Evaluation of a web-based resource to improve menstrual health literacy and self-management in young women

Mike Armour (✉ m.armour@westernsydney.edu.au)

NICM Health Research Institute, Western Sydney University

Kelly Parry

NICM Health Research Institute, Western Sydney University

Christina Curry

Western Sydney University

Tania Ferfolja

Western Sydney University

Melissa Parker

ACT Health

Toobah Farooqi

UNSW Sydney

Freya MacMillan

Translational Health Research Institute (THRI), Western Sydney University

Caroline A Smith

NICM Health Research Institute, Western Sydney University

Kathryn Holmes

Western Sydney University

Research Article

Keywords: Dysmenorrhea, health literacy, internet, menstruation, self-care, endometriosis

Posted Date: March 31st, 2022

DOI: <https://doi.org/10.21203/rs.3.rs-1247940/v2>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Abstract

Objective: Menstrual cycle-related conditions, such as dysmenorrhea and heavy bleeding, are common amongst those under 25 years. Despite having significant impact on work, education, and social activities, most do not seek medical advice, preferring to self-manage their symptoms. We aimed to determine if access to a web-based resource could improve health literacy, reduce menstrual symptoms, and encourage health-seeking behavior in those at risk of conditions, such as endometriosis.

Methods: People were eligible to participate if they were currently living in Australia, aged 14-25 years, and had menstruated for at least 12 months. Access to the resource, comprising evidence-based information on the menstrual cycle, the Period ImPact and Pain Assessment (PIPPA) tool, and guidance on self-care options, was provided for three menstrual cycles.

Results: Seventy-five participants with a mean age of 20.4 years enrolled to use the web-based resource. Forty-three percent visited their doctor regarding their menstrual symptoms during the study period, with 84% indicating that they made the appointment due to the resource; over half (56%) who visited their doctor received a referral to a gynecologist. There were clinically relevant improvements in health literacy reflecting improved confidence of participants regarding having both adequate information and skills to manage their symptoms. Almost half (48.8%) said the resource had changed what they thought was a 'normal' period, and 94% could now identify symptoms of endometriosis.

Conclusion: A low-cost, web-based resource can improve health literacy, provide effective options for self-management of menstrual cycle-related conditions, and motivate young people to seek medical advice.

Introduction

Menstrual conditions, such as dysmenorrhea (period pain) and heavy menstrual bleeding (HMB), are common in young women worldwide (1, 2). Dysmenorrhea is common in young Australian women, with research showing over 90% of those under 25 years reporting regular dysmenorrhea (3, 4). Despite the significant impact menstrual symptoms, such as dysmenorrhea, have on academic attendance and performance (3-5) many women, regardless of age, consider pain a 'normal' part of being a woman (6). Most women do not seek medical help, but rather, use self-management (7). However, they are often unsure which self-management strategies are effective and report only partial symptom relief (7, 8).

The Institute of Medicine defines *health literacy* as “the degree to which individuals have the capacity to obtain, process, and understand basic health-related decisions” (9). In an educational context, the Australian Health and Physical Education (HPE) curriculum (10) focuses on developing knowledge, understanding, and skills related to the three dimensions of health literacy: functional, interactive and critical, where health literacy is considered a personal and community asset to be developed, evaluated, enriched, and communicated. With a specific focus on menstrual health literacy, the HPE curriculum includes sexuality and sexual and reproductive health, puberty, and access to health services.

However, almost 50% of Australian teachers report that they are under-prepared to discuss menstruation as part of the normal curriculum (11). This unpreparedness from teachers may explain why young women and their parents in Australia consistently report low menstrual health literacy (7, 12, 13), and why young women often rate their period as 'normal' despite significant related absenteeism and regular non-cyclical pelvic pain symptoms (7). This is especially concerning when combined with low rates of seeking medical attention as almost half of young women cannot identify the signs of secondary dysmenorrhea, such as endometriosis (7). A significant issue is that menstruation is often explained only insofar as women understand enough to protect themselves from unwanted pregnancy rather than empowering them to understand how it affects their lives (14).

Increasing health literacy through menstrual education can assist women's understanding, positively affecting their ability to engage in self-care, and help identify symptoms that require further investigation (15, 16). In addition, there are various effective, non-pharmacological interventions that can reduce menstrual symptoms including heat, low intensity exercise, such as yoga or stretching, and acupuncture (17-20); however, most young women appear unaware of these (8). Strategies to raise awareness of these interventions are required.

This study aimed to evaluate a web-based resource delivering menstrual education, self-screening for menstrual disturbance and evidence-based self-care, to determine if it was acceptable and feasible for young people and if this resource could increase their menstrual health literacy, improve engagement with health professionals, change their management strategies, and reduce menstrual pain.

Methods

2.1 Study design

Ethical approval for this study was provided by the Western Sydney University Human Ethics Committee (H12599 – March 2018). All research complied with the relevant guidelines and regulations outlined in the National Statement on Ethical Conduct in Human Research (2018) (21). All participants (and their legal guardians if aged <18yrs) provided written informed consent prior to the start of the study. The web-based resource was hosted by Western Sydney University and was developed based on the results of our national survey on menstrual health literacy (7), as well as our team's previous work on exploring effective non-pharmacological self-management strategies for dysmenorrhea and other menstrual symptoms, such as premenstrual syndrome (PMS) (17-19). The resource was co-created with an expert steering group comprising the research team, two gynecologists, two general practitioners (GPs), two secondary HPE teachers, a sexual and reproductive health curriculum expert, and five young women (16-25yrs) from diverse backgrounds. The steering group met twice, first to discuss content and format of information that should be included in the resource, and again, approximately four weeks later to assess suitability of the resource content developed by the research team. Minor changes were made in response to feedback from the steering group. The resource was developed with two main sections: Section one was evidence-based information on the menstrual cycle, covering hormonal changes during the

menstrual cycle, signs, symptoms, and suspected causes of dysmenorrhea (both primary and secondary), PMS, and HMB. Emphasis was placed on the range of symptoms that could be considered 'normal' and those that were likely to require further medical investigation, encouraging participants to speak to their doctor. The second section contained immediate self-care options including guidance on how to use heat effectively, information on usage of over-the-counter medications, such as ibuprofen, and a range of medium- to long-term self-care options including acupressure points, a yoga sequence (Yoga Nidra), and dietary guidance. Upon advice of the steering group, self-management information was delivered as a mixture of text, instructional video clips, and audio recordings. Once developed, the resource was pilot tested with four young women under the age of 21, with further editorial changes made to the content to ensure it was clear and understandable for this age group.

2.2 Participants, recruitment, and study flow

People were eligible to participate if they were currently living in Australia, aged 14-25 years, had menstruated for at least 12 months, had regular periods (within 21 to 35 days), and had internet access on their computer, tablet, or smartphone.

Participants were recruited using a variety of methods. These included paid Facebook and Instagram advertising and social media promotion by Family Planning NSW, Endometriosis Australia, ACHPER, and Kimberly-Clark Australia, as well as via social media networks (both personal and professional) of the research team. Potential participants lodged their interest via a web-portal and a member of the research team (K.P.) contacted them via email. A phone call was undertaken (if under 18yrs including the parents/guardians) to get consent and screen participants.

Participants completed baseline measures after their next menstrual period and were subsequently provided with web-resource login and password. The Period ImPact and Pain Assessment (PIPPA) tool was previously developed to assist young women determine normal from atypical period pain and interference (4, 22). At baseline, all participants filled in an online version of the PIPPA tool, which asked five Y/N questions regarding the impact of their menstrual symptoms. If they answered "Yes" to either four or five of the PIPPA questions, they received an email with a personalized letter advising them to make an appointment and take this letter to their doctor. The letter contained an explanation of the PIPPA tool and the related questions they had answered "Yes" to and requested that further investigations be made if the doctor felt it was appropriate. Access to the resource covered three menstrual cycles. They were asked to log in to the resource at least twice in the first month to read the information section and familiarize themselves with the self-management options, and at least once per month for the next two months. Participants were encouraged to use as many or few self-management techniques as they preferred. Regular automated reminders, either via email or SMS/text messages (based on participant preference), were sent twice per month to remind participants to use their self-management method(s) of choice. The total duration was approximately four months, with three menstrual cycles, using the resource with a one-month follow-up period.

2.3 Sample size

As this was an evaluation study with a single arm no formal sample size calculation was undertaken. Given the lack of previous data on the effectiveness of such web-based interventions, a decision was made to include 75 participants to ensure that rare events and/or small effect sizes would be captured (23).

2.4 Outcome measures and data analysis

Table 1 outlines the outcome measures and collection timepoints. All data were captured using Castor EDC (24).

Descriptive statistics, including frequencies and percentages, means and standard deviations, or median and interquartile range (IQR), were used to report recruitment and dropout rates and demographics information. All outcomes were determined *a priori*, and as this was a pilot study, all *p*-values are considered exploratory. All parametric outcomes were compared using paired t-tests while non-parametric outcomes, such as PIPPA scores, were compared using the Wilcoxon signed-rank test. Missing data were dealt with via last observation carried forward (LOCF) on the assumption that those who dropped out of the trial were non-responders.

[INSERT TABLE 1]

Results

Two hundred and seventy-four young people expressed interest in using the resource over a three-month recruitment period. The most common reasons for exclusion were lack of response to screening phone calls (n=124, 45%) and being outside the age range for eligibility (n=35, 13%). Seventy-five (27%) were eligible to participate, consented and entered the study, with 56 (75%) using the resource for the full three menstrual cycles. The most common reasons for non-completion were lack of time (n=9, 47%), lost to follow up (n=6, 32%) (defined as no response after three weeks of attempted contact), pregnancy (n=2, 11%), or menstrual suppression due to contraceptive use (n=2, 11%).

Table 2 outlines the demographics and menstrual characteristics of the participants. Participants had a mean age of 20 (3.4) years, and the majority were currently at school or university (60%). Eighteen participants (24%) had a confirmed diagnosis of endometriosis. Almost three-quarters (73%) of the participants had previously seen a doctor for menstrual symptoms. However, only 16% were happy with the advice they received from their health professional. Eighty percent of participants were at or had attended co-educational schools, with just over half currently attending or had attended a public school (52%), while under one-quarter (22.5%) attended a religiously affiliated school or a private school (17.5%). Only 40% reported they had learned about menstrual health in their HPE classes.

Those with a diagnosis of endometriosis (n=18) had a median PIPPA score of 5, while those without (n=57) had a significantly lower median score of 3 ($P=.04$). Thirty-eight participants (51%) had a PIPPA score of 4 or greater and received a referral letter for their GP. Half of those who received the referral letter subsequently made an appointment with their GP.

Just under half (n=32, 43%) of the participants visited their doctor regarding their menstrual symptoms during the study period. Of those who visited their doctor, 27 participants (84%) indicated that they made the appointment due to being involved in the study, either due to information they received on the website (n=8, 30%) or the referral letter they received (n=19, 70%). Of the 32 participants who visited their GP, over half (56%) had received a referral to a gynecologist by the end of the one-month follow-up period.

[INSERT TABLE 2]

3.1 Menstrual management

Table 3 outlines the changes in specific self-management strategies that were part of the study between baseline and the third menstrual period. Of the 84% of participants using analgesics, the most common analgesics used prior to the study were ibuprofen (33%), paracetamol (33%), and mefenamic acid (18%). There were no significant changes ($P=.67$) in the type of analgesic used or the dosage used ($P=.72$) between baseline and the third menstrual period. Overall, use of self-management for menstrual symptoms increased from 65% of participants at baseline to 86% at the third menstrual period.

At the end of the one-month follow up, 60% of participants reported that the resource changed the way they managed their menstrual symptoms, and 85% would keep using at least one of the self-care practices they had learned.

[INSERT TABLE 3]

3.2 Menstrual pain and symptoms

Those with a diagnosis of endometriosis (n=18) had a significantly ($P=.005$) higher menstrual pain score at baseline (7.7) compared to those without (n=57) a diagnosis of endometriosis (5.6). Overall, there was a small, non-significant ($P=.22$) decrease in menstrual pain from 6.1 (1.9) at baseline to 5.3 (2.2) at the end of the three months. At one-month follow up, 4% said their menstrual symptoms were ‘very much better’, 1 in 5 (20%) said their menstrual symptoms were ‘much better’ than before they started, almost half (46%) said ‘a little better’, and just over one-quarter (28.6%) said no change.

3.3 Internal health locus of control

There was a small, non-significant ($P=.24$) increase in mean internal health locus of control (IHL_{LoC}) scores from 29.19 (3.39) at baseline to 29.96 (3.25) at one-month follow up.

3.4 Health literacy measures

Table 4 outlines the changes in Pam Activation Measure (PAM) levels and Health Literacy Questionnaire (HLQ) scores. Table 5 details the percentage of reliable change in the Health Education Impact Questionnaire (heiQ) scores.

[INSERT TABLES 4 AND 5]

3.5 Menstrual health literacy

Prior to beginning the study at baseline, only one-quarter of the participants (25%) felt that they had sufficient information about their period and its symptoms, with just over half (53%) reporting that they had some information but felt unsure about a number of aspects, with 15% being unsure if they had enough information at all. At the end of the follow-up period, 59% of participants indicated that they felt they had sufficient information about their period and its symptoms, 35% reported that they had some information but felt unsure about a number of aspects, with 6% being unsure if they had enough information at all.

At baseline, when asked about specific aspects of menstrual health, 60% of the participants indicated that they knew the signs of HMB, and 69% could identify the symptoms of endometriosis. At follow up, 87% could identify the signs of HMB, and 94% could identify the symptoms of endometriosis.

At the end of the follow up, just under half of the participants (48.8%) said the resource had changed what they thought was a ‘normal’ period, and over one-third (35%) said it corrected previous misunderstandings they had about periods and the menstrual cycle. After using the resource, 65% said they were now ‘very comfortable’ talking about periods to others.

3.6 Participant satisfaction

Eighty-five percent of the participants found the web-based resource easy to use, and 90% found the information provided ‘very helpful’. One-quarter of the participants (25%) were ‘very satisfied’ with the changes in their symptoms, and over one-third (34%) were moderately satisfied. Only one participant was unsatisfied.

Discussion

Our study found that access to an online resource for three menstrual cycles could improve some key aspects of menstrual health literacy, encourage engagement with medical professionals, and provide improved understanding of both a ‘normal’ menstrual cycle and how to identify problematic menstrual conditions, such as endometriosis and HMB.

There was an increased uptake of self-care measures over the course of the study, especially in breathing/meditation exercises and acupressure, which were low at baseline. There is some preliminary evidence that mindfulness-style interventions reduce menstrual pain (25, 26), and there is evidence for both mindfulness and acupressure for reducing PMS symptoms (19, 27). Exercise has the most significant reduction in pain compared to other self-care measures, such as heat (17), but uptake was lower than other forms of self-care. This may be because our resource aimed to increase health literacy; content was not included to support behavior change. Incorporating behavior change theory-based content, such as stepping individuals through use of behavior change techniques (28, 29) (e.g., using self-monitoring, setting goals, social support, and/or adding behavior change support intervention methods in addition to the online platform, e.g., face-to-face methods), could further enhance efficacy of the resource in regards to changing behaviors of seeking health care and using self-management strategies, such as exercise. Our team are working to develop such support, including testing of a menstrual pain behavior app (30). Despite the increased uptake of these self-care measures, we did not find evidence of a clinically significant reduction in menstrual pain; however, it is important to note that this study was not powered to detect any such change if it did exist. The pain score itself is also unlikely to capture the complete spectrum of bothersome menstrual symptoms, such as emotional changes (6), which may explain why, despite lack of a significant pain reduction, over half of the participants rated their menstrual symptoms as at least slightly improved.

The addition of a menstrual disturbance self-screening tool (PIPPA) to menstrual education in this study demonstrated health-seeking behavior by women to GPs and reported action by GPs to refer some participants to gynecologists. Young women commonly report GPs' dismissal of pain and interference-related menstrual disturbance (31, 32), which can cause reluctance to engage with health-care professionals (6). In this study, the addition of a letter to GPs with PIPPA scores and explanation of relevance may have provided reverse education of GPs to take seriously young women's reports of menstrual disturbance. The action by GPs to refer women to gynecologists may have been facilitated by the combination of a high PIPPA score, providing external validation of pain and interference, and women's increased menstrual health literacy and confidence to present to GPs. Given that over half of young Australian women report symptoms of non-cyclical pelvic pain but also normalize these symptoms (3), ensuring that these young women are advised and empowered to seek medical advice is vital so that lengthy diagnostic delays are reduced (33, 34).

Certain aspects of health literacy related to agency, empowerment, and improved health management skills all increased during the study period. The significant improvement in the "Having sufficient information to manage my health" domain of the HLQ corresponds to "Feel(ing) confident that they have all the information that they need to live with, and manage, their condition and to make decisions" (35). Several domains of the heiQ also showed reliable improvement, with the largest improvement in the skills and technique acquisition domain; improvement in this domain relates to "highly developed skills in symptom relief and techniques to manage own health" (36). The proportion of reliable positive change in our participants was similar across most domains to previous research on the impact of chronic disease management programs in Australia between 2007-2013 (37), suggesting that, despite the online nature

and minimal interaction between the research team and participants, or between participants themselves, it was similarly effective to more 'traditional' programs. Interestingly, despite these improvements there was no corresponding improvement in the IHLc scores over the course of the trial, but the IHLc scores both at baseline and the end of study were similar to previous data on those with and without a chronic health condition (38), suggesting that these scores were already in the normal range.

These findings illustrate that a relatively large number of young people are not receiving accurate information in schools (from neither parents nor health-care professionals), information is not being delivered in a suitable manner, or they are missing the information they need. Previous research in Australia has shown that when discussing a condition, such as endometriosis, young women wanted to know specific symptoms rather than vague or general information (39). Focusing on high schools, the HPE syllabus does not directly address menstrual health education. Content covered in the later years is linked to sexual and reproductive health through the focus area 'Relationships and Sexuality', which aims to explore resources and strategies to manage personal, physical and social changes, and transitions associated with puberty as they grow older (10). In the later years (years 9 and 10), the focus of this content shifts to sexuality and sexual health education, leaving it to the teacher's discretion to incorporate this content at all or in an effective manner beyond personal experience or from a biological lens. Given the significant number of participants attending co-educational schools (80%), the findings of this study reveal gaps in the HPE curriculum between the menstrual health education delivered in school and what information is needed to develop young people's menstrual health literacy.

We recommend a whole-school approach to develop menstrual health literacy and strategies to support students, teachers, and school staff to promote menstrual health and well-being. This research indicates the need for greater emphasis on menstrual health in HPE classes. Menstrual health education needs to focus on correcting mistaken assumptions about a 'normal' period or menstrual cycle and provide sufficient information about periods, their symptoms, and menstrual management, including self-care options and when to consult a doctor. To develop young peoples' menstrual health literacy within the critical dimension, the HPE curriculum needs to provide menstrual health education that empowers students to selectively access, and critically analyze, menstrual health information and take action to promote their menstrual health (10). Such information could potentially help to alleviate not only dysmenorrhea and related menstrual symptoms but could, by extension, increase their ability to engage fully in the classroom and extra-curricular activities. The provision of an online resource, such as the one reported in this paper, offers young people and teachers additional information that they could access autonomously. Providing such a resource would ensure critical information was more broadly disseminated and independent of individual teacher capacity. Furthermore, such a tool provides young women with the knowledge to take charge of their health. Ideally, use of such a resource would be accompanied by professional learning for teachers and potentially parents and carers of young women to ensure that the health literacy messages received by young women are aligned.

Translational capacity of interventions is essential to consider when designing and evaluating health interventions to ensure follow through to sustainable policy and practice change from research settings.

The Reach, Effectiveness, Adoption, Implementation, Maintenance (RE-AIM) framework (40) is one of the most commonly used implementation science frameworks. Regarding the current study, reach into the intended target population (e.g., total number of eligible women that were exposed to the intervention invite), adoption of the intervention (e.g., number of women out of the total potential eligible sample who joined the study) and implementation of the intervention (e.g., how the intervention was used, such as number of hours of engagement and with which elements of the online resource) were not determined. A range of social media sources were used to recruit women making it challenging to identify the total potential sample, and the online platform used for resource delivery did not capture analytics to inform use and engagement with the resource. This study was a short evaluation study, thus, long-term engagement with the resource (maintenance) was not explored. Our evaluation tools did, however, detect meaningful changes in some outcomes suggesting that further testing is warranted to explore full scale, long-term effectiveness, and implementation processes in a rigorous trial. Future work should also collect in-depth, qualitative data from resource users (e.g., women) and stakeholders (e.g., teachers) to explore how and why outcomes changed the way they did over time (41).

We have suggested that high schools may be an appropriate place to reach young women. However, consideration of other settings to promote the resource in women, and important influencers of women beyond high school, should also be considered (e.g., through universities, pharmacies, health-care settings, community groups, and other social marketing strategies). We did not collect data on ethnicity, educational level, or socio-economic status, which are associated with health disparities, potentially through health literacy(42, 43). It may be that our resources would require tailoring to particular groups, which will need exploration in the future. For example, peer support (support from someone with similar characteristics to the individual and with experiential knowledge) has been shown to be particularly effective for lifestyle behavior change in culturally diverse communities (44); thus, expanding on our current resource to add an element of peer support may be necessary to engage with such communities.

There are several strengths to this study including the use of validated health literacy questionnaires and the previously validated PIPPA tool to encourage engagement with health professionals. However, some important limitations must be acknowledged. Firstly, this is a pilot study and, therefore, was not powered to detect small, even if clinically relevant, changes between baseline to end of trial. Secondly, due to budget constraints and internal University policy, the web-based resource was hosted on the University web platform. This platform lacks many of the features of the “modern” Web 2.0 and, therefore, data on which pages were interacted with, for how long, and what video clips received the most views, was not able to be retrieved. Therefore, we are unable to determine how much actual engagement with the material there was. Future versions of this content will be hosted on modern platforms that will allow the research team to use analytics to help optimize content. Finally, outcomes of the visit to GPs or gynecologists are unknown; therefore, we are unsure about how many participants, if any, received a further diagnosis, such as endometriosis, for their symptoms.

Conclusions

A web-based resource, with minimal setup and ongoing costs, can provide clinically relevant improvements in health literacy, remedy previous misconceptions about menstruation, and increase awareness and up-take of evidence-based self-care methods. The PIPPA tool was a simple, but effective, means of empowering and encouraging visits to health professionals. Future research should explore the most acceptable way to deliver this information, and to ensure that not only young people, but their teachers and parents/guardians, have access to accurate, evidence-based information on menstruation and its management.

References

1. Armour M, Parry K, Manohar N, Holmes K, Ferfolja T, Curry C, et al. The Prevalence and Academic Impact of Dysmenorrhea in 21,573 Young Women: A Systematic Review and Meta-Analysis. *J Womens Health (Larchmt)*. 2019;28(8):1161-71. Epub 2019/06/07. doi: 10.1089/jwh.2018.7615. PubMed PMID: 31170024.
2. Friberg B, Orno AK, Lindgren A, Lethagen S. Bleeding disorders among young women: a population-based prevalence study. *Acta Obstet Gynecol Scand*. 2006;85(2):200-6. Epub 2006/03/15. doi: 10.1080/00016340500342912. PubMed PMID: 16532915.
3. Armour M, Ferfolja T, Curry C, Hyman MS, Parry K, Chalmers KJ, et al. The Prevalence and Educational Impact of Pelvic and Menstrual Pain in Australia: A National Online Survey of 4202 Young Women Aged 13-25 Years. *J Pediatr Adolesc Gynecol*. 2020;33(5):511-8. Epub 2020/06/17. doi: 10.1016/j.jpag.2020.06.007. PubMed PMID: 32544516.
4. Parker MA, Sneddon AE, Arbon P. The menstrual disorder of teenagers (MDOT) study: determining typical menstrual patterns and menstrual disturbance in a large population-based study of Australian teenagers. *BJOG*. 2010;117(2):185-92. Epub 2009/10/31. doi: 10.1111/j.1471-0528.2009.02407.x. PubMed PMID: 19874294.
5. Hillen TI, Grbavac SL, Johnston PJ, Straton JA, Keogh JM. Primary dysmenorrhea in young Western Australian women: prevalence, impact, and knowledge of treatment. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine*. 1999;25(1):40-5. Epub 1999/07/27. PubMed PMID: 10418884.
6. Armour M, Dahlen HG, Smith CA. More Than Needles: The Importance of Explanations and Self-Care Advice in Treating Primary Dysmenorrhea with Acupuncture. *Evid Based Complement Alternat Med*. 2016;2016:3467067. Epub 2016/06/01. doi: 10.1155/2016/3467067. PubMed PMID: 27242909; PubMed Central PMCID: PMC4875987.
7. Armour M, Hyman MS, Al-Dabbas M, Parry K, Ferfolja T, Curry C, et al. Menstrual Health Literacy and Management Strategies in Young Women in Australia: A National Online Survey of Young Women

Aged 13-25 Years. *J Pediatr Adolesc Gynecol*. 2021;34(2):135-43. Epub 2020/11/15. doi: 10.1016/j.jpag.2020.11.007. PubMed PMID: 33188935.

8. Armour M, Parry K, Al-Dabbas MA, Curry C, Holmes K, MacMillan F, et al. Self-care strategies and sources of knowledge on menstruation in 12,526 young women with dysmenorrhea: A systematic review and meta-analysis. *PLoS One*. 2019;14(7):e0220103. Epub 2019/07/25. doi: 10.1371/journal.pone.0220103. PubMed PMID: 31339951; PubMed Central PMCID: PMC6655766.
9. Nielsen-Bohlman L. Health Literacy: A Prescription to End Confusion. In: Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. *Health Literacy: A Prescription to End Confusion*. Washington (DC)2004.
10. Australian Curriculum Assessment and Reporting Authority [ACARA]. Foundation to year 10 curriculum: Health and Physical Education 2014. Available from: <https://www.australiancurriculum.edu.au/f-10-curriculum/health-and-physical-education/>
11. Duffy B, Fotinatos N, Smith A, Burke J. Puberty, health and sexual education in Australian regional primary schools: Year 5 and 6 teacher perceptions. *Sex Education*. 2013;13(2):186-203. doi: 10.1080/14681811.2012.678324.
12. Bellis EK, Li AD, Jayasinghe YL, Girling JE, Grover SR, Peate M, et al. Exploring the Unmet Needs of Parents of Adolescent Girls with Heavy Menstrual Bleeding and Dysmenorrhea: A Qualitative Study. *J Pediatr Adolesc Gynecol*. 2020;33(3):271-7. Epub 2019/12/25. doi: 10.1016/j.jpag.2019.12.007. PubMed PMID: 31874316.
13. Li AD, Bellis EK, Girling JE, Jayasinghe YL, Grover SR, Marino JL, et al. Unmet Needs and Experiences of Adolescent Girls with Heavy Menstrual Bleeding and Dysmenorrhea: A Qualitative Study. *J Pediatr Adolesc Gynecol*. 2020;33(3):278-84. Epub 2019/11/26. doi: 10.1016/j.jpag.2019.11.007. PubMed PMID: 31765795.
14. Diorio JA, Munro JA. Doing Harm in the Name of Protection: Menstruation as a topic for sex education. *Gender and Education*. 2000;12(3):347-65. doi: 10.1080/713668302.
15. Wong CL, Ip WY, Choi KC, Lam LW. Examining self-care behaviors and their associated factors among adolescent girls with dysmenorrhea: An application of Orem's self-care deficit nursing theory. *Journal of Nursing Scholarship*. 2015;47(3):219-27. doi: 10.1111/jnu.12134. PubMed PMID: 2015-19156-005.
16. Bush D, Brick E, East MC, Johnson N. Endometriosis education in schools: A New Zealand model examining the impact of an education program in schools on early recognition of symptoms suggesting endometriosis. *Aust N Z J Obstet Gynaecol*. 2017;57(4):452-7. Epub 2017/03/30. doi: 10.1111/ajo.12614. PubMed PMID: 28349513.

17. Armour M, Smith CA, Steel KA, Macmillan F. The effectiveness of self-care and lifestyle interventions in primary dysmenorrhea: a systematic review and meta-analysis. *BMC Complement Altern Med*. 2019;19(1):22. Epub 2019/01/19. doi: 10.1186/s12906-019-2433-8. PubMed PMID: 30654775; PubMed Central PMCID: PMC6337810.
18. Armour M, Ee CC, Naidoo D, Ayati Z, Chalmers KJ, Steel KA, et al. Exercise for dysmenorrhoea. *The Cochrane database of systematic reviews*. 2019;9:CD004142. Epub 2019/09/21. doi: 10.1002/14651858.CD004142.pub4. PubMed PMID: 31538328.
19. Armour M, Ee CC, Hao J, Wilson TM, Yao SS, Smith CA. Acupuncture and acupressure for premenstrual syndrome. *The Cochrane database of systematic reviews*. 2018;8:CD005290. Epub 2018/08/15. doi: 10.1002/14651858.CD005290.pub2. PubMed PMID: 30105749.
20. Matthewman G, Lee A, Kaur JG, Daley AJ. Physical activity for primary dysmenorrhea: a systematic review and meta-analysis of randomized controlled trials. *Am J Obstet Gynecol*. 2018;219(3):255 e1- e20. Epub 2018/04/10. doi: 10.1016/j.ajog.2018.04.001. PubMed PMID: 29630882.
21. The National Health and Medical Research Council. National Statement on Ethical Conduct in Human Research 2007 (Updated 2018) Commonwealth of Australia, Canberra 2018. Available from: www.nhmrc.gov.au/guidelines/publications/e72.
22. Parker MA, Kent AL, Sneddon A, Wang J, Shadbolt B. The menstrual disorder of teenagers (MDOT) study No 2: Period ImPact and Pain Assessment (PIPPA) tool validation in a large population based cross-sectional study of Australian teenagers. *J Pediatr Adolesc Gynecol*. 2021. Epub 2021/06/26. doi: 10.1016/j.jpog.2021.06.003. PubMed PMID: 34171477.
23. Bell ML, Whitehead AL, Julious SA. Guidance for using pilot studies to inform the design of intervention trials with continuous outcomes. *Clin Epidemiol*. 2018;10:153-7. Epub 2018/02/07. doi: 10.2147/CLEPS146397. PubMed PMID: 29403314; PubMed Central PMCID: PMC5779280.
24. Castor EDC. Castor Electronic Data Capture 2019 [August 28, 2019]. Available from: <https://castoredc.com>.
25. Payne LA, Seidman LC, Romero T, Sim M-S. An Open Trial of a Mind–Body Intervention for Young Women with Moderate to Severe Primary Dysmenorrhea. *Pain Medicine*. 2020;21(7):1385-92. doi: 10.1093/pm/pnz378.
26. Purnamasari KD, Rohita T, Zen DN, Ningrum WM. The Effect of Deep Breathing Exercise on Menstrual Pain Perception in Adolescents with Primary Dysmenorrhea. *Pertanika Journal*. 2020;2(28):649-57.
27. Panahi F, Faramarzi M. The effects of mindfulness-based cognitive therapy on depression and anxiety in women with premenstrual syndrome. *Depression research and treatment*. 2016;2016.

28. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implement Sci.* 2011;6:42. Epub 2011/04/26. doi: 10.1186/1748-5908-6-42. PubMed PMID: 21513547; PubMed Central PMCID: PMC3096582.
29. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. *Ann Behav Med.* 2013;46(1):81-95. Epub 2013/03/21. doi: 10.1007/s12160-013-9486-6. PubMed PMID: 23512568.
30. Wang J, Rogge AA, Armour M, Smith CA, D'Adamo CR, Pischke CR, et al. International ResearchKit App for Women with Menstrual Pain (Development, Access, and Engagement): Pragmatic Randomized Control Trial. *JMIR Mhealth Uhealth.* 2020;8(2):e14661. Epub 9.2.2020. doi: 10.2196/14661. PubMed PMID: 32044758.
31. Young K, Fisher J, Kirkman M. Endometriosis and fertility: women's accounts of healthcare. *Human Reproduction.* 2016;31(3):554-62. doi: 10.1093/humrep/dev337.
32. Moradi M, Parker M, Sneddon A, Lopez V, Ellwood D. Impact of endometriosis on women's lives: a qualitative study. *BMC women's health.* 2014;14(1):123. Epub 2014/10/05. doi: 10.1186/1472-6874-14-123. PubMed PMID: 25280500; PubMed Central PMCID: PMC4287196.
33. Armour M, Sinclair J, Ng CHM, Hyman MS, Lawson K, Smith CA, et al. Endometriosis and chronic pelvic pain have similar impact on women, but time to diagnosis is decreasing: an Australian survey. *Sci Rep.* 2020;10(1):16253. Epub 2020/10/03. doi: 10.1038/s41598-020-73389-2. PubMed PMID: 33004965; PubMed Central PMCID: PMC7529759.
34. O'Hara R, Rowe H, Fisher J. Managing endometriosis: a cross-sectional survey of women in Australia. *J Psychosom Obstet Gynaecol.* 2020:1-8. Epub 2020/10/15. doi: 10.1080/0167482X.2020.1825374. PubMed PMID: 33050751.
35. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health.* 2013;13(1):658. doi: 10.1186/1471-2458-13-658.
36. Osborne RH, Elsworth GR, Whitfield K. The Health Education Impact Questionnaire (heiQ): An outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient Education and Counseling.* 2007;66(2):192-201. doi: <https://doi.org/10.1016/j.pec.2006.12.002>.
37. Elsworth GR, Osborne RH. Percentile ranks and benchmark estimates of change for the Health Education Impact Questionnaire: Normative data from an Australian sample. *SAGE Open Med.* 2017;5:2050312117695716. Epub 2017/06/01. doi: 10.1177/2050312117695716. PubMed PMID: 28560039; PubMed Central PMCID: PMC5435365.

38. Schützler L, Witt CM. Internal health locus of control in users of complementary and alternative medicine: a cross-sectional survey. *BMC Complementary and Alternative Medicine*. 2014;14(1):320. doi: 10.1186/1472-6882-14-320.
39. Shadbolt NA, Parker MA, Orthia LA. Communicating endometriosis with young women to decrease diagnosis time. *Health Promotion Journal of Australia*. 2013;24(2):151-4. doi: <https://doi.org/10.1071/HE12915>.
40. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. *Am J Public Health*. 1999;89(9):1322-7. Epub 1999/09/04. doi: 10.2105/ajph.89.9.1322. PubMed PMID: 10474547; PubMed Central PMCID: PMC1508772.
41. Glasgow RE, Harden SM, Gaglio B, Rabin B, Smith ML, Porter GC, et al. RE-AIM Planning and Evaluation Framework: Adapting to New Science and Practice With a 20-Year Review. *Front Public Health*. 2019;7:64. Epub 2019/04/16. doi: 10.3389/fpubh.2019.00064. PubMed PMID: 30984733; PubMed Central PMCID: PMC6450067.
42. Rikard RV, Thompson MS, McKinney J, Beauchamp A. Examining health literacy disparities in the United States: a third look at the National Assessment of Adult Literacy (NAAL). *BMC Public Health*. 2016;16:975. Epub 2016/09/15. doi: 10.1186/s12889-016-3621-9. PubMed PMID: 27624540; PubMed Central PMCID: PMC5022195.
43. Stormacq C, Van den Broucke S, Wosinski J. Does health literacy mediate the relationship between socioeconomic status and health disparities? Integrative review. *Health Promot Int*. 2019;34(5):e1-e17. Epub 2018/08/15. doi: 10.1093/heapro/day062. PubMed PMID: 30107564.
44. Fisher EB, Boothroyd RI, Coufal MM, Baumann LC, Mbanya JC, Rotheram-Borus MJ, et al. Peer support for self-management of diabetes improved outcomes in international settings. *Health Aff (Millwood)*. 2012;31(1):130-9. doi: 10.1377/hlthaff.2011.0914. PubMed PMID: 22232103.
45. Wallston KA, Wallston BS, DeVellis R. Development of the Multidimensional Health Locus of Control (MHLC) Scales. *Health Educ Monogr*. 1978;6(2):160-70. Epub 1978/01/01. doi: 10.1177/109019817800600107. PubMed PMID: 689890.
46. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health services research*. 2004;39(4p1):1005-26.

Declarations

Acknowledgments

Funding for this study was provided as part of a WSU partnership grant between Western Sydney University and Kimberly-Clark Australia. The sponsor of the study had no role in the data collection, analysis, or interpretation of the manuscript. Thank you to all those organisations who promoted this on their social media including Family Planning NSW, Endometriosis Australia, ACHPER, and Kimberly-Clark Australia.

Author Contributions

All authors contributed significantly to this work. MA, CC, TF, CS, KH and FM designed the study. MA and KP performed the data collection and statistical analysis, MA, CC, TF, CS, MP, KH and FM interpreted the data. MA and TF drafted the article. KP, CC, TF, CS, KH, MP, TF and FM all contributed to critical revisions on the manuscript. All authors reviewed the manuscript and approved the final draft.

Competing Interests

The authors have no competing interests to report.

Data Availability

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Tables

Timepoint: Baseline and at the conclusion of each of the three menstrual periods during the study.	
<i>Menstrual pain/dysmenorrhea severity</i>	A single 0-10 numeric rating scale (NRS) for overall menstrual pain.
<i>Analgesic usage</i>	Type of analgesic and dosage catagorised as 'more than recommended on box', 'same as recommended on box'.
<i>Self-management</i>	Types of self-management used during the most recent menstrual period.
Timepoint: Baseline and end of study.	
<i>Internal Health Locus of Control (IHLCoC)</i>	IHLCoC is a measure of how much control individuals feel that they can exert over their own health was collected at baseline and end of trial (45).
<i>Patient Activation Measure (PAM)</i>	PAM draws on concepts such as health locus of control, self-efficacy in managing health behaviours and readiness to change health behaviours, but is not condition or behaviour specific (46). PAM scores are used to generate one of four levels, in order of increasing levels of activation; from Level 1 suggesting that the person does not yet understand their role in health care up to Level 4 indicating that the person is proactive and engaged in recommended health behaviours.
Health Literacy Questionnaire (HLQ)	The Health Literacy Questionnaire (HLQ) consists of 44 questions and can be either self-administered or orally administered. The HLQ identifies the specific health literacy strengths and limitations of people and communities. It examines nine areas of health literacy. Research has shown the HLQ is a robust independent measure of each of the nine identified health literacy dimensions (35).
Health Education Impact Questionnaire (heiQ)	The Health Education Impact Questionnaire (heiQ) is a perception- and evaluation-based measure that was developed to be a user-friendly, relevant and psychometrically sound instrument for the comprehensive evaluation of patient education programs and activities (36).
Timepoint: At one-month follow up.	
Trial Exit Questionnaire	The trial exit questionnaire collected participant satisfaction, use of self-care, changes in understanding of menstruation, and information on visits to medical practitioners.
Timepoint: Baseline.	
Period ImPact and Pain Assessment Tool (PIPPA)	A 5-item dichotomous Yes/No survey to measure pain and interference related menstrual disturbance (4, 22).

Table 1. Outcome measures by timepoint.

N = 75		Mean (SD)
Age (y)		20 (3.4)
Age at menarche (y)		12 (1.7)
		N (%)
Occupation	<i>At school or university</i>	45 (60%)
	<i>Working for pay</i>	26 (34.7%)
	<i>Other</i>	4 (5.3%)
Response to "I think my periods are normal"	<i>Yes</i>	48 (64%)
	<i>No</i>	21 (28%)
	<i>Unsure</i>	6 (8%)
Regular Dysmenorrhea	<i>Yes</i>	74 (98.7%)
	<i>No</i>	1 (1.3%)
Current pain management	<i>Analgesic medication</i>	63 (84%)
	<i>Contraceptives</i>	22 (29.3%)
	<i>Rest</i>	63 (84%)
	<i>Heat</i>	66 (88%)
	<i>Yoga</i>	9 (12%)
	<i>Acupressure</i>	4 (5.3%)
	<i>Pilates</i>	0
	<i>Low intensity exercise</i>	22 (29.3%)
	<i>Resistance exercise</i>	4 (5.3%)
	<i>High intensity exercise</i>	8 (10.7%)
	<i>Meditation</i>	12 (16%)
	<i>Herbal medicine</i>	14 (18.7%)
	<i>Prayer</i>	4 (5.3%)
	<i>Dietary changes</i>	11 (14.7%)
	<i>Other</i>	3 (4%)
Sources of information on menstruation	<i>Mum</i>	57 (76%)
	<i>Dad</i>	1 (1.3%)
	<i>Female relatives</i>	26 (34.7%)
	<i>HPE teacher^a</i>	15 (20%)
	<i>Doctor</i>	34 (45.3%)
	<i>Friends</i>	32 (42.7%)
	<i>Social media</i>	17 (22.7%)
	<i>Magazines</i>	14 (18.7%)
	<i>Google search</i>	36 (48%)
	<i>Other</i>	7 (9.3%)

^aHealth and Physical Education teacher

PIPPA scores and medical visits:

Table 2. Demographics and menstrual characteristics.

Modality	Baseline (n=73)	Cycle 1 (n=67)	Cycle 2 (n=59)	Cycle 3 (n=56)
	N (%)			
<i>Heat</i>	42 (57.5%)	43 (64.2%)	36 (61%)	37 (66.1%)
<i>Exercise (low intensity e.g., yoga)</i>	22 (30.1%)	40 (59.7%)	33 (55.9%)	23 (41.1%)
<i>Exercise (high intensity e.g., running)</i>	6 (8.2%)	12 (17.9%)	8 (13.6%)	11 (19.6%)
<i>Meditation/breathing exercises</i>	11 (15.1%)	20 (29.9%)	25 (42.4%)	28 (50%)
<i>Acupressure</i>	1 (1.4%)	17 (25.4%)	13 (22%)	11 (19.6%)

Table 3. Usage of self-management strategies over time.

	Baseline	End of trial
	Median (IQR)	Median (IQR)
Patient Activation Measure (PAM) Level	3 (2-4)	3 (2-4)
Health Literacy Questionnaire (HLQ)	Mean (SD)	Mean (SD)
<i>Feeling understood and supported by health-care providers (HPS)</i>	3.05 (0.41)	3.12 (0.30)
<i>Having sufficient information to manage my health (HSI)</i>	2.79 (0.47)	3.09 (0.21) ^a
<i>Actively managing my health (AMH)</i>	3.01 (0.38)	3.05 (0.35)
<i>Social support for health (SS)</i>	3.10 (0.55)	3.09 (0.43)
<i>Appraisal of health information (CA)</i>	2.89 (0.55)	3.04 (0.44)
<i>Ability to actively engage with health-care providers (AE)</i>	3.64 (0.59)	3.74 (0.50)
<i>Navigating the health-care system (NHS)</i>	3.58 (0.65)	3.69 (0.57)
<i>Ability to find good health information (FHI)</i>	3.78 (0.62)	3.89 (0.44)
<i>Understand health information well enough to know what to do (UHI)</i>	4.14 (0.52)	4.14 (0.49)

^a $P=.02$

Table 4: Health literacy outcomes.

	Percentage of participants with reliable positive change between baseline and end of trial ^a
<i>Health-directed Behaviour</i>	12.7
<i>Positive & Active Engagement in Life</i>	10.9
<i>Self-monitoring and Insight</i>	14.5
<i>Constructive Attitudes & Approaches</i>	16.4
<i>Skill and Technique Acquisition</i>	40.0
<i>Social Integration & Support</i>	14.5
<i>Health Services Navigation</i>	20.0
<i>Emotional Distress</i>	21.8

^a reliable positive change is based on an effect size of 0.5 or greater.

Table 5: Health education impact questionnaire outcome (heiQ).