

## ORIGINAL RESEARCH ARTICLE

# Surgically confirmed endometriosis in adolescents in Finland—A register-based cross-sectional cohort study

Elina Rasp<sup>1</sup>  | Liisu Saavalainen<sup>1</sup>  | Anna But<sup>2</sup> | Mika Gissler<sup>3,4,5</sup> | Päivi Härkki<sup>1</sup> | Oskari Heikinheimo<sup>1</sup>  | Kristiina Rönö<sup>1</sup> 

<sup>1</sup>Department of Obstetrics and Gynecology, University of Helsinki and Helsinki University Hospital, Helsinki, Finland

<sup>2</sup>Biostatistics consulting, Department of Public Health, University of Helsinki and Helsinki University Hospital, Helsinki, Finland

<sup>3</sup>Finnish Institute for Health and Welfare (THL), Helsinki, Finland

<sup>4</sup>Academic Primary Health Care Center, Region Stockholm, Stockholm, Sweden

<sup>5</sup>Department of Molecular Medicine and Surgery, Karolinska Institute, Stockholm, Sweden

## Correspondence

Oskari Heikinheimo, Department of Obstetrics and Gynecology, Helsinki University Hospital, PO Box 140, 00029 HUS, Helsinki, Finland.  
Email: [oskari.heikinheimo@helsinki.fi](mailto:oskari.heikinheimo@helsinki.fi)

## Funding information

The Hospital District of Helsinki and Uusimaa

## Abstract

**Introduction:** Increasing awareness of endometriosis in adolescents requires data on the nature of the disease and its management. Our objective was to investigate the subtypes of surgically confirmed endometriosis in adolescents (aged <20 years) and trends in the incidence rates and endometriosis-related procedures during the study period, 1987–2012.

**Material and Methods:** In this register-based cohort study, we identified 526 adolescents receiving their initial surgical diagnosis of endometriosis between 1987 and 2012 from the Finnish Hospital Discharge Register. The age-specific incidence rate of surgically confirmed endometriosis was calculated by dividing the number of adolescents during specific periods by person-years. We calculated the relative differences in incidence rates between the periods using crude incidence ratios.

**Results:** Adolescents were divided into three age groups, <17, 17–18, and 19 years, which comprised 8.2% (43/526), 39.7% (209/526), and 52.1% (274/526) of the study cohort, respectively. Peritoneal endometriosis and ovarian endometriosis were the most common types (379/526 [72%] and 119/526 [23%], respectively). The incidence rate of surgically confirmed endometriosis per 100 000 person-years varied from 5.63 (95% confidence interval [CI] 4.24–7.33) to 11.42 (95% CI 9.64–13.44). The incidence rate in 2001–2005 was significantly higher and was 1.6- to 2.0-fold that of the periods 1987–1990 and 2006–2012, respectively. Comparing the periods in which *International Classification of Diseases, Ninth Revision* (ICD-9; 1987–1995) and *Tenth Revision* (ICD-10; 1996–2012) codes were used, the use of laparoscopy (78.2% vs 88.9%), day surgery (10.3% vs 31.6%), and procedures for ovarian (18.8% vs 34.1%) and deep (0.6% vs 10.8%) endometriosis increased. The types of endometriosis and procedures did not differ between the age groups.

**Conclusions:** Peritoneal endometriosis was the most common type of endometriosis overall and by age group. During the 26-year period, the incidence rate of initial surgical diagnosis of endometriosis peaked in 2001–2005 and decreased thereafter. The

**Abbreviations:** FHDR, The Finnish Hospital Discharge Register; PYs, person-years.

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2022 The Authors. *Acta Obstetrica et Gynecologica Scandinavica* published by John Wiley & Sons Ltd on behalf of Nordic Federation of Societies of Obstetrics and Gynecology (NFOG).

proportion of procedures performed for ovarian and deep endometriosis increased, as did the use of laparoscopy and day surgery.

#### KEYWORDS

adolescent, endometriosis, incidence rate, peritoneal endometriosis, surgical treatment

## 1 | INTRODUCTION

Endometriosis is a common gynecological disease involving estrogen-dependent chronic inflammatory processes and the presence of endometrial glands and stroma outside the uterine cavity.<sup>1,2</sup> Typical symptoms include dysmenorrhea, chronic pelvic pain, dyspareunia, dyschezia, dysuria, subfertility, and fatigue.<sup>3</sup> Pelvic pain is the most common symptom of endometriosis.<sup>4</sup> In particular, worsening dysmenorrhea should raise the suspicion of endometriosis.<sup>4</sup> The three major forms of endometriosis are superficial peritoneal type, ovarian endometriosis, and deep endometriosis.<sup>2</sup> Endometriosis may also occur as extra-pelvic lesions.<sup>2,3</sup>

Approximately 5%–10% of adult women are estimated to have endometriosis.<sup>4</sup> However, large population-based studies have reported somewhat lower prevalences of 1%–6%.<sup>5,6</sup> Conversely, 0.8%–2.0% of female adolescents aged 10–19 years are reported to have endometriosis,<sup>5,7</sup> but the true prevalence remains uncertain.

Dysmenorrhea is a common symptom in the years after menarche, and primary dysmenorrhea is a common gynecological complaint among adolescents. If the empirical treatment (pain medication, and hormonal contraceptives or progestogens) has no effect on the suspected endometriosis symptoms, imaging and diagnostic laparoscopy can be considered.<sup>8</sup> A definite diagnosis of endometriosis often requires verification by invasive means (surgical assessment and/or vaginal ultrasonography), to be used in adolescents only after careful consideration. In a systematic review, Hirsch et al. reported a mean prevalence of endometriosis of 64% among adolescents with pelvic pain.<sup>9</sup> A recent questionnaire-based study among Finnish adolescents reported a 2%–10% prevalence of symptoms compatible with endometriosis.<sup>10</sup>

Little is known of adolescent endometriosis compared with that in adults.<sup>11</sup> Diagnostic delays and misdiagnoses are common.<sup>4</sup> Adolescents who experience symptoms of endometriosis delay seeking medical attention by 4.7 years, with another 4.6 years until diagnosis.<sup>11</sup> Compared with adolescents without a history of endometriosis, those with endometriosis have a greater likelihood of moderate to severe distress.<sup>12</sup> The treatment guidelines for adolescent endometriosis are largely based on studies performed among adults.<sup>13</sup>

Given the rarity of adolescent endometriosis, large patient cohorts are needed. In the present study, the cohort of adolescents was derived from the Finnish nationwide cohort of surgically verified endometriosis between 1987 and 2012, comprising nearly 50 000 females of all ages.<sup>14</sup> The primary aims of the study were to provide data on the characteristics of the surgically confirmed

#### Key message

The incidence rate of surgically confirmed endometriosis in adolescents peaked in 2001–2005 but decreased thereafter. Peritoneal endometriosis was the most common type of endometriosis in adolescents, and the type of endometriosis did not differ between the age groups.

endometriosis in adolescents, specifically of the types of endometriosis and procedures performed according to age. The secondary aim was to determine the trends in the incidence of surgically confirmed endometriosis in adolescents in Finland.

## 2 | MATERIAL AND METHODS

This study was part of a large nationwide Finnish cohort of patients with the first surgically verified diagnosis of endometriosis ( $n = 49\,956$ ) between 1987 and 2012. The cohort formation, description, and quality assessment and the different registries have been described in detail previously.<sup>14</sup> Data were collected from the Finnish Hospital Discharge Register (FHDR), which is maintained by the Finnish Institute for Health and Welfare. The FHDR includes both the main and subsidiary diagnoses and records from all public (inpatient and outpatient care) and private (inpatient care) hospitals.

The cohort was formed by identifying all females with at least one surgical procedure with an endometriosis-related diagnosis (main or subsidiary) in the FHDR. We required a concomitant occurrence of relevant surgical code(s) and diagnosis and considered the first record satisfying our criteria as the initial surgery. The diagnosis of endometriosis was assessed as accurate in over 90% of cases.<sup>14</sup>

For the present study, adolescents at the time of the surgical diagnosis of endometriosis were retrieved from the initial cohort of females of all ages ( $n = 49\,956$ ). The World Health Organization defines adolescence as the ages from 10 to 19 years.<sup>15</sup> In the initial cohort, the youngest age at which endometriosis was surgically confirmed was 12 years. Subgroups of adolescents aged 12–16, 17–18, and 19 years were formed to describe and compare the age-specific distribution of patient and procedure characteristics set at the surgery.

The diagnosis of endometriosis was based on clinical findings at the time of surgery. The definition of surgically confirmed endometriosis

was fulfilled when the diagnosis of endometriosis was set with a relevant surgical procedure by the attending physician(s). Both emergency and elective procedures were considered eligible. The preoperative indications for the procedures are not available in the register. The diagnoses of endometriosis were classified according to the *International Classification of Diseases, Ninth Revision* (ICD-9, used in Finland during 1987–1995) and *Tenth Revision* (ICD-10, used in Finland since 1996). Based on these diagnoses, we further divided endometriosis in this study into peritoneal (6173A, 6173B/N80.2, N80.3); ovarian (6171A/N80.1); peritoneal and ovarian, other/unspecified (6178X/N80.8, N80.89, N80.9); deep (6174A, 6175A/N80.4, N80.5, N80.80, N80.81); and other combinations of endometriosis. Procedures in Finland are classified using the National League of Hospitals (1986–1996) and the Nordic Medico-Statistical Committee Classification of Surgical Procedures (since 1997). Endometriosis-associated procedures, divided into diagnostic procedures and surgical treatment for peritoneal, ovarian, and deep endometriosis, are shown in Table S1. Operations were defined as day surgery when the hospital admission and discharge occurred within the same day.

## 2.1 | Statistical analyses

Descriptive statistics are presented as mean with standard deviation (SD) or median with interquartile range (IQR) for continuous variables and number with percentage for categorical variables. Pearson's Chi-squared test, Fisher's exact test, and the Mann–Whitney U test were performed to examine the independence between the age groups as well as between the study (ICD-9, ICD-10) periods.

The incidence rate was calculated by dividing the number of adolescents by person-years (PYs) and was reported per 100 000 PYs. PYs were determined as the size of the Finnish female population of the corresponding age reported by Statistics Finland for the end of each year.<sup>16</sup> To compare age groups, we assessed the age-specific incidence rates, and to assess the trend in the incidence rates, the cohort was divided into six sub-cohorts according to the year of initial surgery (1987–1990, 1991–1995, 1997–2000, 2001–2005, 2006–2010, 2011–2012). The relative differences in the incidence rate between the study periods were calculated by the (crude) incidence rate ratios: the incidence rate of the period with the highest incidence divided by the incidence rate of other periods. During 1996, the FHDR introduced the ICD-10 and started to use the new classification of surgical procedures. This year was excluded from the calculation of incidence because diagnosis entries were incomplete in the FHDR.

The analyses were performed using R Studio version 1.1.463.

## 2.2 | Ethical approval

The ethics committee of the Hospital District of Helsinki and Uusimaa approved the study (238/13/03/03/2013). The following registry-keeping authorities also approved data retrieval and linkage: the Finnish Institute for Health and Welfare (THL/546/5.05.00/2014),

the Population Register Center (D1794/410/14), and Statistics Finland (Dnro TK53-547-14).

## 3 | RESULTS

Altogether, 526 adolescents (1% of the initial cohort) had surgically confirmed endometriosis between 1987 and 2012 in Finland. Of all adolescents with the initial surgical diagnosis of endometriosis between 1987 and 2012, only 43 (8.2%) were aged <17 years, 209 (39.7%) were aged 17–18 years, and 274 (52.1%) were aged 19 years. The diagnoses and procedures did not differ according to age group (Tables 1 and 2). Overall, and in each age group, peritoneal endometriosis was the most common surgically confirmed type of endometriosis. In total, 225 (42.8%) of the adolescents had at least one other disease or symptom-based diagnosis in addition to endometriosis (Tables 1 and 3).

Both the annual number and the incidence rate of surgically confirmed endometriosis varied considerably during the study period (Figure 1). The incidence of surgically confirmed endometriosis and rate ratios of the initial surgical diagnosis of endometriosis in adolescents are shown in Table 4. When calculated by periods, the lowest incidence rate was observed between 1987 and 1990 (5.63/100 000 PYs) and the highest was observed between 2001 and 2005 (11.42/100 000 PYs). The incidence rate was 2.0 times higher between 2001 and 2005 than in the 1987–1990 period and 1.9 and 1.6 times higher than in the later periods, 2006–2010 and 2011–2012, respectively.

Between the ICD-9 and ICD-10 periods, the use of laparoscopy (78.2% vs 88.9%) and day surgery (10.3% vs 31.6%) and the proportion of procedures for ovarian (18.8% vs 34.1%) and deep (0.6% vs 10.8%) endometriosis increased (Table 5). Further, the distribution of the types of endometriosis changed during the study period (Table 3). At least one concurrent procedure, such as chromopertubation or appendectomy, was performed in 73 (13.9%) of the adolescents (Tables 2 and 5). When comparing the age distribution between ICD-9 and ICD-10 periods, a shift toward a younger age at initial surgery was observed during the latter (Figure S1). However, the difference remained statistically non-significant (Table 2).

## 4 | DISCUSSION

In our Finnish population-based cross-sectional cohort study of adolescents with initial surgically confirmed endometriosis, peritoneal endometriosis was the most common type. The incidence rate of surgically confirmed endometriosis increased from 5.6 per 100 000 PYs between 1987 and 1990 to 11.4 between 2001 and 2005 and decreased to 7.1 between 2011 and 2012. During the 26-year study period, the use of laparoscopy and day surgery increased, as did the number of procedures for ovarian and deep endometriosis.

The types – as against stages – of endometriosis among adolescents have been reported in a few studies with surgical diagnoses.<sup>17,18</sup>

**TABLE 1** Initial surgical diagnosis of endometriosis of adolescents in Finland between 1987 and 2012: diagnoses according to age subgroups

	Total <20 years, n = 526	Subgroups, age in years			p-value <sup>a</sup>
		12–16, n = 43	17–18, n = 209	19, n = 274	
Age at index surgery, years	19.1 (18.19–19.54)	16.2 (14.96–16.71)	18.3 (17.83–18.67)	19.5 (19.30–19.74)	
Endometriosis as the main diagnosis at surgery	408 (77.6)	33 (76.7)	157 (75.1)	218 (79.6)	0.506
Type of endometriosis <sup>b</sup>					
Peritoneal	342 (65.0)	26 (60.5)	144 (68.9)	172 (62.8)	0.596
Ovarian	82 (15.6)	8 (18.6)	27 (12.9)	47 (17.2)	
Peritoneal and ovarian	37 (7.0)	4 (9.3)	11 (5.3)	22 (8.0)	
Other/unspecified	32 (6.1)	2 (4.7)	12 (5.7)	18 (6.6)	
Deep	19 (3.6)	3 (7.0)	9 (4.3)	7 (2.6)	
Other combinations <sup>c</sup>	14 (2.7)	0 (0.0)	6 (2.9)	8 (2.9)	
Endometriosis as only diagnosis	324 (61.6)	26 (60.5)	138 (66.0)	160 (58.4)	0.229
Other and symptom-based diagnoses					
Benign ovarian tumors excl. endometriomas <sup>d</sup>	60 (11.4)	3 (7.0)	28 (13.4)	29 (10.6)	0.438
Abdominal pain <sup>e</sup>	51 (9.7)	5 (11.6)	14 (6.7)	32 (10.7)	0.157
Pain and other conditions associated with female genital organs and menstrual cycle <sup>f</sup>	25 (4.8)	3 (7.0)	10 (4.8)	12 (4.4)	0.634
Peritoneal adhesions <sup>g</sup>	19 (3.6)	2 (4.7)	6 (2.9)	11 (4.0)	
Infertility <sup>h</sup>	14 (2.7)	3 (7.0)	3 (1.4)	8 (2.9)	
Early pregnancy issues <sup>i</sup>	12 (2.3)	1 (2.3)	3 (1.4)	8 (2.9)	
Infection <sup>j</sup>	9 (1.7)	0 (0.0)	3 (1.4)	6 (2.2)	
Gynecological malformations <sup>k</sup>	8 (1.5)	1 (2.3)	2 (1.0)	5 (1.8)	
Other <sup>l</sup>	27 (5.1)	2 (4.7)	9 (4.3)	16 (5.8)	

Note: Data are presented as n (%) or median (interquartile range) unless indicated otherwise.

<sup>a</sup>Between subgroups.

<sup>b</sup>Peritoneal (6173A, 6173B/N80.2, N80.3), ovarian (6171A/N80.1), peritoneal and ovarian, other/unspecified (6178X/N80.8, N80.89, N80.9), deep (6174A, 6175A/N80.4, N80.5, N80.80, N80.81), and all other combinations of endometriosis.

<sup>c</sup>Other combinations of diagnosis of endometriosis included the diagnosis of deep endometriosis altogether in ten (1.9%) adolescents; none of the adolescents aged 12–16 years, four aged 17–18 years, and six aged 19 years.

<sup>d</sup>Benign neoplasm of ovary or other and unspecified female genital organs (2200A, 2218A/D27, D28); neoplasm of uncertain or unknown behavior of female genital organs (2395A/D39); noninflammatory disorders of ovary, fallopian tube, and broad ligament (620/N83); developmental ovarian cyst/embryonic cyst of fallopian tube or broad ligament (Q50.1, Q50.5, Q50.5).

<sup>e</sup>Abdominal and pelvic pain or acute pain (7890A/R10, R52).

<sup>f</sup>Pain and other conditions associated with female genital organs and menstrual cycle (6253A/ N94).

<sup>g</sup>Peritoneal adhesions or female pelvic peritoneal adhesions (5680A, 6146A/K660, N73.6).

<sup>h</sup>Infertility (628/N97).

<sup>i</sup>Pregnancy with abortive outcome (632, 633, 634, 637/ O00, O02, O03, O04).

<sup>j</sup>Salpingitis and oophoritis (614/N70).

<sup>k</sup>Congenital malformations of ovaries, uterus, and cervix (752/Q50.0, Q51).

<sup>l</sup>Miscellaneous diagnoses.

The most common type in our cohort was peritoneal endometriosis, with or without ovarian endometriomas (72%). This finding is in line with two previous studies (48%–56%).<sup>17,18</sup> The proportion of ovarian endometriosis varies considerably between different studies, ranging from 33% to 87%.<sup>17–19</sup> In our study, the proportion of ovarian endometriosis (23%) was the second most common but remained

lower than in previous studies. In addition, the diagnosis of deep endometriosis was rarer in our study than in a French study from 1998 to 2013 and a Brazilian study from 2008 to 2013 (5.5% vs 11–33%, respectively).<sup>17,18</sup> This might be explained by the different study periods, study designs, and varying diagnosis and treatment practices between countries. In addition, the use of hormonal treatment might

**TABLE 2** Initial surgical diagnosis of endometriosis of adolescents in Finland between 1987 and 2012: procedures according to the age subgroups

	Total <20 years, n = 526	Subgroups, age in years			p-value <sup>a</sup>
		12–16, n = 43	17–18, n = 209	19, n = 274	
Age at index surgery, years	19.1 (18.19–19.54)	16.2 (14.96–16.71)	18.3 (17.83–18.67)	19.5 (19.30–19.74)	
Laparoscopy	450 (85.6)	34 (79.1)	176 (84.2)	240 (87.6)	0.261
Day surgery	131 (24.9)	9 (20.9)	54 (25.8)	68 (24.8)	0.794
Endometriosis-associated procedure(s)					
Only diagnostic	128 (24.3)	8 (18.6)	53 (25.4)	67 (24.5)	0.642
Peritoneal	248 (47.1)	18 (41.9)	103 (49.3)	127 (46.4)	0.627
Ovarian <sup>b</sup>	154 (29.3)	14 (32.6)	57 (27.3)	83 (30.3)	0.682
Deep <sup>c</sup>	40 (7.6)	5 (11.6)	15 (7.2)	20 (7.3)	0.534
Adolescents with other procedures	73 (13.9)	8 (18.6)	32 (15.3)	33 (12.0)	0.38
Number of other procedures					
Chromopertubation	13 (2.5)	0 (0.0)	5 (2.4)	8 (2.9)	
Appendectomy	11 (2.1)	2 (4.7)	3 (1.4)	6 (2.2)	
Curettage of cervix, corpus, or both or dilation of the cervix	11 (2.1)	1 (2.3)	7 (3.3)	3 (1.1)	
Insertion of intrauterine device, endometrium biopsy, or hysteroscopy	10 (1.9)	0 (0.0)	3 (1.4)	7 (2.6)	
Other <sup>d</sup>	32 (6.1)	5 (11.6)	16 (7.7)	11 (4.0)	

Note: Data are presented as n (%) or median (interquartile range) unless otherwise indicated.

<sup>a</sup>Between subgroups.

<sup>b</sup>Oophorectomy was performed for 21 (4.0%) adolescents, for two adolescents aged 12–16, for ten aged 17–18 years, and for nine aged 19 years.

<sup>c</sup>Resection of sacrouterine ligament(s) performed for seven (1.3%) adolescents; one adolescent aged 12–16, one aged 17–18 years, and five aged 19 years.

<sup>d</sup>Other concurrent procedures (n < 10): other operation of the abdominal wall, intestine, peritoneum, mesentery or omentum<sup>6</sup>; colposcopy, conization of cervix uteri or laser/coagulation/biopsy/excision of lesion of the vagina<sup>4</sup>; laparoscopic salpingostomy and removal of products of extrauterine pregnancy<sup>4</sup>; salpingectomy<sup>4</sup>; hysterectomy<sup>3</sup>; excision of vaginal septum or repair of vulva and perineum<sup>3</sup>; laparoscopic biopsy of the uterus or uterine ligaments or other excision of lesion of the uterus<sup>2</sup>; sterilization<sup>2</sup>; ureterocystoscopy including insertion of ureter catheter<sup>1</sup>; removal of subcutaneous tumor<sup>1</sup>; reoperation for deep hemorrhage in gynecologic surgery<sup>1</sup>; procedural code incorrect.<sup>1</sup>

partly explain these differences; however, these data were unavailable for the present study. We found no differences in the types of endometriosis between the different adolescent age groups.

In the present study, the incidence of surgically confirmed adolescent endometriosis varied significantly during the study period, whereas the overall incidence rate of surgically confirmed endometriosis among women of all ages (median age 38.5 years) decreased by one-third in Finland from 1987 to 2012.<sup>14</sup> In contrast, the use of laparoscopy more than doubled during this time.<sup>14</sup> The increasing use of less invasive laparoscopic techniques might partly explain the increasing incidence of surgically confirmed adolescent endometriosis from the beginning of the 1990s until the 2000–2006 period. The increased awareness of endometriosis among adolescents reported in the USA from 1980 to 1998 is also important.<sup>11</sup> The use of non-surgical diagnostics, improved conservative treatments for endometriosis,<sup>20–23</sup> and the favoring of more general diagnoses of chronic pelvic pain<sup>24</sup> are likely to have contributed to the decrease in the incidence of surgically confirmed adolescent endometriosis

in our cohort after 2005. Moreover, the previous and most recent guidelines for endometriosis encourage noninvasive diagnostics and treatment methods.<sup>8</sup> However, it remains unknown whether this explains the shift in first surgical diagnosis. Similarly, a recent study from 2006 to 2015 from the USA found a significantly decreasing incidence of surgically diagnosed endometriosis among adolescents aged 16–20 years.<sup>24</sup>

We compared the ICD-9 and ICD-10 periods to assess the evolution in diagnosis and treatment of endometriosis. We found an increased use of laparoscopy, day surgery, and procedures for ovarian and deep endometriosis. Minimally invasive operative techniques and day surgeries seem to also be beneficial for adolescents.<sup>25,26</sup> The increased proportion of procedures for ovarian and deep endometriosis might better reflect improvements in diagnostics and laparoscopic surgery.

In the present study, 62% of the adolescents had endometriosis as the only diagnosis set at the surgery. Besides endometriosis, the most common diagnostic code sets in the same

	ICD-9 (n = 165)	ICD-10 (n = 361)	p <sup>a</sup>
Age at index surgery	19.1 (18.4–19.6)	19.0 (18.1–19.5)	0.162
Number of adolescents per age group			
12–16 years	11 (6.7)	32 (8.9)	0.222
17–18 years	59 (35.8)	150 (41.2)	
19 years	95 (57.6)	179 (49.6)	
Endometriosis as the main diagnosis at surgery	126 (76.4)	282 (78.1)	0.738
Type of endometriosis diagnosis <sup>b</sup>			0.012
Peritoneal	117 (70.9)	225 (62.3)	
Ovarian	23 (13.9)	59 (16.3)	
Peritoneal and ovarian	16 (9.7)	21 (5.8)	
Other/unspecified	5 (3.0)	27 (7.5)	
Deep <sup>c</sup>	2 (1.2)	17 (4.7)	
Other combinations <sup>c</sup>	2 (1.2)	12 (3.3)	
Endometriosis as the only diagnosis	97 (58.8)	227 (62.9)	0.424
Other and symptom-based diagnosis			
Benign ovarian tumors excl. endometriomas <sup>d</sup>	20 (12.1)	40 (11.1)	0.841
Abdominal pain <sup>e</sup>	22 (13.3)	29 (8.0)	0.081
Pain and other conditions associated with female genital organs and menstrual cycle <sup>f</sup>	7 (4.2)	18 (5.0)	0.880
Peritoneal adhesions <sup>g</sup>	5 (3.0)	14 (3.9)	0.817
Infertility <sup>h</sup>	3 (1.8)	11 (3.0)	0.565
Early pregnancy issues <sup>i</sup>	4 (2.4)	8 (2.2)	1
Infection <sup>j</sup>	3 (1.8)	6 (1.7)	1
Gynecological malformations <sup>k</sup>	2 (1.2)	6 (1.7)	1
Other <sup>l</sup>	9 (5.4)	18 (5.0)	0.99

Note: Data are presented as n (%) or median (interquartile range) unless indicated otherwise. Abbreviation: ICD-9/10, *International Classification of Diseases, Ninth/Tenth Revision*.

<sup>a</sup>Between subgroups.

<sup>b</sup>Peritoneal (6173A, 6173B/N80.2, N80.3); ovarian (6171A/N80.1); peritoneal and ovarian, other/unspecified (6178X/N80.8, N80.89, N80.9); deep (6174A, 6175A/N80.4, N80.5, N80.80, N80.81); and all other combinations of endometriosis.

<sup>c</sup>Other combinations of diagnosis of endometriosis included the diagnosis of deep endometriosis in two cases with the ICD-9 and in eight with the ICD-10.

<sup>d</sup>Benign neoplasm of ovary or other and unspecified female genital organs (2200A, 2218A/D27, D28); neoplasm of uncertain or unknown behavior of female genital organs (2395A/D39); noninflammatory disorders of ovary, fallopian tube, and broad ligament (620/N83); developmental ovarian cyst/embryonic cyst of fallopian tube or broad ligament (Q50.1, Q50.5, Q50.5).

<sup>e</sup>Abdominal and pelvic pain or acute pain (7890A/R10, R52).

<sup>f</sup>Pain and other conditions associated with female genital organs and menstrual cycle (6253A/N94).

<sup>g</sup>Peritoneal adhesions or female pelvic peritoneal adhesions (5680A, 6146A/K660, N73.6).

<sup>h</sup>Infertility (628/N97).

<sup>i</sup>Pregnancy with abortive outcome (632, 633, 634, 637/O00, O02, O03, O04).

<sup>j</sup>Salpingitis and oophoritis (614/N70).

<sup>k</sup>Congenital malformations of ovaries, uterus, and cervix (752/Q50.0, Q51).

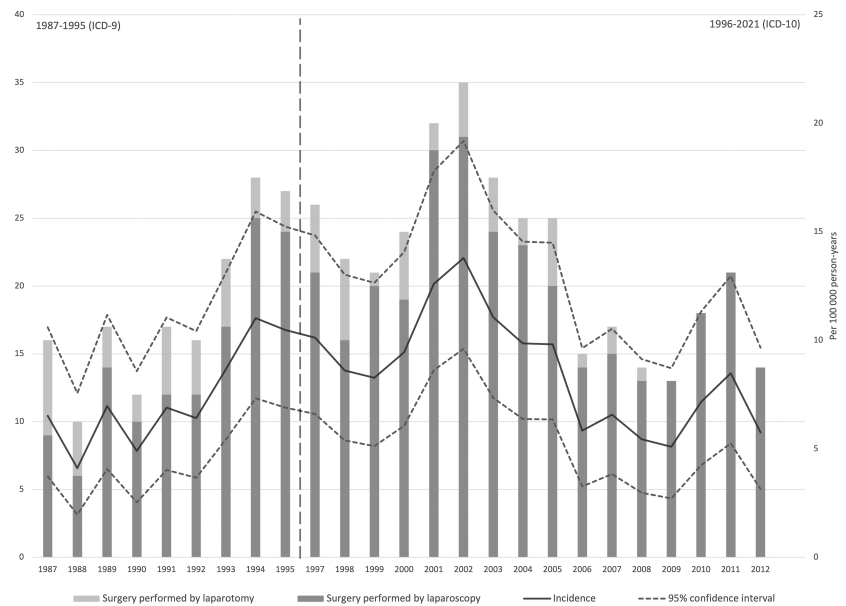
<sup>l</sup>Miscellaneous diagnoses.

TABLE 3 Initial surgical diagnosis of endometriosis of adolescents in Finland between 1987 and 2012: diagnoses according to periods related to ICD-9 (1987–1995) and ICD-10 (1996–2012)

procedure included benign ovarian tumors and symptom-based diagnoses such as abdominal pain or pain associated with female genital organs and menstrual cycle. A French study in adolescent

endometriosis reported that 96% of patients presented with dysmenorrhea and 9% with infertility,<sup>18</sup> whereas a Chinese study in adolescent endometriosis reported that 92% presented with

**FIGURE 1** Initial surgical diagnosis of endometriosis of adolescents aged 12–19 years in Finland between 1987 and 2012: the number of surgical diagnoses with the proportion of laparoscopies and laparotomies (bars; y-axis on the left) and the yearly incidence with 95% confidence intervals (solid and dashed lines; y-axis on the right). The data from 1996 were excluded because of the transition from the Ninth to the Tenth revision of the *International Classification of Diseases* (ICD-9 and ICD-10, respectively) diagnostic coding system.



**TABLE 4** Initial surgical diagnosis of endometriosis of adolescents aged 12–19 years in Finland between 1987 and 2012: numbers, PYs, IRs of surgically confirmed endometriosis by periods, and IRRs with their 95% CIs between the periods

Period of initial surgery	Number of adolescents with endometriosis	PYs	IR	IRR
1987–1990	55	976 355	5.63 (4.24–7.33)	2.03 (1.72–2.39)
1991–1995	110	1 263 799	8.70 (7.15–10.49)	1.31 (1.12–1.54)
1997–2000	93	1 020 099	9.12 (7.36–11.17)	1.25 (1.06–1.47)
2001–2005	145	1 269 244	11.42 (9.64–13.44)	Reference
2006–2010	77	1 278 539	6.02 (4.75–7.53)	1.90 (1.61–2.23)
2011–2012	35	490 921	7.13 (4.97–9.92)	1.60 (1.36–1.89)

Note: The year 1996 was excluded from the analyses because the Finnish Hospital Discharge Register switched to using the *International Classification of Diseases, Tenth Revision*, which included new classifications of surgical procedures.

Abbreviations: CI, confidence interval; IRs, incidence rates, IRR, incidence rate ratios; PYs, person-years.

pelvic pain, 30% with abdominal pain, and 30% with gastrointestinal dysfunction.<sup>19</sup>

The natural course of endometriosis is poorly understood. Earlier studies suggested that adolescents have more stage I–II endometriosis, as classified by the American Society of Reproductive Medicine, representing “milder” forms of the disease. However, later studies have challenged this.<sup>27</sup>

Congenital Müllerian anomalies are probably associated with endometriosis via obstruction of the outflow.<sup>28</sup> In our cohort, only 1.5% were diagnosed with a congenital Müllerian anomaly. Two other studies with different selection criteria reported a prevalence of congenital anomalies ranging from 7% to 24% in adolescents with endometriosis.<sup>18,19</sup>

The strengths of our study include the large nationwide cohort covering 26 years and the use of the FHDR, known for its high accuracy.<sup>29,30</sup> In addition, the quality of the endometriosis diagnosis in the register has been assessed as good, with an accuracy of over 95%.<sup>14</sup> National legislation ensures the registration of the specific health-related data gathered using the unique personal identity code given to each Finnish citizen and permanent resident at birth

or immigration. To our knowledge, this study is one of the largest of this issue. Reassuringly, our findings are in agreement with previous studies in adolescent endometriosis.

The most important limitation is that the overall incidence and therefore also the prevalence of adolescent endometriosis remains unknown since we could only study the incidence among patients with surgically confirmed endometriosis. Surgically confirmed diagnosis of endometriosis in adolescents was rare, comprising only 1% of all cases, so the cohort remained small. Another limitation was selection bias due to the historical study design and because we concentrated on those with surgical diagnosis, in other words, patients with disease that was probably more symptomatic or complicated and that was not responding to medical treatment. This limitation includes the lack of data on conservative medical treatment. Moreover, the indications for surgery were not available in the register and might differ from those of patients aged  $\geq 20$  years. Other limitations include that the study does not contain data beyond 2012. Furthermore, the diagnosis of deep endometriosis became its own entity in the 1990s and is therefore also more prominent during the later years of the study. This and other changes, including in diagnostic criteria and methods, mean the two periods are not entirely

**TABLE 5** Initial surgical diagnosis of endometriosis of adolescents (aged 12–19) in Finland between 1987 and 2012: procedures according to periods related to ICD-9 (1987–1995) and ICD-10 (1996–2012)

	ICD-9 (n = 165)	ICD-10 (n = 361)	p-value <sup>a</sup>
Laparoscopy	129 (78.2)	321 (88.9)	0.002
Day surgery	17 (10.3)	114 (31.6)	<0.001
Endometriosis-associated procedure(s)			
Diagnostic	35 (21.2)	93 (25.8)	0.308
Peritoneal	109 (66.1)	225 (62.3)	0.467
Ovarian <sup>b</sup>	31 (18.8)	123 (34.1)	<0.001
Deep <sup>c</sup>	1 (0.6)	39 (10.8)	<0.001
Adolescents with other, concurrent procedures	21 (12.7)	52 (14.4)	0.704
Number of concurrent procedures			
Chromopertubation	1 (0.6)	12 (3.3)	0.073
Appendectomy	2 (1.2)	9 (2.5)	0.516
Curettage of cervix, corpus or both, or dilation of the cervix	5 (3.0)	6 (1.7)	0.333
Insertion of intrauterine device, endometrium biopsy, or hysteroscopy	3 (1.8)	7 (1.9)	1
Other <sup>d</sup>	10 (6.0)	22 (6.1)	1

Abbreviation: ICD-9/10, International Classification of Diseases, Ninth/Tenth Revision.

<sup>a</sup>Between subgroups.

<sup>b</sup>Oophorectomy was performed for eight adolescents using the ICD-9 and for 13 using the ICD-10 classifications.

<sup>c</sup>Resection of sacrouterine ligament(s) performed for one adolescent using the ICD-9 and six using the ICD-10 classifications.

<sup>d</sup>Other operation on the abdominal wall, intestine, peritoneum, mesentery or omentum;<sup>6</sup> colposcopy, conization of cervix uteri or laser/coagulation/biopsy/excision of lesion of the vagina;<sup>4</sup> laparoscopic salpingostomy and removal of products of contraception;<sup>4</sup> salpingectomy;<sup>4</sup> hysterectomy;<sup>3</sup> excision of vaginal septum or repair of vulva and perineum;<sup>3</sup> laparoscopic biopsy of the uterus or uterine ligaments or other excision of lesion of the uterus;<sup>2</sup> sterilization;<sup>2</sup> ureterocystoscopy including insertion of ureter catheter;<sup>1</sup> removal of subcutaneous tumor;<sup>1</sup> reoperation for deep hemorrhage in gynecologic surgery;<sup>1</sup> procedural code incorrect.<sup>1</sup>

comparable. In addition, the completeness and accuracy of procedure codes has not been specifically assessed, and the sample size remained small in different age subgroups. Lastly, the rather homogeneous population of Finland limits the generalizability of the findings.

## 5 | CONCLUSION

The most common type of endometriosis in adolescents with surgically confirmed endometriosis was peritoneal endometriosis,

and the distribution of endometriosis between the age groups did not differ. The incidence rate of surgically confirmed adolescent endometriosis varied from 5.6 to 11.4 and down to 7.1 per 100 000 PYs during the 26 years between 1987 and 2012. The estimate is based on cases treated in hospitals. Thus, the true incidence and prevalence remains unknown. The increasing incidence until the period from 2000 to 2005 could be partly explained by the more common use of less invasive operative methods, whereas the subsequent decreased incidence could be due to the increasing use of non-surgical modalities in diagnostics and improved conservative treatment of endometriosis. Further research focused on more recent periods and larger samples of adolescents, including those with endometriosis diagnosed using modern noninvasive techniques, are needed to provide up-to-date and more comprehensive figures on the incidence and treatment of endometriosis in adolescents.

## AUTHOR CONTRIBUTIONS

ER, LS, AB, MG, PH, OH, and KR participated in the design of the study. AB planned the analyses. ER and AB managed the data. ER performed the analysis. AB, LS, and KR contributed to interpreting the data. ER wrote the first draft of the manuscript, and this was further thoroughly edited by LS, AB, MG, PH, OH, and KR. OH obtained funding. Each author provided input to all phases of the study, contributed to critical revision of the manuscript, and approved the final version.

## FUNDING INFORMATION

The Hospital District of Helsinki and Uusimaa.

## CONFLICT OF INTEREST

OH occasionally serves on advisory boards organized by Bayer AG and Gedeon-Richter and has planned and lectured at educational events organized by these companies. The other authors declare no conflicts of interest.

## ORCID

Elina Rasp  <https://orcid.org/0000-0003-1611-3037>

Liisu Saavalainen  <https://orcid.org/0000-0001-8002-0789>

Oskari Heikinheimo  <https://orcid.org/0000-0002-8671-130X>

Kristiina Rönö  <https://orcid.org/0000-0002-6344-1159>

## REFERENCES

- Vercellini P, Viganò P, Somigliana E, Fedele L. Endometriosis: pathogenesis and treatment. *Nat Rev Endocrinol*. 2014;10:261-275.
- Bulun SE, Yilmaz BD, Sison C, et al. Endometriosis. *Endocr Rev*. 2019;40:1048-1079.
- Zondervan KT, Becker CM, Missmer SA. Endometriosis. *N Engl J Med*. 2020;382:1244-1256.
- Taylor HS, Kotlyar AM, Flores VA. Endometriosis is a chronic systemic disease: clinical challenges and novel innovations. *Lancet*. 2021;397:839-852.
- Eisenberg VH, Weil C, Chodick G, Shalev V. Epidemiology of endometriosis: a large population-based database study from a health-care provider with 2 million members. *BJOG*. 2018;125:55-62.



6. Rowlands J, Abbott JA, Montgomery GW, Hockey R, Rogers P, Mishra GD. Prevalence and incidence of endometriosis in Australian women: a data linkage cohort study. *BJOG*. 2021;128:657-665.
7. Haas D, Chvatal R, Reichert B, et al. Endometriosis: a premenopausal disease age pattern in 42,079 patients with endometriosis. *Arch Gynecol Obstet*. 2012;286:667-670.
8. Members of the Endometriosis Guideline Core Group, Becker, C. M., Bokor, A., et al. ESHRE guideline: endometriosis. *Hum Reprod Open*. 2022; 2022:hoac009.
9. Hirsch M, Dhillon-Smith R, Cutner AS, Yap M, Creighton SM. The prevalence of endometriosis in adolescents with pelvic pain: a systematic review. *J Pediatr Adolesc Gynecol*. 2020;33:623-630.
10. Suvitie PA, Hallamaa MK, Matomäki JM, Mäkinen JI, Perheentupa AH. Prevalence of pain symptoms suggestive of endometriosis among Finnish adolescent girls (TEENMAPS study). *J Pediatr Adolesc Gynecol*. 2016;29:97-103.
11. Ballweg ML. Big picture of endometriosis helps provide guidance on approach to teens: comparative historical data show endo starting younger, is more severe. *J Pediatr Adolesc Gynecol*. 2003;16:21-26.
12. Rowlands IJ, Teede H, Lucke J, Dobson AJ, Mishra GD. Young women's psychological distress after a diagnosis of polycystic ovary syndrome or endometriosis. *Hum Reprod*. 2016;31:2072-2081.
13. Sieberg CB, Lunde CE, Borsook D. Endometriosis and pain in the adolescent- striking early to limit suffering: a narrative review. *Neurosci Biobehav Rev*. 2020;108:866-876.
14. Saavalainen L, Tikka T, But A, et al. Trends in the incidence rate, type and treatment of surgically verified endometriosis—a nationwide cohort study. *Acta Obstet Gynecol Scand*. 2018;97:59-67.
15. World Health Organization 2022, Adolescent health. Available online at: [https://www.who.int/health-topics/adolescent-health#tab=tab\\_1](https://www.who.int/health-topics/adolescent-health#tab=tab_1) (Accessed 30 January 2022).
16. Statistics Finland 2022, StatFin online service. Available online at: [https://www.stat.fi/tup/statfin/index\\_en.html](https://www.stat.fi/tup/statfin/index_en.html) (Accessed 10 January 2022).
17. Andres M, Podgaec S, Carreiro KB, Baracat EC. Endometriosis is an important cause of pelvic pain in adolescence. *Rev Assoc Med Bras*. 2014;60:560-564.
18. Audebert A, Lecointre L, Afors K, Koch A, Wattiez A, Akladios C. Adolescent endometriosis: report of a series of 55 cases with a focus on clinical presentation and long-term issues. *J Minim Invasive Gynecol*. 2015;22:834-840.
19. Yang Y, Wang Y, Yang J, Wang S, Lang J. Adolescent endometriosis in China: a retrospective analysis of 63 cases. *J Pediatr Adolesc Gynecol*. 2012;25:295-299.
20. van den Bosch T, van Schoubroeck D. Ultrasound diagnosis of endometriosis and adenomyosis: state of the art. *Best Pract Res Clin Obstet Gynaecol*. 2018;51:16-24.
21. Foti PV, Farina R, Palmucci S, et al. Endometriosis: clinical features, MR imaging findings and pathologic correlation. *Insights Imaging*. 2018;9:149-172.
22. Mama ST. Advances in the management of endometriosis in the adolescent. *Curr Opin Obstet Gynecol*. 2018;30:326-330.
23. Benagiano G, Guo SW, Puttemans P, Gordts S, Brosens I. Progress in the diagnosis and management of adolescent endometriosis: an opinion. *Repro BioMed Online*. 2018;36:102-114.
24. Christ JP, Yu O, Schulze-Rath R, Grafton J, Hansen K, Reed SD. Incidence, prevalence, and trends in endometriosis diagnosis: a United States population-based study from 2006 to 2015. *Am J Obstet Gynecol*. 2021;225:500.e1-500.e9.
25. Deer JD, Sawardekar A, Suresh S. Day surgery regional anesthesia in children: safety and improving outcomes, do they make a difference? *Curr Opin Anaesthesiol*. 2016;29:691-695.
26. Qazi SH, Jeelani SM, Dogar SA, Das JK, Saxena AK. Approaches to the management of pediatric ovarian masses in the 21st century: systematic review and meta-analysis. *Pediatr Surg*. 2020;55:357-368.
27. Smorgick N, As-Sanie S, Marsh CA, Smith YR, Quint EH. Advanced stage endometriosis in adolescents and young women. *J Pediatr Adolesc Gynecol*. 2014;27:320-323.
28. Dovey S, Sanfilippo J. Endometriosis and the adolescent. *Clin Obstet Gynecol*. 2010;53:420-428.
29. Gissler M, Haukka J. Finnish health and social welfare registers in epidemiological research. *Nor Epidemiol*. 2004;14:113-120.
30. Sund R. Quality of the Finnish hospital discharge register: a systematic review. *Scand J Public Health*. 2012;40:505-515.

## SUPPORTING INFORMATION

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

**How to cite this article:** Rasp E, Saavalainen L, But A, et al. Surgically confirmed endometriosis in adolescents in Finland—A register-based cross-sectional cohort study. *Acta Obstet Gynecol Scand*. 2022;101:1065-1073. doi: [10.1111/aogs.14419](https://doi.org/10.1111/aogs.14419)