

# Endo-Teach: An innovative secondary school teaching package to educate on menstrual health and to build awareness of endometriosis in Switzerland

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A Part of Sage

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## Abstract

**Introduction:** Endometriosis, a chronic inflammatory disease often beginning in adolescence, significantly impacts quality of life. Delayed diagnosis contributes to prolonged suffering, educational disruption, and high healthcare costs. Promoting menstrual health education in schools may aid early recognition and intervention. This study aimed to implement and evaluate *Endo-Teach*, a menstrual health and endometriosis education program for seventh and eighth grade students, assessing its effectiveness in improving their understanding of endometriosis.

**Methods:** The implementation of the teaching package *Endo-Teach*, developed by a group of specialists at the certified endometriosis center of the Bern University Hospital, Switzerland, was evaluated using a voluntary questionnaire distributed before and after the class.

**Results:** Within a total collective of 177 students, the mean age was 14.37 years. Awareness of endometriosis among adolescents was initially low (30.4%). Just over half (50.6%) of female adolescents reported having very painful menstruation; 54.5% of the adolescents reporting very painful period or insecurity about it needed to take pain medication, and 23.6% missed school regularly due to menstrual pain. The teaching package was evaluated as clear (96.5%) and educative (97.7%).

**Conclusion:** The teaching package *Endo-Teach* in its actual form is a valid option to promote awareness of menstrual health and endometriosis in secondary schools. In Switzerland, the prevalence of severe menstrual pain in secondary-school students, including the use of pain medication and school absenteeism, is high, whereas awareness of endometriosis is low. This shows that offering age-appropriate educational measures in a broader context is important to reduce the burden of the disease.

## Keywords

Adolescent, awareness, dysmenorrhea, education, endometriosis, menstruation

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## Introduction

Endometriosis is a common inflammatory disease that is characterized by the presence of endometrium (uterine mucosa) like tissue outside the uterus.<sup>1</sup> Estimations of its prevalence vary among different populations; 1 in 10 women at reproductive age assumed to be affected.<sup>2</sup> The prevalence of endometriosis in adolescents is less clear than in adults.<sup>3,4</sup>

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The disease is chronic, often recurrent, and manifesting itself heterogeneously, in phenotype as well as in clinical outcomes.<sup>5,6</sup> The most common symptoms are pelvic pain (dysmenorrhea, dyspareunia, dyschezia, and acyclic pelvic pain) and infertility.<sup>1,4,6</sup> However, symptoms can differ in younger patients.<sup>4</sup> Endometriosis is the leading cause of (chronic) pelvic pain as well as the main cause of secondary dysmenorrhea (dysmenorrhea due to pelvic pathology) in adolescents and young women.<sup>7–10</sup>

Symptoms very often start in adolescence.<sup>11,12</sup> According to a study by Treloar et al.,<sup>13</sup> dysmenorrhea at an early age increases the risk of endometriosis. Data of a large registry show that two-thirds of all recorded women with endometriosis experience their first symptoms before the age of twenty.<sup>10,14</sup>

For treatment, either hormonal-based therapies or laparoscopic surgical excision of the lesions is recommended.<sup>5,15</sup> It is important to provide an interdisciplinary, individual, and multi-modal care, including physiotherapy and other additional interventions, to achieve a long-lasting therapy outcome.<sup>16</sup> Lukas et al.<sup>17</sup> shows that many patients with endometriosis are not satisfied with the medical support they receive. Providing comprehensive information about the disease after diagnosis is reported to be very important to ensure patients satisfaction; this is just as important as general information about the disease in adolescent and adult population.<sup>17</sup>

In comparison with unaffected adolescents, adolescents diagnosed with endometriosis have a significantly worse quality of life.<sup>18</sup> A recent study by Missmer et al.<sup>19</sup> shows that most women with endometriosis report having lost time, being less positive about the future, and not having reached their full potential in life due to the disease. Symptoms can have a remarkable negative impact on adolescents sex life,<sup>20</sup> mental and emotional health, educational attainment, and career choices, as well as on social life and activities.<sup>21,22</sup>

Time from the onset of symptoms to diagnosis can reach up to 10 years.<sup>15</sup> This diagnostic delay can cause chronic pelvic pain, reduced fertility due to progression of the disease, and a substantially lower of quality of life.<sup>23,24</sup> Besides the impact at the patient level, high direct and indirect healthcare costs are generated.<sup>25</sup> This delay also stems from the lack of awareness regarding normal menstrual parameters and endometriosis in adolescents.<sup>26</sup>

In recent years, public awareness of endometriosis has increased. There are more and more countries in the world that actively promote a menstrual health and endometriosis teaching in schools. In the international literature and guidelines, we can observe consensus that education about endometriosis is an useful tool for promoting early intervention and, with this, for minimizing menstrual morbidity.<sup>22,27–29</sup> At the international level, the World Health Organization (WHO) recognizes the importance of promoting increased awareness and specific policies for endometriosis.<sup>30</sup>

The aim of this study was, as a sense of quality control, to implement and evaluate Endo-Teach, the menstrual health and endometriosis education program for students in secondary school.

## Methods

### *The Endo-Teach project*

The menstrual health and endometriosis education program called Endo-Teach was launched in 2019. It was developed by an interdisciplinary working group consisting of endometriosis nurses, gynecologists specialized in endometriosis and adolescents, and marketing experts. The main aims of the project are (a) to encourage adolescents to talk and learn about menstrual health; (b) to strengthen adolescents' ability to identify menstrual symptoms that deviate from the norm; (c) to promote health-seeking behavior in adolescents; and (d) to thematize, discuss and explain abnormal menstrual symptoms in school and in doing so, to raise awareness of endometriosis.

A teaching package for a 45-min lesson, including detailed documents for lesson planning, a video explaining endometriosis, and a fact sheet with background information is provided online, free of charge, at the homepage of the Department of Obstetrics and Gynecology at the University Hospital of Bern. In addition, teachers can invite members of the program team to offer an Endo-Teach session.

### *Data collection*

Several teaching sessions were held from the team-member EC, primarily in the Canton of Bern; one teaching session was held in the Canton of Graubünden. In the beginning of each class, students were asked to fill out a short, voluntary pen-to-paper questionnaire. The following parameters were recorded: demographics (age and sex), awareness of endometriosis, information sources, presence of menstruation and menstrual pain, use of pain medication, and school absenteeism due to pain. The questions about age and appearance of menstruation were asked in order to evaluate whether seventh and eighth grade is the right time for such teaching package. We then wanted to evaluate the need for a menstrual health and endometriosis education program by asking all the points listed above. At the end of the lesson, another short, voluntary questionnaire was handed out in order to collect the following information: (a) awareness, following the lesson, of where to find help in case of endometriosis symptoms, (b) evaluation of the class, and (c) additional feedback on the class. Asking specific questions evaluating the class provided the opportunity to assess its accessibility and its level of difficulty.

### *Ethical approval*

No ethic approval was needed, as the study was designed as quality control. This was confirmed by the Ethics

Commission of the Canton of Bern, Switzerland (reference number: Req-2023-00107)

### Statistics

All data from the pen-to-paper questionnaires were brought into a digital form on Microsoft Excel spreadsheet (Version 16.16.27). Statistical analysis was performed using IBM-SPSS (Version 25.0). For patient and evaluation data, basic descriptive statistics were applied.

Although this study is not strictly cross-sectional, most STROBE checklist items are applicable and have been addressed. Compliance with the relevant items is documented in Supplemental Material 1.

### Language

Use of the terms “male” and “female” refers to sex and not to gender.

### Results

Results from the pen-to-paper questionnaire are summarized in Table 1.

### Demographics

Data from a total of 177 students in the seventh and eighth grades were recorded. The mean age was 14.37 years (13–17 years). In this collective, 48.9% of the adolescents were born with female sex, 51.1% with male sex, and none with inter\* sex.

### Awareness and menstrual health

In the entire collective, 69% of the students had never heard of endometriosis before; 30.4% had heard of it; and 0.6% were unsure. Among the young female students, 45.2% had already heard of endometriosis, whereas of the male students only 17.1% had heard of it (Figure 1). School, social media/internet, family, friends, and gynecologists were mentioned as sources of information.

Female adolescents reported on their menstruation as follows: in 50.6% as very painful, in 34.1% as not very painful, in 12.9% as unsure about it, and in only two persons (2.4%) as no/not yet having their period. Among those having a painful period or being unsure about it, 54.5% needed to take pain medication for menstrual pain on a regularly basis, and 23.6% missed school due to menstrual pain (Figure 2).

### Evaluation of the teaching package

The evaluation of the teaching package itself offered the following results: After the teaching lesson, 94.2% of the

students knew where and when to seek help in case of strong menstrual pain; 2.3% were unsure and 3.5% did not know. On a four-level evaluation asking whether adolescents liked the teaching in general, 88.9% rated the lesson at the highest level, 10.5% at the second-highest level and 0.6% on the third (mean=level 1.1). Female students (97.6% level 1, 2.4% level 2) liked the lesson more than male students (80.2% level 1, 18.6% level 2, 1.2% level 3). For 96.5% of the adolescents, the teaching content was fully understandable. 97.7% learned something new during class, whereas 1.7% were unsure about it and 0.6% did not learn new things.

Written comments of interest and to be highlighted include the following:

- “I think it is very good that we speak about it in school. It is never thematized.”
- “I think it is good to speak openly about it.”
- “I think it is a very interesting topic. It is important that we speak openly about endometriosis and pain in general, so that as much pain as possible can be prevented.”
- “I think it is very good and important that we discuss it in school—also with the boys.”
- “Thank you so much for coming, it helped me a lot.”

### Discussion

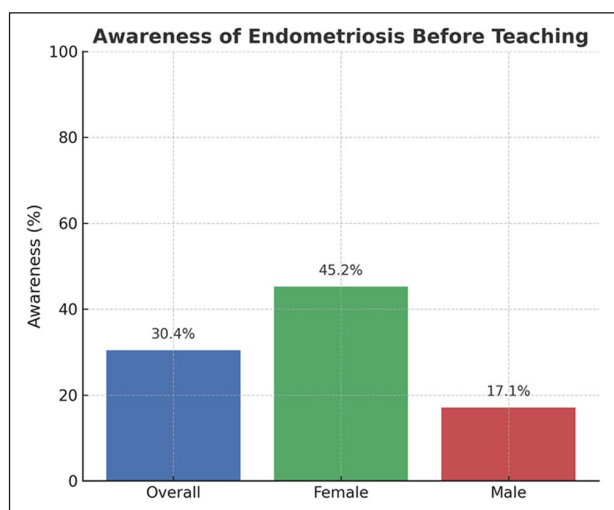
To our knowledge, a menstrual health and endometriosis education program such as Endo-Teach is, as of now, unique in Switzerland. Its inspiration is the What About Me ® Program in New Zealand.<sup>22</sup> Following the implementation of the program and its evaluation, we can show the first data reported about menstrual health and endometriosis awareness in adolescents in Switzerland, an environment that can be considered to be under researched and underfunded.<sup>22</sup> Our data strengthen the premise that education about menstrual health and endometriosis is urgent; in our collective, prevalence of severe dysmenorrhea (including the use of pain medication and school absenteeism) in secondary school students is high, whereas the awareness of endometriosis was found to be low.

### Limitations

One limitation of this study is the small number of participants. Furthermore, the questionnaire is short and not validated or derived from a standardized instrument, thereby compromising the reliability and comparability of the findings. Also, outcomes, such as long-term knowledge retention or behavioral modification, were not assessed beyond self-reported comprehension just after class. Therefore, it remains uncertain how effectively information retention endures or if students proactively seek assistance for symptoms at an early

**Table 1.** Results from the pen-to-paper questionnaire handed out before and after performing Endo-Teach.

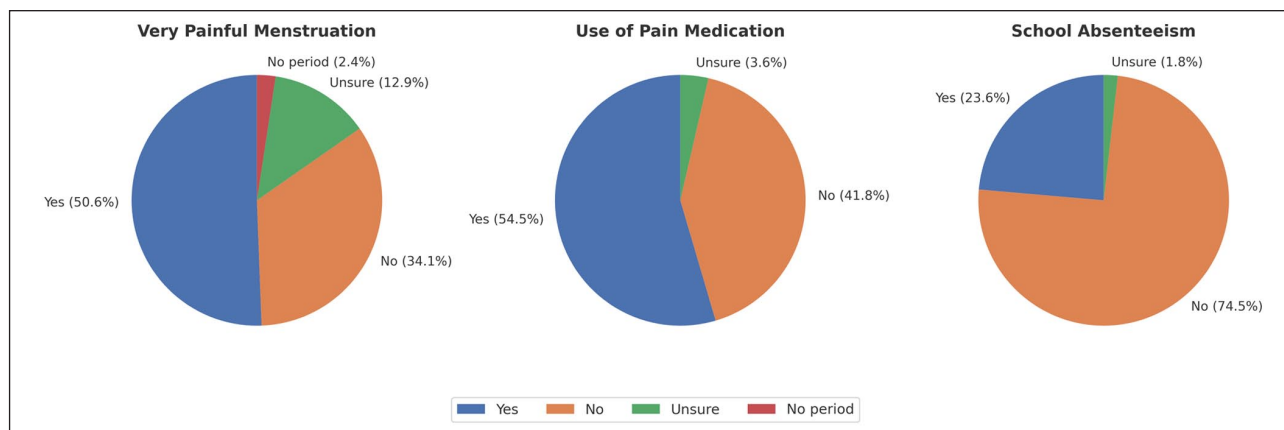
Questions before Endo-Teach class					
Age (n = 175)	Median	Mean	Range		
	14	14.37	13–17		
Sex (n = 174)	Female	Male	Other		
	85 (48.9)	89 (51.1)	0 (0)		
Awareness (n = 174)	Yes	No	Unsure		
	53 (30.4)	120 (69)	1 (0.6)		
Awareness in female adolescents (n = 84)			46 (54.8)		
Awareness in male adolescents (n = 88)			1 (1.1)		
	15 (17.1)	72 (81.8)	p < 0.001		
Very painful menstruation in female adolescents (n = 85)	Yes	No	Unsure	No period	
	43 (50.6)	29 (34.1)	11 (12.9)	2 (2.4)	
Pain medication in female adolescents with painful menstruation (n = 55)	Yes	No	Unsure		
	30 (54.5)	23 (41.8)	2 (3.6)		
School absenteeism in female adolescents with painful menstruation (n = 55)	Yes	No	Unsure		
	13 (23.6)	41 (74.5)	1 (1.8)		
Questions after Endo-Teach class					
Do you know now where and when to seek help? (n = 171)	Yes	No	Unsure		
	161 (94.2)	6 (3.5)	4 (2.3)		
Acceptability of the teaching in general (n = 171)	Level 1	Level 2	Level 3	Level 4	Mean
	152 (88.9)	18 (10.5)	1 (0.6)	0 (0)	1.1
Acceptability in female students (n = 84)			2 (2.4)		
Acceptability in male students (n = 86)			1 (1.2)		
	69 (80.2)	16 (18.6)	0 (0)		
Understandability of the teaching content (n = 171)	Yes	No	Unsure		
	165 (96.5)	1 (0.6)	5 (2.9)		
Understandability of the teaching content for female adolescents (n = 84)			0 (0)		
Understandability of the teaching content for male adolescents (n = 86)			5 (5.8)		
	80 (93)	1 (1.2)	p = 0.04		
Ability to learn something new (n = 171)	Yes	No	Unsure		
	167 (97.7)	1 (0.6)	3 (1.7)		
Ability to learn something new for female adolescents (n = 84)			1 (1.2)		
Ability to learn something new for male adolescents (n = 86)			2 (2.3)		
	83 (96.5)	1 (1.2)	p = 0.41		

**Figure 1.** Awareness of endometriosis in adolescent students before teaching Endo-Teach in general, and compared depending on sex.

stage. However, the main goal was the roll-out of the teaching lesson itself. We did not want to distract the students from the class itself and its program content; we therefore decided at the outset that we did not want to have participants fill out an extensive and time-consuming questionnaire. Also, the program was executed in a resource-rich environment (a Swiss hospital-affiliated team within a well-equipped educational institution). Outcomes may vary across different contexts or educational frameworks.

### Menstrual health, awareness for endometriosis, and school absenteeism

It is noteworthy that 50.6% of all female students included in our survey reported having very strong menstrual pain (see Figure 2). Nevertheless, 69% of all students had never heard of the disease, which is the most common cause of (chronic) pelvic pain and secondary dysmenorrhea in adolescents.<sup>7–10</sup> These results can be compared with similar



**Figure 2.** Experience among female adolescent students of very painful menstruation; use of pain medication due to menstrual pain on a regularly bases in adolescent students; and school absenteeism in adolescents on a regularly bases because of menstrual pain.

survey studies from other countries,<sup>22,28,29,31–34</sup> where the prevalence of dysmenorrhea reaches 21–94%. Severe dysmenorrhea, especially if left untreated, can lead to chronic pelvic pain, with many other health-related, social, and economic consequences.<sup>22,35</sup> A health issue in adolescents such as this should be taken very seriously. As shown in Figure 2, our data indicate that 54.5% of the students with strong menstrual pain regularly take pain killers. This number is relevant, and therefore it is crucial to teach not only about possible diseases leading to dysmenorrhea such as endometriosis, but also to educate about pelvic pain in general and its possible basic treatment options.<sup>33,34</sup> The awareness of endometriosis is low (30.4%) in secondary students in Switzerland (see Figure 1). The results should be seen in comparison with studies conducted in the United Kingdom,<sup>33</sup> Italy,<sup>34</sup> Japan,<sup>26</sup> Australia,<sup>27</sup> and New Zealand,<sup>22</sup> which show a range of awareness from 8 to 52% of endometriosis in adolescents. Greater public awareness could shorten the length of time to diagnosis and certainly reduce the high burden of the disease. The awareness in adolescents of endometriosis is lower than of other chronic conditions with similar prevalence rates.<sup>33</sup> One possible reason for this is the fact that due to cultural and particularly societal attitudes towards menstruation, menstrual health is not discussed openly in public, and period pain in every form is often considered to be normal, and something to be endured.<sup>36</sup> As shown in Figure 1, male students were less aware of endometriosis (17.1%) than female students (45.2%); this suggests that a teaching program should be delivered to students of all sexes. According to studies by Randhawa et al.<sup>33</sup> and Shadbolt et al.,<sup>27</sup> about 80% of female adolescents believe that male adolescents should also learn about endometriosis and menstrual health. Educating everyone—without distinguishing by sex, symptoms, or other categories—might contribute to the destigmatization of menstruation in general and could address the fact that the symptoms of many affected people are not taken seriously.<sup>12</sup>

It is noteworthy that in our cohort, 23.6% of the students with severe dysmenorrhea miss school on a regularly bases due to pain (see Figure 2). Comparable to our results, similar studies report that school absenteeism caused by menstrual pain affects from 12 to 31% of students.<sup>22,28,29,31–34</sup> Missmer et al.<sup>19</sup> from 2022 shows that 40 % of women with self-reported endometriosis experienced, as a consequence, difficulties in achieving educational goals.

These results strongly emphasize the importance of the teaching.

### Evaluation of the package

The teaching package Endo-Teach was considered to be clear (96.5%) and educative (97.7%); on this basis, the lesson can be implemented in its current form in a wider context in Switzerland. Given the fact that only two of the students born with female sex had no or not yet their period at the time of program implementation, the timing of the program in seventh and eighth grade seems to be a suitable. It could be discussed whether the teaching should be offered even earlier, since we know that endometriosis patients can have symptoms beginning with their very first period.<sup>11</sup> The evaluation of the lesson content itself shows that the mix of video, presentation, and interactive questionnaire is an appropriate teaching package for this topic. As Bush et al.<sup>22</sup> did in New Zealand, it is recommended that the teaching be evaluated along the way, so the form can be adapted to changing needs of adolescents. One strength of this study is that the program was developed by an interprofessional group of specialists. Therefore, from the beginning on, different aspects of the menstrual cycle and initial diagnosis of endometriosis have been included. This made it possible for the topic to be seen from different viewpoints and thereby making the program applicable for both teacher and students. Male students evaluated the lesson less favorably than female students; this suggests that the program should be better adapted to male adolescents.

It is very important to be able to reach out to every individual.

On the basis of the lesson content, 94.2% of the students knew when and where they should seek help. Enabling adolescents in need to get help in a self-determined way is a very important aspect in this work. At the same time, greater menstrual health awareness can also help to avoid pathologizing the period on its own, and to acknowledge and embrace differences in menstruation.<sup>22</sup> Adolescents who are unaware of physiological menstrual characteristics and possible diseases such as endometriosis may not recognize abnormal symptoms and seek for help.<sup>33</sup> The identification of abnormal symptoms can lead to early diagnosis in adolescents and therefore to early intervention. This can bring more rapid relief to the affected people, prevent central sensitization and limit disease progression.<sup>24</sup> Bush et al.<sup>22</sup> expressed the opinion that given the absence of any screening tool for endometriosis, educating adolescents to identify abnormal menstrual symptoms is imperative. Besides education on social media and the internet, school education is an important platform to reach out to every adolescent, no matter the socioeconomic demographic.

The comments provided in our survey can be seen as positive overall, indicating that it is important to talk about menstrual health and endometriosis in school in a straightforward and open manner. These comments are consistent with data from similar studies, where more than 80% of adolescents report wanting to know more about this topic.<sup>27,33,34</sup>

### *School education and future*

Worldwide, there are some important similar education programs to be discussed. In Australia, the United States, and New Zealand, the comprehensive teaching programs Period, Pain and Endometriosis Program Talk® (PPEP-Talk ®),<sup>37</sup> the Teen Outreach Program,<sup>38</sup> and the What About Me® program<sup>31</sup> were developed with the significant work of specialists and government funding. In France, a national action plan for endometriosis was developed in 2022, in which educating in schools is also an integral part.<sup>39</sup>

In 1998, a group of specialists in New Zealand launched educational programs in schools about menstrual health and endometriosis with the program Me®, comparable to Endo-Teach. Today, 25 years later, it is an internationally respected health education program, which can be delivered to all New Zealanders in an online form.<sup>22</sup> A study by Bush et al.<sup>22</sup> showed that in regions where the Me® program was delivered, students' awareness of endometriosis increased. Significantly more adolescents with symptoms suggestive of endometriosis sought medical help, and were diagnosed earlier.<sup>22</sup> With this valuable work, the negative impact of menstrual health issues in lives of thousands of adolescents can be minimized. These initiatives collectively underscore the importance of early education as a

public health strategy to mitigate diagnostic delay and disease burden associated with endometriosis. Endo-Teach extends this global approach by adapting similar evidence-informed educational concepts to the Swiss context, providing preliminary data that support the feasibility and acceptability of menstrual health education in co-educational secondary school settings. As the WHO promotes, menstrual health should be recognized as a public health and human rights issue.<sup>30</sup>

Appropriate teaching about menstrual health and endometriosis in young people should be mandatory and (co)-funded by the governments. Endo-Teach supports the human right to the highest standard of sexual and reproductive health, quality of life, and overall well-being.<sup>30</sup> This study supports further action by providing data on the implementation and first evaluation of a menstrual health and endometriosis teaching program. A next step will be to expand the Endo-Teach program at the cantonal level. In the future, it could be possible to work at the political level to introduce menstrual health and endometriosis teaching at the national level.

## **Conclusions**

The teaching package Endo-Teach in its actual form is a valid option to promote awareness of menstrual health and endometriosis and to encourage help-seeking behavior in case of an abnormal menstruation in adolescents. Following acknowledgment of the high prevalence of menstrual pain, pain medication use, school absenteeism, and the low awareness, it is necessary that to carry out appropriate educational measures about menstrual health and endometriosis in a broader context in Switzerland, so that the burden of the disease can be greatly reduced.

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## **Authorship**

Sara Imboden.

## **Declaration of conflicting interests**

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## **Ethical approval**

No ethic approval was needed, as the study was designed as quality control. This was confirmed by the Ethics Commission of the Canton of Bern, Switzerland (reference number: Req-2023-00107).

**Informed consent to participate**

Yes.

**Informed consent to publish**

No.

**Trial registration (where applicable)**

None.

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Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

**Supplemental material**

Supplemental material for this article is available online.

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