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Spectrum Of Symptoms In Women Diagnosed With Endometriosis During Adolescence Versus Adulthood.

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Abstract

BACKGROUND: Endometriosis symptoms often start at a young age, and the time between symptom onset and endometriosis diagnosis can be several years. It is not clear if symptoms experienced by adolescents differ from adults. Better understanding may shorten the often lengthy delay in diagnosis.

OBJECTIVE: To further elucidate the symptom presentation of adolescents as compared to adults to determine if differences existed based upon age at surgical diagnosis that could impact time to diagnosis.

STUDY DESIGN: This investigation was a cross-sectional study at enrollment within a longitudinal cohort of adolescents and women with endometriosis. The population-based cohort was recruited from two tertiary care centers and the surrounding communities. Participants included adolescents (diagnosed ≤ 18 y, n=295) and adults (diagnosed >18 y, n=107) with surgically-confirmed endometriosis who were enrolled into The Women's Health Study: From Adolescence to Adulthood. Participants completed an expanded version of the World Endometriosis Research Foundation Endometriosis Phenome and Biobanking Harmonization Project (WERF EPHeCT) standard clinical questionnaire including items regarding menstrual history, associated symptoms, and pain. Chi-square or Fisher's exact tests were applied to categorical data, and Wilcoxon rank sum tests to continuous data.

RESULTS: Most participants (90%) experienced moderate-severe menstrual pain. On average, 3 doctors were seen before diagnosis, regardless of age at presentation (range 0-25). Time from symptoms to diagnosis averaged 2y for adolescents and 5y for adults ($p<0.001$). More adolescents (50%) than adults (33%) reported pain starting at menarche ($p=0.002$) and nausea accompanying pain (69% vs. 53%, $p=0.01$). Non-cyclic, general pelvic pain was prevalent. Half of participants reported relief of their general pelvic pain after a bowel movement. Pain interfered with work/school, daily activities, exercise, and sleep to a moderate-extreme degree; difficulties were similar by age at diagnosis.

CONCLUSIONS: Pelvic pain was severe, non-cyclical, and negatively impacted quality of life. At our tertiary care centers, symptoms of endometriosis did not differ between women surgically diagnosed during adolescence compared to those diagnosed as adults. Adolescents had more nausea and symptom onset at menarche. Multi-year delays in diagnosis were common. Clinicians should be aware of these alternate symptom patterns, and include endometriosis in their differential diagnosis for both adolescent and young adult women experiencing non-cyclic pelvic pain and nausea.