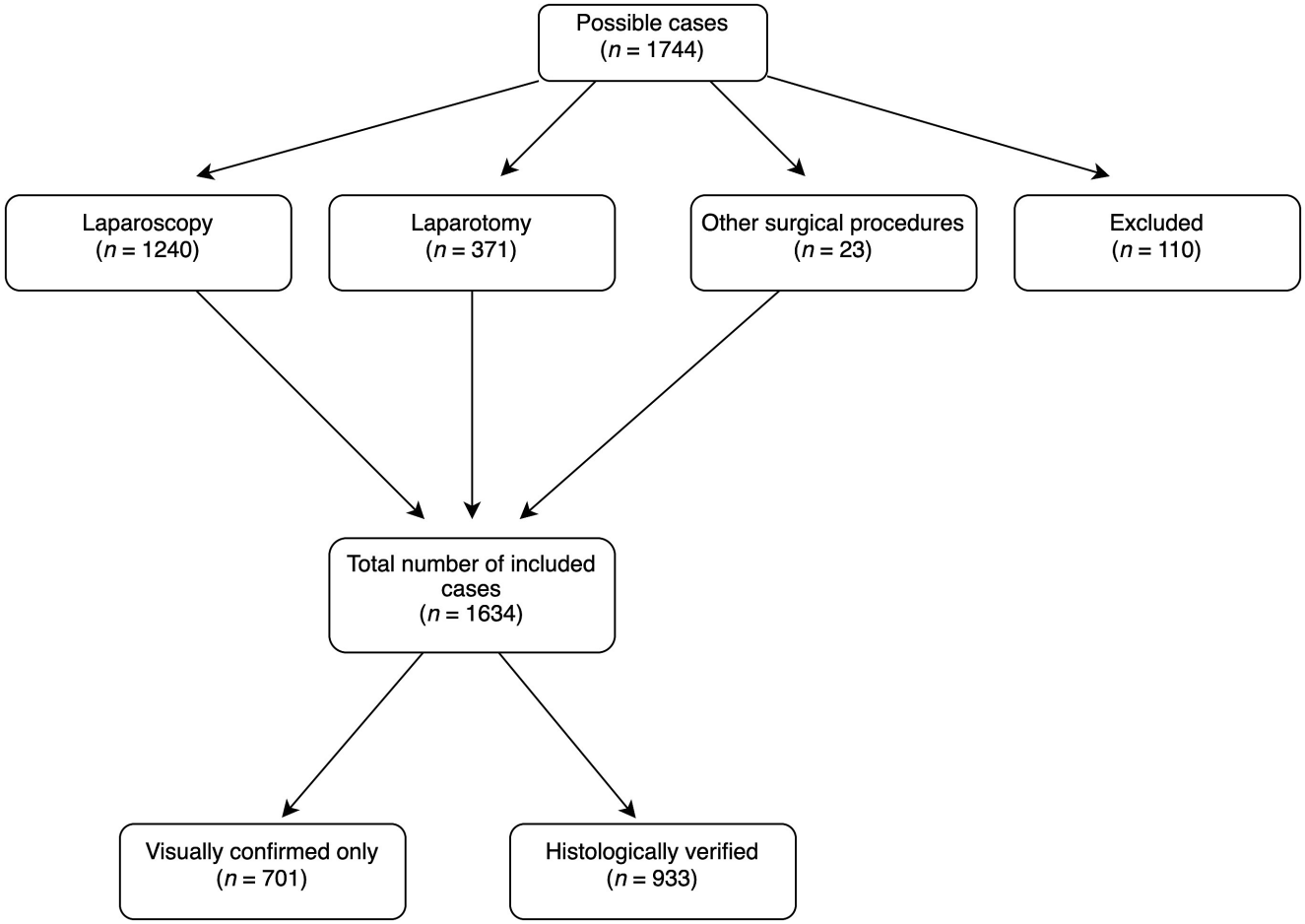

FIGURE 1 Overview of the case-finding process for visually confirmed and histologically verified endometriosis in the Icelandic population, 2001–2015.

TABLE 1 Estimates of crude annual incidence and age-standardized annual incidence per 10000 person-years of all confirmed endometriosis and histologically verified endometriosis in women aged 15–49 years according to the national register mid-year population, 2001–2015.

		All confirmed endometriosis			Histologically verified endometriosis		
Calendar year	Female population person-years	*n*	Crude rate	Standardized rate	*n*	Crude rate	Standardized rate
2001	72369	62	8.6	8.1	43	5.9	5.5
2002	72595	117	16.1	15.3	60	8.3	7.8
2003	72630	106	14.6	14.0	65	8.9	8.4
2004	72988	118	16.2	15.5	60	8.2	7.7
2005	73537	128	17.4	16.8	74	10.1	9.5
2006	74891	109	14.6	13.7	64	8.5	7.8
2007	76094	103	13.5	12.9	53	7.0	6.5
2008	78161	114	14.6	13.9	57	7.3	6.9
2009	78369	110	14.0	13.5	47	6.0	5.7
2010	77633	96	12.4	11.9	46	5.9	5.6
2011	77183	108	14.0	13.4	59	7.6	7.4
2012	77019	85	11.0	10.6	42	5.5	5.2
2013	77162	73	9.5	9.1	37	4.8	4.6
2014	77478	77	9.9	9.4	45	5.8	5.4
2015	77799	81	10.4	9.8	41	5.3	4.8
Total	1135908	1487	13.1	12.5	793	7.0	6.6

TABLE 2 Estimates of crude annual incidence and age-standardized annual incidence per 10000 person-years of all confirmed endometriosis and histologically verified endometriosis in women aged 15–69 years according to the national register mid-year population, 2001–2015.

		All confirmed endometriosis			Histologically verified endometriosis		
Calendar year	Female population person-years	*n*	Crude rate	Standardized rate	*n*	Crude rate	Standardized rate
2001	96811	71	7.3	6.9	51	5.3	4.9
2002	97717	131	13.4	13.0	72	7.4	7.0
2003	98536	116	11.8	11.5	75	7.6	7.3
2004	99645	126	12.6	12.4	68	6.8	6.5
2005	101127	147	14.5	14.3	92	9.1	8.7
2006	103453	116	11.2	10.9	71	6.9	6.5
2007	105667	111	10.5	10.4	61	5.8	5.5
2008	108944	126	11.6	11.4	69	6.3	6.1
2009	110221	121	11.0	11.0	57	5.2	5.1
2010	110529	103	9.3	9.5	53	4.8	4.7
2011	111062	116	10.4	10.7	67	6.0	6.1
2012	111797	91	8.1	8.4	48	4.3	4.3
2013	112835	80	7.1	7.3	43	3.8	3.8
2014	114063	87	7.6	7.7	55	4.8	4.7
2015	115211	92	8.0	8.1	51	4.4	4.3
Total	1597618	1634	10.2	10.2	933	5.8	5.7

the uterine peritoneum diagnosed after a hysterectomy for other causes (vesicouterine and central pelvic locations). The lesions were small and not noticed as the actual operation proceeded. Thus, they were not recorded as diagnoses on discharge from hospital or during follow-up and were only noticed when the histopathological SNOMED diagnoses were reviewed. Endometriosis was also seen incidentally during procedures for other causes, such as tubal sterilization, appendectomy, cancer removal or

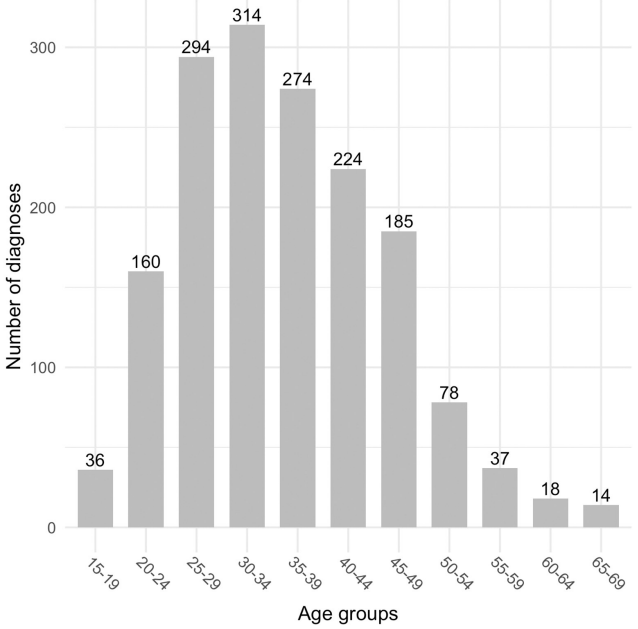

FIGURE 2 Age distribution at first diagnosis of endometriosis among women aged 15–69 years.

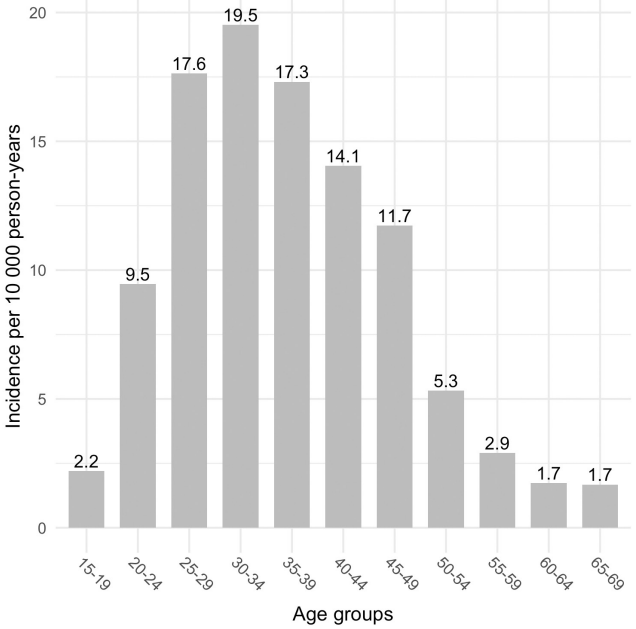

FIGURE 3 Age-specific incidence per 10 000 person-years among women aged 15–69 years with confirmed endometriosis diagnosis in the Icelandic population, 2001–2015.

cesarean surgery. Of the incidental findings, 177 (81.9%) were among women over 40 years.

When incidental data for the age 15–49 years were excluded, the crude incidence of visually confirmed endometriosis was 11.9/10 000 person-years and the respective age-standardized annual incidence 11.5/10 000 person-years (Table S1). For age 15–69 years, the crude incidence of visually confirmed endometriosis was 8.9/10 000 person-years, and the respective age-standardized annual incidence 9.0/10 000 person-years (Table S2).

Actual age at diagnosis ranged from 16 to 69 years, with a mean of 35.9 years (standard deviation 9.96; median 35.0). For histologically verified cases, the mean age was 38.9 years (standard deviation 10.61; median 39.0). The proportion of cases diagnosed after age 40 years was 31.5% (46.0% of histologically verified cases). Age at diagnosis was divided into 5-year age-groups, showing that most diagnoses were made among women aged 30–34 years (Figure 2).

The age-specific incidence was highest in the age-groups 25–29, 30–34, 35–39 and 40–44 years, at 17.6, 19.5, 17.3 and 14.1 per 10 000 person-years, respectively (Figure 3). Age-standardized annual incidence per 10 000 person-years (World Standard million) for women 15–49 and 15–69 years was calculated for all confirmed diagnoses and separately for histologically verified endometriosis (Figure 4). The age-standardized annual incidence showed a similar pattern in both age-groups for both visually confirmed and histologically verified diagnoses. There were fewer diagnoses in the last 4 years of the study (Tables 1 and 2, Figure 4), although there was a rise in the number of women in the background study population.

For the 1634 women, 2548 locations were assigned. The most common were the ovaries (one or both; n = 787), followed by deep pelvis (n = 783), central pelvis (n = 400), vesicouterine pouch (n = 355) and appendages (n = 223). Of the women, 976 (59.7%) had visible lesions in only one location and 658 (40.3%) had lesions in more than one location.

Of the women, 1080 (66.1%) had minimal/mild and 553 (33.8%) had moderate/severe disease; one case could not be staged. All incidental histological findings were staged as minimal/mild. Among histologically verified cases, 528 (56.6%) had minimal/mild and 404 (43.3%) had moderate/severe disease; one case could not be staged.

Prevalence proportions according to the above-stated equation, based on the total incidences in Table 1 and assuming the variable duration of symptoms of endometriosis to be from 5, 10, 20 and up to 30 years, were 0.6%, 1.2%, 2.4% and 3.6%, respectively. Using similar calculations for histologically confirmed endometriosis, assuming the same variable duration of symptomatic disease, prevalence proportions ranged from 0.3% to 1.9%, respectively.

4 | DISCUSSION

This was a new study to assess the incidence of surgically diagnosed endometriosis in the pelvis, both visually confirmed and histologically verified in a complete nation over a considerable length of time, analogous to our previous study.[9] The main results confirm what was found in the previous Icelandic study covering the 20 years before this one, namely, an annual total incidence of just over 0.1% among women in the reproductive ages of 15–49 years counting all cases. As the Icelandic population was not large, ranging from about 280 000 to 350 000 in the study period, we covered close to every

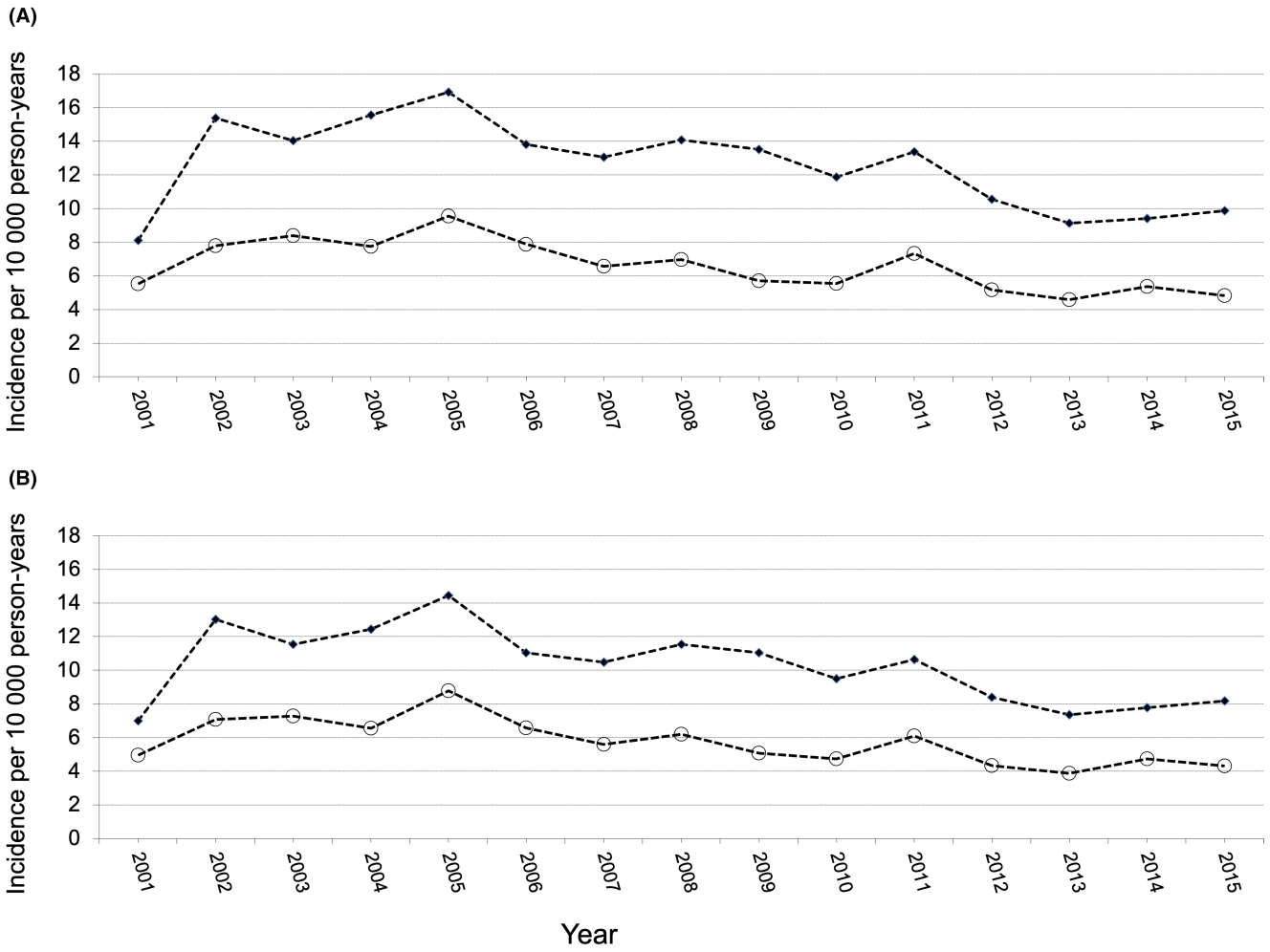

FIGURE 4 Age-standardized annual incidence per 10 000 person-years of all endometriosis diagnoses (dark circles) and histologically verified endometriosis (white circles) in women aged. (A) 15–49 years and (B) 15–69 years, during the whole study period (2001–2015).

case diagnosed. The study provides information on how commonly endometriosis is diagnosed in a high-resource population where there is no hindrance to surgical diagnosis performed on clinical indications, and where we had good accessibility to clinical, operative and pathology records. The material should be representative in terms of sampling frame, numerator/denominator, no response bias and ICD-codes, giving an acceptable case definition. The same mode of data collection was used for all potential cases. We included incidental and thus often symptomless pathological findings which would overestimate symptomatic/clinical disease and add numbers to those cases classified as minimal/mild (rASRM stages I–II).

As elsewhere, some of the operating gynecologists/surgeons may not have been sufficiently trained in recognizing subtle signs in the abdominal/pelvic cavity and this would have led to underestimation if lesions were missed, as well as reducing the number of lesion sites. Biopsies were only taken in about half the visually diagnosed cases, particularly not where infertility was the indication for laparoscopy. Although endometriosis can regress, such as during or after successful pregnancy, the more common progression[21] is likely in our population to have led to later diagnosis at a subsequent laparoscopy (incidental findings excluded). We do not have obvious explanations for variations in the annual number of diagnoses per year or for the modest decrease in the number of diagnoses in the last few years of the study period (Figure 4), except that the population is small and local diagnostic operative activity may have varied between years depending on circumstances or availability of the specific gynecologic services required. There was no definite information within the confines of the study material to explain this. There were changes within medical services in Iceland and treatment options for endometriosis during the period that the study covered, but these were not consistently at a level that would have had an effect on the possibilities for diagnosis. Comparable and usually not easily explained variations have also been observed in other studies.[12–15,22] This includes an even more pronounced and steady lowering of the incidence seen in Finland during a largely comparable study period.[13]

The staging results showed a higher proportion of minimal/mild disease, which may in part have been due to researcher interpretation differences, but primarily to better diagnosis of minor lesions at a time of increasing video-laparoscopy as compared with open

surgery in our former study. The incidental findings, particularly on the uterine peritoneal surface, also added to this difference.

Although most women in Iceland are white (Caucasian), prevalence rates in other ethnic groups may not be very different or lower.[16] A recent study from South Korea reported similar incidence rates.[23] The influence of lifestyle factors, contraceptive practices and reproduction patterns have been studied, but they have a limited effect on incidence.[5] Awareness in the health sector and access to diagnostic facilities does, however, matter. Although awareness of doctors, even gynecologists, will have varied as elsewhere, access to laparoscopic diagnosis was not a barrier when needed. All the surgeons were trained specialists. These aspects, along with other long suggested criteria for assessment of the incidence and prevalence of endometriosis, were largely in place for our study.[24]

In the earliest reliable study on endometriosis epidemiology, the clinically diagnosed cases were added to visually verified and histologically confirmed cases for estimation of the incidence rate.[6] There was, as in the present study, a focus on first diagnosis. It has not always been clear how medical records were consulted and the diagnosis verified,[25] and in some instances the study period was relatively short, introducing added uncertainty.[10,11,15,22] Often it has not proved possible to count out-of-hospital or private clinic diagnoses and thus these were not included along with information from hospital discharge registers.[8,11–15,22] Nor were incidental findings considered. We were able to address and incorporate these aspects.

We have now studied operative diagnosis of endometriosis for a total of 35 years in our previous and present studies. The incidence figure from both our studies of 0.1%–0.15% may appear small; however, these figures allow us to estimate the prevalence proportion to about 1% and up to 4% of women in this country, ie among women who will have had the condition at varyingly symptomatic stages during a considerable part of their reproductive years, ranging from no symptoms, infertility only and towards severe physical disability and multiple therapeutic attempts. Some will have had considerable symptoms for much of the time from menarche to menopause, occasionally even at older ages, whereas others will have suffered during shorter periods or not appreciably. It is easy to extrapolate from a small and well-defined population to a larger one and realize the actuarial burden for health systems that endometriosis represents, even if it does not reach the often cited but possibly inflated prevalence of 10%.[2,5,21,26] In population-based studies with designs that resemble the present study, the yearly incidence rates ranged from 0.1% to 0.3%.[6–15,27] Our new results concur with studies in the last 20–30 years.

A main strength of our study was the reporting from all electronic and paper records in a comprehensive and universally accessible public healthcare system, enabling us to include women with acute or chronic pelvic pain, fertility problems or other abdominal/pelvic symptoms who would have sought medical assistance and were likely to be diagnosed surgically in a healthcare system where such diagnosis was available. There is, however, not a clear link between the existence, magnitude or extent of endometriotic lesions and symptoms.[1,2,25] We therefore chose to report all instances diagnosed, symptomatic or incidental, in order to keep the study comprehensive and all-inclusive. While MRI or ultrasound are useful diagnostic tools for ovarian endometriomas and deep infiltrating endometriosis, they have limitations in relation to diffuse and small lesions[1,2] and, anyway, are likely in a society with comprehensive low-cost care to be followed by operative procedures if positive.

Limitations which our study shares with many others is that endometriosis as a possible explanation for malaise, pelvic pain and infertility may have been downplayed by medical practitioners. Women would thus in some cases not have been given the chance of further visual or histopathological verification, although this cannot be assessed in numerical terms. Advanced imaging facilities such as MRI was also not universally available at the time. While some of the operating surgeons were sub-specialized, others may not have been trained to recognize subtle endometriosis under the ovarian germinal epithelium, sub-peritoneally or where adhesions could have indicated the presence of disease. This would have led to underestimation, which on the other hand may have been compensated for by the access to laparoscopy and by including incidentally diagnosed cases from the pathology registers. We noted that superficial cautery was used too often in our material, biopsies were not taken and image-recording was underused. We also could not exclude from the denominator, women with already diagnosed endometriosis, which tends to underestimate incidence. It is, though, unlikely that this would have changed the result to an extent that would have brought the prevalence up towards the often stated 10%.

5 | CONCLUSION

We have shown that the incidence and likely prevalence of endometriosis, a disease causing considerable and protracted suffering for so many women in the prime of their lives, is substantial, even if our figures do not reach traditionally mentioned and perhaps inflated rates. This calls for universal better practices to optimize diagnostic approaches and procedures.

AUTHOR CONTRIBUTIONS

AK contributed to the research conception, design, data acquisition, analysis, statistics and interpretation of the data. RTG conceived the study and design and took part in data acquisition and interpretation. VR contributed to the statistical analysis and interpretation. AK and RTG wrote the article with input and revision from VR. All authors approved the final version to be published and agree to be accountable for all aspects of the work.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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