How do adolescent girls and boys perceive symptoms suggestive of endometriosis among their peers?
Findings from focus group discussions in New York City


**Participants (N=54)**

More than two-thirds of participants (70%) were female

- Male: 29.6%
- Female: 70.4%

Half of participants had two parents born outside the United States

- Both parents: 50.0%
- One parent: 14.8%
- None: 35.2%

The majority of participants (85%) were born in the United States

- USA: 85.2%
- Other: 14.8%

4 in 10 (40.7%) identified as Hispanic/Latino/a

- Hispanic/Latino/a: 40.7%
- White: 25.9%
- Black/African-American: 14.8%
- Multiple race/ethnicity: 9.3%
- Asian: 9.3%

**Purpose**

To examine how, among adolescents, endometriosis and symptoms suggestive of endometriosis, are perceived at the family, peer/school, and community/society levels.

**Background**

Endometriosis, a chronic condition characterized by cells similar to the uterine lining that exist outside of the uterus 1, is estimated to impact 10% of women of reproductive age. 2 Symptoms may include painful, heavy, or irregular menstruation; bowel and urinary disorders; back and pelvic pain; dyspareunia; nerve pain, and infertility. 3-7 Endometriosis has been documented to adversely impact multiple aspects of women and girls’ lives. 8-10, 3, 11-15 Understanding how adolescents view endometriosis can provide data to inform evidence-based messaging for public health initiatives. 16 Such research is consistent with the recently published priorities in endometriosis research 17-18, as such data can provide an opportunity to positively influence the trajectory of those who may be suffering from this disease.

**Approach**

Eight gender-specific focus group discussions (FGDs) were conducted with 54 adolescents residing in New York City (NYC) with an age range of 14 to 18 years. Vignettes were utilized to explore perceptions of symptoms suggestive of endometriosis, how these symptoms may impact different aspects of girls’ lives, and help-seeking opportunities. Vignettes covered common endometriosis symptoms, including heavy bleeding, debilitating cramps, painful sex, and painful bowel movements. Discussion questions were designed to examine perceptions of endometriosis at family, peer/school, and community/societal levels to elicit factors that potentially shape girls’ experiences of endometriosis symptoms.
Findings: Factors that contribute to teens’ perceptions of endometriosis

**Menstrual stigma at the societal level can prevent help-seeking**

“It's the fact that women don't like to talk about having their period because, alright, because it's gross to men. And men don't like to hear it and men are the more dominant people in society, and if a man doesn't like it being talked about then women are not going to talk about it in front of people in general. And so it's kind of seen as taboo to talk about your period. Something that has to do with your vagina, that's taboo you can't talk about that you know?” (Adolescent girl)

**Gender norms among peers inhibit discussion of painful sex with male partners**

“Sam wants to please her boyfriend, but even though she knows that it’s gonna hurt, she kinda just wants to, like, sit there and take it, because she wants to please her boyfriend.” (Adolescent girl)

“She feels like, he might think that she got an STI or something…She's hesitant, or uncomfortable because, she's probably afraid of the response or of how he would react.” (Adolescent girl)

**Lack of training among school personnel**

“The school nurse [feels] like she understands Dominique’s pain, so it's like, 'oh it’s nothing, I’ve gone through the same thing.’ She’s like, ‘Oh I know this already. There’s no way her pain is that bad.’ So, at some point the school nurse would feel like she can relate to Dominique and so it’s just like, ‘Oh, she’ll get over it. It’s nothing.’”(Adolescent boy)

**Stigma toward teen sex within families**

“It depends on culture…if it’s like parents that are very traditional…you would just be afraid to explain or tell them anything [about sex] and so if there’s like a significant problem you won’t be able to tell them.” (Adolescent boy)

**Educational costs of symptoms of endometriosis and psychological distress**

“Yeah I'd be kind of like devastated. Honestly like if I worked that hard and then like something out of my control…like you worked so hard to get those grades and once something out of your control kind of like gets in the picture it’s like really frustrating.” (Adolescent boy)

**Recommendations for Public Health Programming**

- **Implement stigma reduction efforts**
  - At all levels of social context (family, peer/school, community/societal)

- **Foster supportive social environment**
  - Inform and engage adolescent boys and girls peers on endometriosis, including its symptoms and impacts

- **Develop validated measures**
  - Assess societal attitudes towards endometriosis and symptoms
  - Monitor/evaluate efforts to shift attitudes

- **Develop social screenings**
  - Create strategies for non-medical personnel to screen for and refer regarding endometriosis symptoms