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Title Page

Title: Secondary School Girls' Experiences of Menstruation and Awareness of Endometriosis: A cross-sectional study

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Title: Secondary School Girls' Experiences of Menstruation and Awareness of Endometriosis: A cross-sectional study

Structured Abstract

Study Objective: To characterise typical (ie, normal) menstrual characteristics in a large sample of secondary school girls, as well as knowledge of typical menstruation, endometriosis awareness and educational needs. To establish whether self-reported atypical period symptoms indicate menstrual characteristics suggesting the need for further clinical review for a specialist opinion.

Design: Cross-sectional survey.

Setting: Secondary schools in West Midlands, England.

Participants: 442 girls, 15-19 years.

Interventions and Main Outcome Measures: The questionnaire determined demographic characteristics, age at menarche, menstrual cycle patterns and experiences, awareness of endometriosis, and preferences for learning about it.

Results: Period pain was common (94%), with pain reported as moderate/severe (86%). Girls reported missing school due to their periods (23%), mainly due to pain. Most believed their period was typical (63%); however, 27% were unsure, and 30% did not know if it was regular. Self-report of atypical periods was associated with symptoms suggesting need for clinical review and with consulting a doctor ($\chi^2(2) = 36.272, p < 0.001$). Only 8% could describe endometriosis, though 86% wanted to learn more about it.

Conclusion: Most secondary school girls report dysmenorrhea. Although most reporting atypical periods had seen a doctor, over a quarter did not know whether their period was typical or regular. The majority do not have knowledge of endometriosis, contrasting with adolescents' familiarity with other common chronic conditions such as diabetes and epilepsy. We suggest Menstrual Health Education (MHE) to improve knowledge of typical menstruation and pain treatment, aiding earlier identification of problematic period symptoms that might indicate underlying pathology.

Key Words: Adolescent, menstruation, dysmenorrhea, endometriosis, delayed diagnosis, education

Introduction

Menstrual pain (dysmenorrhea) is the main gynaecological complaint of adolescents.¹ The majority of adolescents with menstrual pain have *primary* dysmenorrhea, painful menstruation in the absence of pathology, but a significant minority have *secondary* dysmenorrhea, painful menses due to pelvic pathology.² Endometriosis, the chronic condition defined by the presence of endometrial gland and stroma outside the uterine lining, is the leading cause of secondary dysmenorrhea as well as chronic pelvic pain (CPP) in this age group.^{2,3} Approximately two-thirds of adolescent girls with CPP or secondary dysmenorrhea who undergo laparoscopy have evidence of endometriosis.^{4,5}

The true prevalence of adolescent endometriosis is unclear due to delayed recognition and intervention.^{3,6} Two to 10% of women of reproductive age have endometriosis,⁷ and a majority of those diagnosed as adults report first experiencing symptoms in adolescence.^{8,9} Delays from symptom onset to diagnosis can result in persistent chronic pain, significant adverse impacts on quality of life,^{10,11} potential progression of the disease,¹² and possible infertility.¹³ Adolescents unaware of typical menstrual characteristics may not recognise, or seek out help for, abnormal symptoms.^{14,15} This study aims to characterise typical menstrual characteristics in a large sample of secondary school girls, and to explore this age groups' knowledge of typical menstruation, endometriosis awareness and educational needs. An additional further aim is to establish whether those who experience menstrual characteristics that might indicate the need for clinical review and specialist opinion, report their period to be atypical.

Materials and Methods

Participants and setting

A descriptive cross-sectional survey study was carried out with secondary school girls aged 15 to 19 years old. AR recruited participants from secondary schools in the West Midlands, England. Schools included an independent girl's school (A), an independent mixed-sex

boarding school (B), and a government run mixed-sex academy school (C), representing a diverse range of recruitment sites. Non-random convenience sampling was used.

Questionnaire and Procedure

A self-administered pen and paper survey was designed specifically for this research. The survey consisted of questions newly developed to meet the aims of the study and also included existing questions used by other researchers conducting similar studies.^{16-19,26} AR and AH developed survey questions in consultation with GR and AW. The final questionnaire consisted of four sections: 1) demographic characteristics (e.g. age, ethnicity, and school type); 2) age at menarche, cycle patterns, and menstrual experiences; 3) preferences for communicating about menstruation with others; and 4) awareness of endometriosis, and preferences for learning about it in future.

The opening question to section four was ‘Do you know what endometriosis is?’

Respondents who answered ‘yes’ were then asked to describe endometriosis in their own words. This allowed for the assessment of respondents’ levels of awareness and understanding, in line with previous endometriosis research.¹⁸ After being asked if they know what endometriosis is, as done in previous similar surveys with adolescents,¹⁸ a short lay (non-medical) description of endometriosis, was provided to participants on a separate page. The description was based on a definition of the condition employed in an information leaflet produced for teenagers by Endometriosis UK in 2014.^a Participants were then asked if they would like to learn more about endometriosis, as well as how they would like to learn about it, who they were comfortable talking about it with and whether they thought boys should learn about it too.

^a Leaflet, “Is This Normal? About Endometriosis: What Every Girl Needs to Know” available at: <https://www.endometriosis-uk.org/sites/default/files/files/campaign%20materials/print-is-this-normal-leaflet-endometriosis-Feb2014-final.pdf>

The survey was piloted with 10 girls from the target population (aged 15-19) to assess the clarity of wording, acceptability of formatting, and ease of implementation. Following pilot testing, data collection was completed between November 2017 and March 2018. At least a week prior to survey completion, all female students meeting the target criteria were given verbal information about the research by the first author or a teacher at their school. They were also given a study information sheet, and a parent/guardian information sheet if under 16 years. Schools were given the choice between opt-in and opt-out parental consent as they were best positioned to know which would be most acceptable to students and parents/guardians. One school (A) requested that all students were given the parent/guardian information sheet and used opt-in parental consent, whilst two schools (B & C) used opt-out parental consent for under 16s. Participants had the opportunity to ask questions before providing consent and completing the survey. Survey completion took approximately 5-10 minutes.

Ethics and Data Analysis

The university ethics committee at Birmingham City University granted ethical approval for this study. After survey completion, all participants received a leaflet signposting relevant and locally accessible health and support organisations should they want further information, or have concerns about, their menstrual health. All questionnaires were reviewed and checked for completion and accuracy by the principal investigator before inputting the data into an electronic database using a pre-constructed codebook. Responses to the free-text question asking participants to define endometriosis were transferred into QSR's NVivo 11, to be coded using content analysis, in line with previous endometriosis research.¹⁸ AR read and re-read the answers to enable familiarisation, and then they were grouped to obtain categories. Final categories were reached upon agreement by two researchers (AR & AH). Each category was given a number to allow for further statistical analysis.

Data was analysed using SPSS Version 24. Tests for normality were performed on the continuous variables (i.e. current age, age of menarche), which were found to be non-normally distributed. Therefore, subsequent analysis of data used either the Mann-Whitney U test or the Kruskal-Wallis test for continuous data, and Chi-squared tests for the categorical data. For the latter, if expected cell counts were less than 5 for >20% of the cells, a Fisher's exact test was used for 2x2 tables, and a likelihood ratio chi-squared test for larger tables.²⁰ A *p* value of <0.05 was considered to show a statistically significant result.

Results

Sample Demographic Characteristics and Menstrual Experiences

A total of 442 secondary school girls, aged 15 to 19 years, participated in the survey, with a median age of 17 years. The overall response rate to the survey was 53%.

At the time of survey completion, 99.5% of participants had started their periods (440/442). The median age of menarche was 12.5 years and ranged from 9 to 16.42 years. Most participants reported menstrual bleeding between 4 and 7 days (88.9%), and the median duration was 5 days. Only 48.6% of the sample reported the length of their menstrual cycle, and for those reporting between 21-45 days, the median length was 28 days. Irregular periods were reported by 31.3% of responders, and 29.6% indicated that they did not know the length of their cycle. Those who provided the length of their cycle, and did not tick 'don't know' or 'irregular periods' were assumed to have regular periods (39.1%). The full response rates by school, demographic and menstrual bleeding pattern information collected for the sample are shown in Table I.

Table I. Sociodemographic factors and menstrual bleeding patterns.

Table II shows period pain rates for the sample as well as medication usage and school absences. Their pain responses were categorised as 'mild pain' (answers 1 to 3), 'moderate

pain' (4-7), and 'severe pain' (8-10), using the similar cut-off scores as in previous research.¹⁶ The effectiveness of their pain medication was rated from 0 to 10, and these responses were categorised into 'no/low effectiveness' (0 to 3), 'moderate effectiveness' (4-7), and 'high effectiveness' (8-10), using the same cut-off scores as in previous research.¹⁶

School absence due to periods was reported by 100 (22.7%) responders with the majority missing 1 day, and 2 days given as the maximum response. The reason most often stated was that their period was 'too painful' (91.0%). Almost a third of the sample had visited a doctor about periods (29.5%).

Table II. Menstrual pain, medication use and school absence

Perceived typicality of periods

Participants indicated whether they thought their periods were typical (ie, normal) for someone their age, with 274 (63.1%) responding 'yes', 44 (10.1%) responding 'no', and 116 (26.7%) responding 'unsure'. Further analysis was conducted using this data to examine if those who perceive their period to be atypical also report symptoms comparable with National Institute for Health and Care Excellence (NICE) criteria³¹ for referral for further clinical review and specialist investigation. NICE guidelines are standard clinical guidelines developed for the UK National Health Service and are developed by independent committees comprised of professionals, members of the public, and relevant stakeholders. Finally, knowledge of endometriosis was compared across the groups according to whether the girls thought their period was typical for someone their age.

Grouping by Self-reported Typicality of Period

The girls who believed that their periods were not typical for someone their age were more likely to report irregular periods ($\chi^2(2) = 46.42, p < 0.001$), take medication for period pain ($\chi^2(2) = 8.75, p < 0.05$), take oral contraceptive pills (OCPs) ($\chi^2(2) = 9.58, p < 0.01$), have

knowledge of endometriosis ($\chi^2(2) = 8.75, p < 0.05$), and have seen a doctor about their periods ($\chi^2(2) = 36.272, p < 0.001$). Pain severity ratings were significantly different between the groups, with those who thought their periods were typical having lower pain scores than those who thought their periods were not typical and those that were unsure ($H(2)=11.62, p = 0.003$). Those who thought that their periods were not typical also reported that their pain medication was less effective than those who reported that their periods were typical ($H(2)=10.465, p = 0.005$). Although school absence was not significantly related to perceived typicality (i.e., ‘normalness’) of periods, it was related to pain severity, with those in the highest pain group (8-10 on the pain scale) missing more school ($\chi^2(2) = 49.78, p < 0.001$).

Awareness of Endometriosis

Although forty-four participants (10.1%) answered ‘yes’ to the question ‘Do you know what endometriosis is?’, forty-six participants provided a description of endometriosis, which were coded and categorised into description types. Only 8.2% went on to accurately describe the condition. Descriptions were based on symptoms, the biological mechanisms involved in endometriosis, or a combination of both. Pain as a symptom was mentioned most frequently, representing 50% (23/46) of descriptions. Descriptions including biological mechanisms were based on the lining of the womb appearing elsewhere (15/46) and blood being unable to leave the body (5/46). Some descriptions were vague, or did not capture any element of the definition of endometriosis. Five responders’ descriptions were simply of a period, and four could be categorised as ‘something to do with a period’, which was likely evident given the nature of the survey. Participants who stated that they knew what endometriosis was also indicated how they knew; almost half (21/43) knew about endometriosis from the internet or media.

The majority of participants (85.9%) indicated that they would like to learn more about endometriosis. Over half (51.3%) indicated school as their preferred source of learning, via lessons or the school nurse. However, only 26.5% indicated they were comfortable discussing

endometriosis with a schoolteacher. The majority of participants (82.8%) thought boys should learn about endometriosis as well.

Discussion

This study characterises typical menstrual characteristics for secondary school girls; it explores this age groups' knowledge of typical menstruation and awareness and educational needs regarding endometriosis. It further establishes if self-reported atypical period symptoms indicate menstrual characteristics suggesting the need for further specialist clinical review.

This study demonstrates the critical need for improved adolescent menstrual health education (MHE). One in four girls (27%) were unsure if their periods were typical, 1 in 10 (10%) considered their periods non-typical and nearly 1 in 3 (30%) did not know if their periods were regular. Female pupils report available MHE provision to be overly abstract (focused on the biological aspects of menstruation) and that it does not address their concerns about whether their periods are 'normal.'²¹⁻²⁴ Those unaware of typical menstrual characteristics may not recognise, or seek out help for, abnormal symptoms.^{14,15}

Pain remains a significant factor in girls' period experiences, with a majority (86%) reporting their period pain to be moderate or severe, reflecting similarly high levels of adolescent dysmenorrhea from past research^{1,17,25-30}. Nearly 1 in 3 girls report visiting a doctor about their periods, a rate reflecting the wide-spread experiences of pain and uncertainties around typical menstruation. Period pain is the primary reason for missing school (91%) and those with severe pain are more likely to miss school (45%). While most girls (66%) have taken medication or OCPs to manage pain, a significant number have not. Girls want to learn more about menstrual cramps and how to manage pain.²⁴ A key component, therefore, of MHE is

the inclusion of discussions of pain treatment options, including medication options such as non-steroidal anti-inflammatory drugs and OCPs.

This study demonstrated that those reporting non-typical periods were significantly more likely to report irregular periods, severe period pain, taking medication for period pain, finding medication inadequate for pain, taking OCPs, seeing a doctor about their periods, and knowing what endometriosis is. Contact with medical services might have resulted in OCP prescriptions, as well as discussions with health care professionals about possible endometriosis. As per recent clinical updates³ and UK and European guidelines,^{7,31} those reporting higher pain levels and ineffective pain relief from medication exhibit atypical periods indicative of the need for possible clinical review for a specialist opinion.

Findings also demonstrate the acute need for improved endometriosis awareness amongst adolescents. Only 8% of secondary school girls knew what endometriosis was, approximately half the rate in Italy (19%)¹⁹ and a third of that in Australia (24%).¹⁷ Adolescents in the general population report comparatively high familiarity with other health conditions.³² The majority are familiar with asthma (88%), arthritis (84%), diabetes (81%), HIV/AIDS (78%), and breast cancer (72%); approximately one-third are familiar with Parkinson's disease (39%) and epilepsy (31%).³² Girls are considerably less aware of endometriosis than other chronic conditions with similar adult prevalence rates, specifically diabetes and epilepsy.

Improving individuals' awareness of endometriosis may help improve time to diagnosis. The average delay from symptom onset to diagnosis is eight years in the United Kingdom.³³ In the United States, where referrals are not needed to access gynaecological specialist care, the average delay is four and a half years.³⁴ While improving adolescents' knowledge of menstruation and endometriosis may reduce diagnostic times, stigma around speaking about periods must also be addressed, as research shows girls and adult women may be reluctant to

speak about their menstrual health even with health professionals.³⁵ Further, there is evidence health care professionals may dismiss or ‘normalise’ the endometriosis symptoms of those who come to seek care.³⁶

This research showed that girls want to know more about endometriosis (86%), and school lessons are the preferred mode of learning about the condition (41%). Girls are less comfortable speaking with their teachers (27%) than with school nurses (37%), doctors (44%), friends (56%) or parents (64%) about endometriosis. Previous research shows most teen girls (63%) are uncomfortable talking about periods with teachers,³⁷ thus, as found elsewhere,³⁸ students may prefer outside experts (youth workers, sexual health professionals, etc.) deliver MHE content. Girls worry about being shamed at school about their periods, particularly by boys.^{23,39} The majority of girls feel boys should learn about endometriosis (83%), and inclusion of boys in general MHE could reduce period-related bullying.^{24,37}

In addition, MHE needs to allow girls to not just learn about biological factors associated with menstrual cycles and menstrual bleeding, but also provide safe spaces for girls to discuss what having a period is really like for them. Research shows that girls want to discuss the psychological and social aspects of having a period – not just the biological aspects.^{21,23,24,40} Gunson et al., (2016)⁴¹ found that overly positive and naturalistic descriptions of menstruation could lead girls to feel that their experiences did not live up to expectations. Most adolescent girls feel comfortable talking about menstruation with female friends,³⁷ and this allows them to provide support for each other around the aspects of menstruation that girls view negatively.⁴² MHE should also take into account a wide age-range since although the average age of menarche was 12.5 in this study, some girls started as early as 9. MHE would therefore ideally start early and continue in an ongoing fashion, instead of as a one-off.

Strengths and Limitations

The survey was modelled on those from similar previous studies¹⁶⁻¹⁹ and designed to address this study's aims. A limitation was an absence of validated questionnaires to draw upon. Despite the pilot study indicating that the questionnaire was fit for purpose, some main survey respondents confused the length of their period with the length of their menstrual cycle (resulting in 37 respondents reporting menstrual cycles of between 2 and 7 days). The 23 respondents linking endometriosis to pain in their descriptions of the condition may have deduced this connection from survey questions focused on their period pain experiences. However, as only 5% of the total number surveyed responded to the endometriosis definition question with an answer including pain, it does not appear to have overly influenced the results on endometriosis awareness. It is also worth noting that a higher percentage of girls may have reported wanting to learn about endometriosis because the condition was introduced to them in this survey, therefore increasing its salience. The survey did not include questions regarding secondary school girls' experiences of heavy menstrual bleeding, a common adolescent gynaecological concern and possible symptom of underlying pathology⁴³ that warrants investigation in future research. The frequency of OCP use was somewhat low in this sample (13.7%). Previous research⁴⁴ suggests that the percentage of girls receiving a prescription for OCPs in the UK is 19%. The low frequency of OCP use may also be due to delays in access reported for adolescents in the UK.⁴⁵ It is possible that cycle length, perceived cycle regularity and pain levels could have been influenced by OCP use; however, as described above, the percentage of the sample using OCPs was low. The survey did not include questions regarding use of other menstrual management or contraceptive medications (e.g. intrauterine devices, contraceptive injections, etc.).

To our knowledge, this is the first England-based study on the typical experience of menstruation for adolescents (of any age) as well as their knowledge of typical menstruation

and endometriosis. Only two recent similar studies on menstrual characteristics in adolescents and young women have been conducted in Australia¹⁷ and Italy.¹⁹ This study had a large and ethnically diverse sample, nearly half (49.1%) of participants identified as Asian, 35.8% as White, 10.7% as Black and 4.4% as Mixed Race. Such diversity is important given menstrual experiences of ethnic minority populations have been under-represented in the literature previously.^{14-19,37}

Conclusion

Most secondary school girls experience period pain, many do not know if their periods are regular or typical, and an overwhelming majority do not know what the common chronic condition endometriosis is. Findings demonstrates the critical need for better MHE provision to improve girls' knowledge of typical menstruation and period pain experiences, pain management options, and common gynaecological health conditions. Such provision is key to improving girls' menstrual health knowledge, experiences and outcomes.

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Disclosure/Conflicts of Interests

None.

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