Intrauterine Device Use in Adolescents With Disabilities

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abstract

BACKGROUND AND OBJECTIVES: Intrauterine devices (IUDs) are increasingly being used in adolescents and nulliparous women for contraception. Levonorgestrel IUDs also have beneficial effects on bleeding and pain. Although they are recommended for menstrual suppression in adolescents with disabilities, there are limited data on their use in this population. Our objective is to describe the characteristics and experiences of levonorgestrel IUD use in nulliparous children, adolescents, and young adults with physical, intellectual, and developmental disabilities.

METHODS: A retrospective chart review was conducted for all nulliparous patients ages ≤22 with physical, intellectual, or developmental disabilities who had levonorgestrel IUDs placed between July 1, 2004, and June 30, 2014, at a tertiary-care children's hospital. Descriptive statistical analysis and survival analysis were performed.

RESULTS: In total, 185 levonorgestrel IUDs were placed in 159 patients with disabilities. The mean age was 16.3 (3.3; range of 9–22) years. Only 4% had ever been sexually active; 96% of IUDs were inserted in the operating room. IUD continuation rate at 1 year was 95% (95% confidence interval: 93%–100%) and at 5 years was 73% (95% confidence interval: 66%–83%). The amenorrhea rate was ∼60% throughout the duration of IUD use among those with available follow-up data. Side effects and complications were ≤3%.

CONCLUSIONS: In this study, we provide evidence for the therapeutic benefit and safety of levonorgestrel IUD use in adolescents and young adults with physical, intellectual, and developmental disabilities. It should be considered as a menstrual management and contraceptive option for this population.

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Dr Schwartz conceptualized and designed the study, performed and interpreted data analysis, drafted the initial manuscript, and reviewed and revised the manuscript; Dr Alexander contributed to the design of the study, performed all data collection, performed and interpreted data analysis, assisted in preparation of the initial manuscript, and critically reviewed and revised the manuscript; Dr Breech contributed to the conceptualization and design of the study and critically reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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WHAT'S KNOWN ON THIS SUBJECT: Intrauterine devices (IUDs) reduce unintended pregnancies and improve bleeding, pain, and quality of life for women with heavy menstrual bleeding and dysmenorrhea. There are minimal data on IUD use for menstrual management and contraception in young women with disabilities.

WHAT THIS STUDY ADDS: This is the largest study of IUD use in young women with physical, intellectual, and developmental disabilities. With these data, we provide evidence that IUDs are effective, well-tolerated, safe menstrual management and contraceptive options for this population.

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There are increasing data on intrauterine device (IUD) use in adolescents and nulliparous women, but these are usually limited to contraceptive use. The 5-year 52-mg levonorgestrel IUD has also been shown to have beneficial effects on heavy menstrual bleeding[1–3] and dysmenorrhea[4,5] in adults. There are minimal data on the use of levonorgestrel IUDs for other indications, especially in adolescents.

Desire for menstrual management or suppression is common in young women with special needs, including complex medical conditions and physical, intellectual, and developmental disabilities.[6] Patients request hormonal management for abnormal bleeding, hygiene, mood issues, exacerbation of other medical conditions, and prevention of pregnancy. Many young women with disabilities require methods without estrogen because of medical comorbidities, medication interactions, or decreased mobility that may increase the risk for thrombosis.[7] Levonorgestrel IUDs have great potential for use in this population for multiple reasons. They are convenient and long lasting, with a 5-year duration of use for the 52-mg levonorgestrel IUD (Mirena), although a newer 52-mg levonorgestrel IUD (Liletta) is approved for 6 years, and there are data that support efficacy for up to 7 years.[8,9] They result in significantly decreased bleeding, with an amenorrhea rate of up to 50% at 1 year in adults, depending on the definition of amenorrhea.[10,11] Unlike other hormonal methods, their actions are localized with minimal systemic absorption, side effects, or interactions with other medications or medical problems. This may be particularly beneficial in this population given the high rates of medical comorbidities and use of other medications, including antiepileptic drugs that can have interactions with hormonal medications.[12,13] A disadvantage of IUD use in this population is that it often requires anesthesia because of the inability to tolerate or be adequately positioned for office placement. This can sometimes be coordinated with other examinations or procedures under anesthesia.

Because of the many benefits, the American College of Obstetricians and Gynecologists lists off-label use of the 52-mg levonorgestrel IUD as an option for menstrual management in adolescents with disabilities.[14] However, there is a paucity of data on levonorgestrel IUD use in this population. In this study, our objective is to describe the characteristics, experiences, and outcomes of levonorgestrel IUD use in nulliparous children, adolescents, and young adults with physical, intellectual, and developmental disabilities.

METHODS

We conducted a retrospective chart review of successful levonorgestrel IUD placements at Cincinnati Children's Hospital Medical Center between July 1, 2004, and June 30, 2014. Patients were identified by querying hospital electronic medical records and billing databases. All identified charts were manually reviewed. The inclusion criteria were nulliparity, age ≤22, and either a physical disability that limited mobility (including conditions such as cerebral palsy, spina bifida, and caudal regression syndrome), an intellectual disability, or global or specific developmental delays. If a patient had ≥1 IUD insertion during this time period, each insertion was included separately. Patients with a history of pregnancy beyond 20 weeks' gestation were excluded, as were those with known uterine anomalies, because of the contraindication to IUD use in patients with significant uterine cavity distortion.[15] Because of reliance on coding and billing databases for subject identification, we were unable to include unsuccessful IUD placements, which are typically due to patient inability to tolerate an office pelvic examination or procedure, provider inability to sound the uterus or pass the inserter, or the uterus sounding too small to fit an IUD.

Data abstraction was performed by a single reviewer for consistency. The data collected included demographics (age, race, BMI, insurance, and parity), indications for IUD use, insertion location, sexual activity, comorbidities, and previous contraceptive or menstrual management methods. Baseline bleeding and pain were abstracted. Continuation and amenorrhea rates were recorded at each year. Amenorrhea was defined as the complete absence of bleeding for 3 months, as defined by the World Health Organization and used in many contraception trials, including a recent systematic review and meta-analysis of amenorrhea with levonorgestrel IUD use.[16,17] We considered a patient amenorrheic if they reported no current bleeding or spotting and no bleeding in the 3 months preceding the visit. If they were amenorrheic for the majority of the year but had some current or recent bleeding, they were not considered amenorrheic. Change in bleeding was abstracted from the chart by comparison of reported bleeding frequency, duration, and flow to that described at the time of insertion. Bleeding was determined to be increased if explicitly documented or if bleeding was more frequent, prolonged, or heavier in flow. Bleeding was recorded as decreased if explicitly documented or if bleeding was less frequent, of shorter duration, or lighter in flow. Bleeding was considered unchanged if explicitly documented or the described

bleeding was similar to before the IUD insertion. Change in pain was similarly abstracted by comparison to baseline data.

All reported side effects beyond the 6-week initial follow-up appointment were recorded, given the known initial adjustment period, as well as any complications, including pregnancy, pelvic inflammatory disease (PID), device expulsion, malposition, or uterine perforation. PID was clinically defined by the provider seeing the patient in the outpatient, inpatient, or emergency department setting. It was considered a complication of IUD use only when it occurred within 20 days of insertion because of the known increased risk of infection due to IUD insertion during that time period.[18] Expulsion was defined as partial extrusion of the device through the cervix or complete expulsion from the uterus. Malposition was noted when the device was in the uterus but with concern on imaging that it was embedded in the myometrium or positioned in the lower uterine segment. Uterine perforation was defined as an IUD positioned in the abdominal or pelvic cavity outside the uterus. Descriptive statistical analysis was performed on abstracted data by using SAS version 9.3 (SAS Institute, Inc, Cary, NC). Kaplan-Meier survival analysis was used to estimate IUD continuation rates at each year after insertion. Subjects were censored at their last known contact point. They were also censored at the end of the study period if IUD use was ongoing. Survival curve graphs were generated by using GraphPad Prism version 8.4.2 (GraphPad Software, San Diego, CA). This study was approved by the Cincinnati Children's Hospital Medical Center Institutional Review Board.

RESULTS

During the study period, 874 IUDs were placed: 227 were placed in patients with disabilities, of which

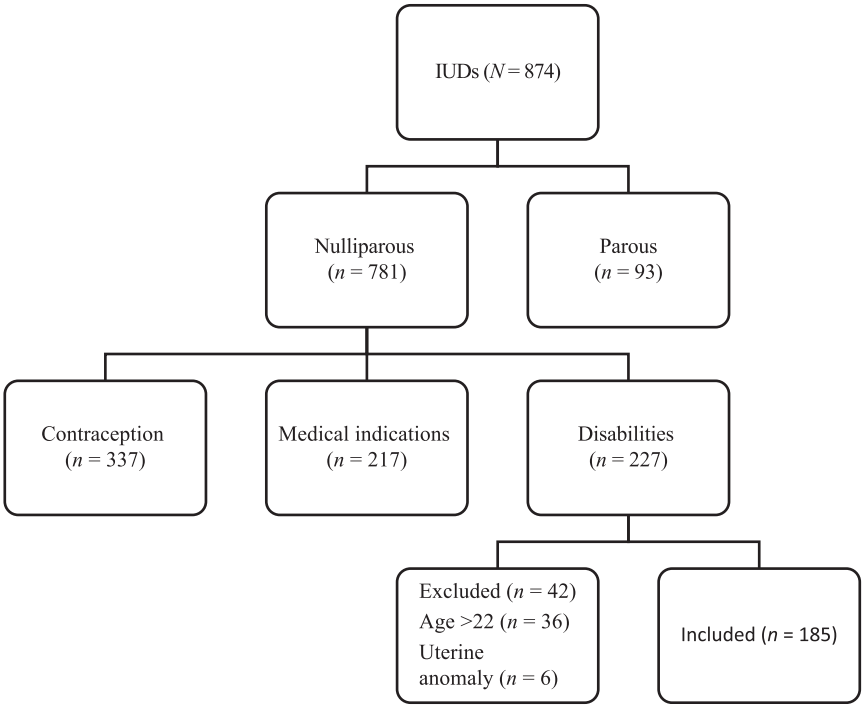

FIGURE 1
Flowchart of study subjects.

185 IUDs in 159 women met inclusion criteria (Fig 1). Twenty-six patients received 2 IUDs: 22 reached at least the full 5-year duration of IUD use and had a removal and replacement, 2 had a simultaneous removal and replacement because of malposition, and 2 had expulsions and desired replacement. Twenty-six patients used their IUDs off label for beyond the 5-year approved duration: 24 for 5 to 6 years and 2 for 6 to 7 years. No detailed data on extended use were collected.

Table 1 reveals patient demographics and baseline characteristics. The mean age at IUD insertion was 16.3 (range of 9–22) years. Only 7 (4%) patients had ever been sexually active. Although the majority of IUD placements occurred at least 1 year after menarche, 17% were within the first year after menarche. Most patients had tried at least 1 previous menstrual management method, but 32% chose an IUD as their first-ever method.

Almost all (96%) IUDs were placed in the operating room. Of those, 83 (45%) were inserted at the time of another procedure. The most common concurrent procedures were dental (n = 33), ophthalmic and/or otolaryngological (n = 14), and urologic (n = 12). Dilation of the cervix was required for only 9 (5%) insertions. Mean uterine length as measured by uterine sound was 7.3 cm (range 5–9.5 cm). Seventeen patients had preplacement ultrasounds for various reasons, ordered at the discretion of their providers and not necessarily to guide IUD insertions. Of these, 8 (47%) had uterine length measurements within 1 cm of the uterine sound length. There was a ≥2 cm discrepancy for 3 (18%) patients. In 2 cases, the ultrasound measurement was larger than the sound length. In the case in which the ultrasound length was smaller, the ultrasound measurement was 4.2 cm, but the sounded uterine length was 9 cm. The smallest uterine cavity

TABLE 1 Demographics and Baseline Characteristics of Study Participants

Characteristic	
Age, y, mean (SD)	16.3 (3.3)
Age at insertion, y, *n* (%)	
<13	35 (19)
13–15	43 (23)
16–18	56 (30)
19–22	51 (28)
Race, *n* (%)	
Black	30 (16)
White	153 (83)
Other	2 (1)
BMI[a],*n* (%)	
Underweight	9 (5)
Normal	74 (40)
Overweight	28 (15)
Obese	54 (29)
Unknown	20 (11)
Insurance, *n* (%)	
Private	104 (56)
Public	81 (44)
Disability status, *n* (%)	
Physical	19 (10)
Intellectual and/or developmental	115 (62)
Both	51 (28)
Time since menarche, y, *n* (%)	
<1	31 (17)
1–2	39 (21)
>2	91 (49)
Unknown	24 (13)
Sexually active,[b]*n* (%)	
Yes	7 (4)
No	177 (96)
Primary indication for IUD use, *n* (%)	
Menstrual suppression	163 (88)
Heavy menstrual bleeding	9 (5)
Dysmenorrhea	2 (1)
Contraception	10 (5)
Contraindication to estrogen, *n* (%)	
Yes	17 (9)
No	168 (91)
Immediate previous hormonal method, *n* (%)	
Estrogen containing	
Combined OCP	14 (8)
Patch	1 (<1)
Progestin only	
Progestin-only pills[c]	23 (12)
DMPA	44 (24)
Implant	2 (1)
IUD	29 (16)
None	68 (37)
No. previous hormonal methods, *n* (%)	
0	60 (32)
1	85 (46)
≥2	36 (19)
Unknown	4 (2)
Insertion site, *n* (%)	
Office	8 (4)
OR	177 (96)

DMPA, depot medroxyprogesterone acetate; OCP, oral contraceptive pills; OR, operating room.

[a] Underweight was defined as BMI below the fifth percentile; normal BMI was defined as BMI fifth to 84th percentile; overweight was defined as BMI 85th to 94th percentile; obese was defined as ≥95th percentile.

[b] Sexually active was defined as ever having had vaginal intercourse with a male partner.

[c] Progestin-only pills include both contraceptive-dose norethindrone and higher doses of norethindrone acetate.

measurement on ultrasound was 4.1 cm; the sound measurement was 6 cm.

A Kaplan-Meier survival curve for IUD continuation over time is shown in Fig 2. The continuation rate at 1 year was 95% (95% confidence interval: 93%–100%). Continuation rates decreased each subsequent year; however, an estimated 73% (95% confidence interval: 66%–83%) were still using their IUDs at 5 years. Of note, the number of patients with follow-up data declined over time, with full 5-year follow-up data available only for 64 patients. Forty-two IUDs were removed because they had been in place for ≥5 years. Discontinuations earlier than 5 years were due to bleeding issues (*n* = 7), systemic hormonal side effects (*n* = 3), and concern for vaginal or uterine infection (*n* = 2).

Gynecologic outcomes are reported in Table 2. More than one-half of patients with available data (*n* = 63 of 106; 59%) reported amenorrhea at 1 year. This rate increased slightly over the course of IUD use, with a peak of 65% (*n* = 43 of 66) at 3 years. The numbers were again limited by decreasing follow-up data over time. The exception to this high amenorrhea rate was a rate of only 4% (*n* = 4 of 100) at 2 years. A comparison of bleeding profiles before and after IUD insertion revealed that 65% (*n* = 67 of 103) of patients reported less bleeding 1 year after IUD placement. Only 7% (*n* = 7 of 103) endorsed worsened bleeding. Twenty-three patients required management of persistent, heavy, or bothersome bleeding after IUD insertion. The majority of management was with norethindrone acetate (*n* = 19; 82%), but a few patients were treated with estrogen or combined oral contraceptive pills (*n* = 4; 17%). Among patients with dysmenorrhea or pelvic pain before IUD insertion, 76% (*n* = 16 of 21) reported improvement at 1 year.

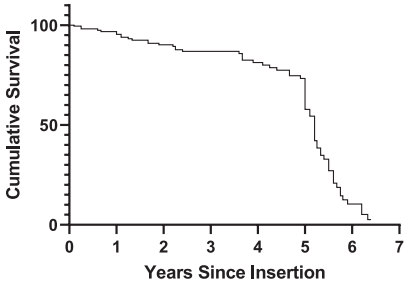

FIGURE 2
Kaplan-Meier survival curve of IUD continuation.

There were minimal reported side effects. Complications were rare. Device malposition and expulsion were the most common, with a combined rate of 5%. Of the 5 expulsions, 1 was partial, diagnosed by ultrasound; the other 4 were completely expelled from the uterus. There were no cases of PID, uterine perforation, or pregnancy. There were no significant differences in continuation, amenorrhea, changes in bleeding or pain, side effects, or complications by age.

DISCUSSION

In this study, we describe levonorgestrel IUD use in a large pediatric, adolescent, and young adult special needs population. This population is significantly different even from other nulliparous adolescent populations because of medical comorbidities and logistic concerns. We also reported on successful IUD placements in 35 patients <13 years of age, including as young as 9. IUD use is rarely described in this age group. In addition, 96% of our patients were never sexually active, another population with limited data on IUD use.[19]

The IUD continuation rates of 95% at 1 year and 73% at 5 years are far higher than those reported for other adolescent or adult populations.[20–23] Amenorrhea rates are also relatively high, greater than the ≤50% reported in other studies.[10,11] It is difficult to explain the low amenorrhea rate at year 2, especially when the rates at years 1 and 3 were both high. This may be due to a small amount of bleeding that precluded classification as amenorrhea on the basis of our criteria of the complete absence of bleeding for 3 months. However, this may also be used to indicate more unpredictable bleeding than is shown by our numbers. This may be especially problematic for young women with disabilities, who often have issues related to hygiene and menstrual exacerbation of behaviors or other medical problems. Further information is needed to delineate the exact amount and pattern of bleeding in this population, but we are reassured by the overall high amenorrhea and continuation rates.

There are minimal previous data on IUD use in adolescents and young women with disabilities. In a small case series of adolescents with medical disorders or physical or learning disabilities in the United Kingdom, researchers describe use of the levonorgestrel IUD for treatment of menstrual problems. In total, 12 of the 14 patients reported significant therapeutic benefit and kept their devices in place for the full 5-year duration of use. The authors describe similar rates of bleeding, amenorrhea, and expulsion (n = 1; 7%) to those reported in adults.[24] In a cohort study on menstrual suppression trends in adolescents with developmental disabilities, 26 patients with levonorgestrel IUDs were included.[25] The only complications with insertion were introital tears (12%). One (4%) IUD was removed for persistent bleeding, 3 (12%) were expelled, and 1 (4%) was removed because of malposition. Savasi et al[26] reported on complications in 56 subjects with disabilities who had attempted IUD insertions. Two insertions were abandoned intraoperatively, and 1 (2%) subject had an expulsion 5 months after insertion. There were no infections, uterine perforations, or pregnancies in their cohort. Hillard[27] noted satisfaction with levonorgestrel IUD use in 20 of 21 adolescents with special needs and their families. Our data reveal similarly excellent benefits for bleeding and pain and low complication rates.

There are many unique concerns related to IUD use in this population.

TABLE 2 IUD Continuation Rates, Gynecologic Outcomes, and Complications

	n (%)
Amenorrhea by y	
1 (*n* = 106)	63 (59)
2 (*n* = 100)	4 (4)
3 (*n* = 66)	43 (65)
4 (*n* = 56)	34 (61)
5 (*n* = 47)	30 (64)
Side effects: pain and/or cramping by y	
1 (*n* = 124)	2 (2)
2 (*n* = 100)	1 (1)
3 (*n* = 75)	2 (3)
4 (*n* = 63)	2 (3)
5 (*n* = 52)	1 (2)
Complications	
PID[a]	0 (0)
Malposition[b]	4 (2)
Expulsion[c]	5 (3)
Uterine perforation[d]	0 (0)
Pregnancy	0 (0)

[a] PID was clinically defined; it was considered a complication of IUD use when it occurred within 20 d of insertion.
[b] Malposition was defined as incorrect positioning but within the uterus.
[c] Expulsion was defined as partial extrusion of the device through the cervix or complete expulsion from the uterus.
[d] Uterine perforation was defined as presence of the device in the abdominal or pelvic cavity outside the uterus.

The first is that some perceive an IUD not to be a palatable option for patients and their families, especially as a first menstrual management or contraceptive method. Kirkham et al[25] concluded that levonorgestrel IUD use is a well-accepted second-line option in adolescents with developmental disabilities. However, approximately one-third of our patients chose an IUD as their first-ever method. Another concern is the likely need for anesthesia for IUD insertion because of the inability to tolerate or be properly positioned for IUD insertion in the office. Although almost all of our IUDs were placed in patients under general anesthesia in the operating room, almost one-half were combined with other examinations or procedures.

Another common fear is that the small body habitus of some patients may indicate a small uterine size that may not be able to accommodate an IUD or would predispose the patient to a higher rate of expulsion or perforation. Some experts advocate waiting until a few years after menarche to allow full uterine growth. Although we do not include unsuccessful IUD insertions in our study, we were able to successfully place the 52-mg levonorgestrel IUD in 1 patient whose uterus sounded to only 5 cm. Although this patient had improved bleeding and pain and no complications, we acknowledge that this was off-label use. In addition, 17% of patients had their IUDs placed within the first year after menarche, indicating that this is a viable option for anyone once menarche has occurred. Few of our patients had preprocedure ultrasounds. For those who did, there was often a discrepancy between the uterine size measured on ultrasound and by direct sounding. Because of this, we would argue against the need for preinsertion ultrasound. Although some authors recommend preplacement ultrasounds in this population,[13] others have also concluded that this is not necessary.[28] The rate of IUD expulsion (3%) was low, and there were no perforations in our cohort.

Many families are apprehensive that the irregular bleeding and cramping after IUD insertion may cause distress for patients with disabilities. Although those complaints are unable to be directly assessed in this study, the IUD continuation rate was high, and reported side effects were minimal. A common source of apprehension for families and providers is that patients who are nonverbal or who have intellectual or developmental disabilities may not be able to indicate discomfort that would prompt evaluation for IUD malposition or expulsion. They are also often unable to tolerate examinations to evaluate IUD position. With these data, we provide reassurance that these complications are rare. Transabdominal ultrasound can be used for assessment of IUD position, especially with changes in bleeding pattern or other concerns. In our population, 7 patients had ultrasounds after IUD insertion: 3 immediately after the procedure to ensure proper positioning and 4 more remotely because of bleeding or pain complaints.

There are also other concerns about IUD use in adolescents that are not specific to a special needs population, including an increased risk of PID. However, this is known to be caused by ascending sexually transmitted infections in the first 20 days after insertion. Infection screening can be performed at the time of insertion, which was done for all our patients with no positive test results and no cases of PID. Another common concern is a possible increased risk of IUD expulsion in nulliparous women. Our rate of expulsion is lower than reported in other studies of adolescents or adults.[23,29]

The major limitation of this study is its retrospective nature, which involved loss of patients to follow-up, missing data, and reliance on adequate documentation. Although some patients may have presented to outside providers or hospitals with complications or for IUD removal, this is much less likely in this population because our institution is the only pediatric hospital in the region and patients are often followed into young adulthood. In addition, some of the patients with IUD placement in the later years of the study period had not reached the full duration of IUD use at the time of data analysis and were thus unable to be included in the analysis on long-term outcomes. Only approximately one-third of patients had full 5-year follow-up data. Lastly, because unsuccessful IUD insertions were unable to be accurately identified and included, the study population and results may have been skewed. However, because the majority of IUDs were placed in the operating room, unsuccessful insertions are much less likely to have occurred. Anecdotally, the authors are only aware of a single patient in this population who had an unsuccessful insertion, which was due to small uterine size.

CONCLUSIONS

This is by far the largest study on levonorgestrel IUD use in adolescents and young adults with disabilities. With it, we provide much needed data on the therapeutic benefit and safety of this option for menstrual management and contraception in this population, for which data are lacking despite recommendations for use. Further research is needed to prospectively assess continuation, outcomes, and satisfaction with levonorgestrel IUD in this population. However, these data are promising and should be used to allow more accurate counseling of adolescents with special needs and their families

about this highly effective, safe menstrual management and contraceptive method. It should be considered as an option for this population.

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ABBREVIATIONS

IUD: intrauterine device
PID: pelvic inflammatory disease

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