

ORIGINAL ARTICLE

Endometriosis education in schools: A New Zealand model examining the impact of an education program in schools on early recognition of symptoms suggesting endometriosis

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Conflicts of interest: Deborah Bush owns the Intellectual Property (IP) of the *me* program which operates under no-fee license to the New Zealand Endometriosis Foundation Inc (operating as Endometriosis New Zealand). The program has been funded by New Zealand registered philanthropic trusts (Rata Foundation, Royston Health Trust Board). The New Zealand Endometriosis Foundation Inc has not received licensing fees or honoraria from the *me* program. No royalties from the *me* program have been paid to any recipient, including Deborah Bush and the authors. Deborah Bush has received conference expenses from Bayer Pharma and Fisher and Paykel Healthcare. Neil Johnson has received conference expenses from Bayer Pharma, Merck-Serono and MSD, research funding from AbbVie, and has been a consultant to Vifor Pharma.

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Background: Menstrual morbidity plays a significant role in adolescent females' lives. There are no studies to date reporting such data from menstrual health education programs in schools.

Aims: The aim of our study was to report results from an audit of a menstrual health and endometriosis education program in secondary schools and observe age patterns of young women presenting for menstrual morbidity care.

Materials and methods: Audit data from education in secondary schools and audit data of patients from an Endometriosis and Pelvic Pain Coaching clinic operating in a private endometriosis specialised centre are reported.

Results: In a region of consistent delivery of the education program, student awareness of endometriosis was 32% in 2015. Overall in 2015, 13% of students experienced distressing menstrual symptoms and 27% of students sometimes or always missed school due to menstrual symptoms. Further, in one region of consistent delivery of the menstrual health education program, data show an increase in younger patients attending for specialised endometriosis care.

Conclusions: There is strong suggestive evidence that consistent delivery of a menstrual health education program in schools increases adolescent student awareness of endometriosis. In addition, there is suggestive evidence that in a geographical area of consistent delivery of the program, a shift in earlier presentation of young women to a specialised health service is observed.

KEYWORDS

adolescent, dysmenorrhea, early intervention (education), endometriosis

INTRODUCTION

Endometriosis is a gynaecological condition estimated to affect over 176 million women of reproductive age worldwide (10%) of all ethnicities and socioeconomic backgrounds.¹⁻³ Typically there is a delay of eight or more years from symptom onset to diagnosis,⁴ and an average of seven visits or three years visiting a primary care doctor prior to gynaecologist referral.^{1,4} Symptom onset is often from a young woman's first menstrual period.^{1,4-6} The symptoms of endometriosis can have a considerable negative impact on a woman's physical, psychological, economic, social and cultural wellbeing, and may be associated with compromised fertility.⁷⁻¹⁴ Treatment for endometriosis relies on pain medication, hormonal therapies including the oral contraceptive pill (OCP), laparoscopic excision of the disease, and a multidisciplinary approach to treatment.^{15,16}

Internationally, the prevalence of dysmenorrhoea in adolescents is 25–93%.¹⁷⁻²¹ Of those experiencing dysmenorrhoea, 20–31% report school absence¹⁷⁻²¹ and 24–66% report high interference with daily life activities^{20,21} such as sport and exercise, relationships with family and friends, and social activities. There is a high association between severity of pain and symptoms, with interference in school attendance and life activities.^{20,21} Dysmenorrhoea can progress into persistent pelvic pain early on, sometimes from the onset of symptoms, particularly if left untreated or unmanaged.²²

Severe dysmenorrhoea may indicate underlying pathology. Endometriosis has been reported in 69.6–73% of adolescent females with severe dysmenorrhoea non-responsive to non-steroidal anti-inflammatory drugs (NSAIDs) or the OCP.^{23,24} Adolescent females who experience severe dysmenorrhoea are at greater risk of disrupted cognitive development, interrupted education and academic performance, missed career opportunities, and poor emotional, psychosocial and physical outcomes.^{13,19-21,25} Azurah *et al.* (2013)²⁶ found that adolescent females with dysmenorrhoea from a tertiary referral clinic scored similarly to children with chronic conditions, such as cystic fibrosis, on the paediatric quality of life (PedsQL) questionnaire.

Menstrual dysfunction in adolescent females is an international public health issue warranting immediate awareness and action. There is consensus in international literature, guidelines and recommendations that education about endometriosis is an appropriate tool to promote early intervention for endometriosis.^{7,13,15,17-21}

The aim of this study is to report audit data of a menstrual health and endometriosis secondary school education program, and observe age patterns of younger women presenting for menstrual morbidity care to a tertiary referral setting.

MATERIALS AND METHODS

To address the aim of the study, two sources of data were employed: (i) audit data from a menstrual health education program

in secondary schools; and (ii) observational longitudinal data of patient age from an Endometriosis and Pelvic Pain (EPP) Coaching clinic. Ethics approval/advice was sought from the New Zealand Health and Disability Ethics Committee (HDEC); clearance was confirmed by correspondence from the HDEC Ethics Committee dated 8 September 2015.

The menstrual health and endometriosis education program

In 1996, Endometriosis New Zealand (ENZ) developed the *me* program (Menstrual Health and Endometriosis) to improve adolescent knowledge of menstrual health and endometriosis. The first pilot program was implemented in 1997 and has since been consistently delivered in secondary schools in some regions of New Zealand (NZ); specifically, the Canterbury and Marlborough regions.

The *me* program is a unique, well-health education program grounded in World Health Organization education principles and practices.²⁷ It integrates into levels 5–8 (students aged 14–18) of the NZ secondary school curriculum targeting achievement objectives across the following health strands; personal health and physical development, relationships with other people, and healthy communities and environments. The aims of *me* are:

- identify menstrual symptoms that stray from the norm
- raise awareness of endometriosis
- improve physical, emotional and social wellbeing and protect future fertility
- improve health-seeking behaviours
- remove social stigmas, awkward attitudes and taboos relating to menstruation and menstrual irregularities.

The program reaches 13–18-year-old male and female students in co-ed schools and females in single sex schools, in public and private secondary schools. The program is delivered in regions where philanthropic funding sources have been actively sought by ENZ, or when requested and funded by an independent school. The program is consistently delivered annually, although it is funding-reliant.

Program educators are employed by ENZ. They undergo a comprehensive training program to address teenage audiences ranging from small class sizes of 30 to assemblies of up to 1000. Their training includes an overview in the treatment, management and understanding of dysmenorrhoea, endometriosis and persistent pelvic pain, youth health services and interactive presentation skills.²⁷ Educators follow a training manual and work alongside trained educators until they are confident and knowledgeable to independently deliver the program and collaboratively evaluate the results. Audit processes ensure reporting accuracy based on public health program evaluation principles.²⁸

When delivering *me* to a region, ENZ actively engages with community groups, students, teachers, the medical community

and funders as a whole-community approach. The program is continually evaluated, audited and updated to meet best practice medical evidence and research, and current educational trends.

Data collection

At the end of each *me* program session, female and male students were asked to complete an evaluation form for audit purposes. The evaluation took 3–5 min and investigated the acceptability of the program and endometriosis awareness, and for young women, menstrual patterns and the effect of menstrual symptoms on their lifestyle. The data were then collated and analysed by the ENZ educators.

Patient age data was collected from audit records of the EPP Coaching clinic. This is a specialised ‘well health clinic’ integrated into a multi-disciplinary tertiary referral centre offering expertise in the treatment and management of endometriosis. Longitudinal data from this clinic were collected since 2001 and are reported as part of the patient centred curriculum. Due to the limitations and restrictions of accessing data from the public health system, data from the EPP Coaching clinic was used. It is important to note that the EPP clinic operates in the geographical region in which the *me* program has been delivered consistently since 1998.

RESULTS

Participant responses

In 2015, the *me* program was presented to 5337 students. Of these, 3732 were asked to complete evaluation forms when

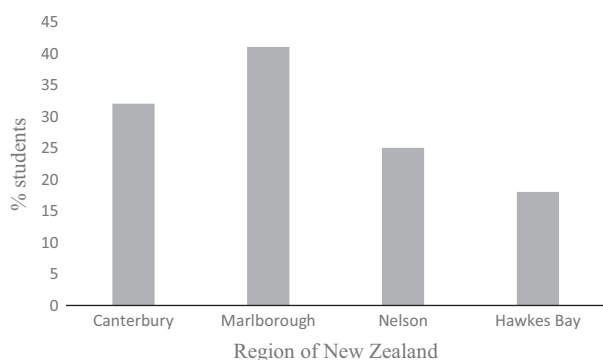


FIGURE 1 Student awareness of endometriosis, 2015.

TABLE 1 Student evaluation data, 2015

Region of New Zealand	Experience discomforting menstrual symptoms <i>n</i> (%)	Experience distressing menstrual symptoms <i>n</i> (%)	Sometimes or always miss school due to menstrual symptoms <i>n</i> (%)
Canterbury <i>n</i> = 1209	780 (65%)	165 (14%)	326 (27%)
Hawkes Bay <i>n</i> = 431	277 (64%)	43 (10%)	109 (25%)
Nelson <i>n</i> = 479	300 (63%)	58 (12%)	122 (25%)
Marlborough <i>n</i> = 121	64 (53%)	28 (23%)	45 (37%)
Overall 2015 <i>n</i> = 2240	1421 (63%)	294 (13%)	602 (27%)

practicable, given the constraints of a teaching program. In total 2643 students fully or partially completed an evaluation form.

Student awareness of endometriosis

In 1998, less than 10% of students in Canterbury and Marlborough had previously heard of endometriosis, compared to 32% in Canterbury and 41% in Marlborough in 2015 (Fig. 1). The *me* program has had consistent delivery in the following regions of NZ: Canterbury and Marlborough since 1998, Nelson since 2000 and Hawkes Bay since 2013 (see Fig. 1).

Menstrual health of adolescents

In 2015 (Table 1), 63% of female students experienced discomforting menstrual symptoms and 13% reported distressing menstrual symptoms. Overall, 27% of female students sometimes or always missed school due to discomforting or distressing menstrual symptoms.

EPP Coaching clinic data

Figure 2 shows longitudinal data from 2001 to 2015 of the proportion of patients in different age groups. In 2006, 96% (*n* = 46) of those women under the age of 20 undergoing laparoscopic review for endometriosis were diagnosed with endometriosis.

A gap in these data exists from 2010 to 2013 (Fig. 2), due to the earthquakes that occurred in the Canterbury region. During this time, there were multiple unforeseen circumstances that resulted in loss of data, clinic relocation and limited resources.

DISCUSSION

In geographical regions where the *me* program has had consistent delivery, students' awareness of endometriosis increased. Observational study data from the EPP Coaching clinic from 2001 to 2015 show a greater proportion of women under 25 years of age attending the clinic in the geographical region where the *me* program has had consistent delivery.

This study is the first to comprehensively report on a practical menstrual health and endometriosis education program which has been delivered since 1998. The program is delivered to both

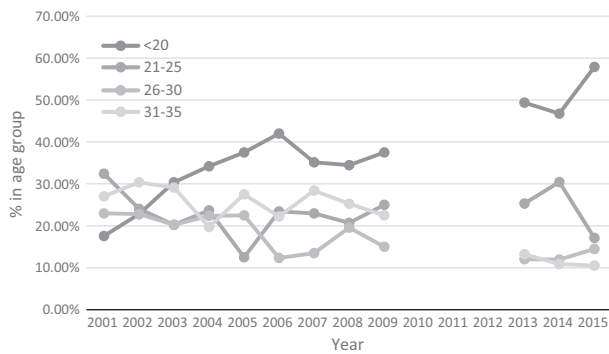


FIGURE 2 Proportion of patients attending Endometriosis and Pelvic Pain (EPP) Coaching clinic by age, 2001–2015.

male and female students at schools across all socioeconomic demographics. A major strength of this study is the opportunity to report longitudinal data and reveal observations from audit of a longstanding menstrual health and education program and an EPP Coaching clinic in a tertiary referral, multidisciplinary centre of expertise. It is acknowledged that confounding factors exist due to practical constraints of program delivery, data collection gaps and inconsistencies.

Program evaluation of the *me* program is used for internal audit required by philanthropic grant providers, to measure acceptability of the program, establish a need for the program by detailing menstrual health of students, and as a tool to reiterate the importance of distinguishing between ‘discomforting’ and ‘distressing’ period symptoms to the students. While subjective, the words ‘discomfort’ and ‘distress’ are used in the program as a means for students to differentiate normal and abnormal menstrual symptoms. This is explained in the program in detail using examples and case histories.

There are limitations in these data. The evaluation forms are completed at the end of the session, with the educator present and they are not compulsory. These limitations introduce bias and confounding factors and may skew the data. Evaluation forms are continually updated to align with current educational trends, current medical evidence and to improve data collection. Thus, for the purposes of this study, direct measured comparison across years of delivery for some information was not possible. However, the data collected in earlier years show similar trends.

The EPP Coaching clinic is integrated into an endometriosis tertiary treatment centre and for the purposes of these records, is a cohort with recognised selection bias and may not reflect the general population, as it operates in a private tertiary referral setting. In 2015, 89% ($n = 68$) of patients had private medical insurance. Therefore, selection bias exists as this cohort has greater access to tertiary health care. The proportion of laparoscopy is reported in 2006 as a snapshot in time of the proportion of patients who underwent laparoscopy. Post-2006 the process of referral to the EPP Coaching clinic changed, and all patients attending the clinic had laparoscopic surgery. The EPP Coaching clinic operates in one region of NZ; therefore data from other regions are not available.

These data offer important initial understanding of an environment that is largely under-researched and under-funded. To date, there are no other data available to observe. Of course, there remain challenges in assessing fundamentally just how far the *me* program has changed knowledge, as well as other important issues such as other sources from which young women obtain information and, in each locality, where young women should first go to get the best advice about pelvic pain. Since the *me* program was introduced in 1997, young people are increasingly using the internet for health information, which has the potential to improve health-seeking behaviours.²⁹ However, to our knowledge, there is currently no approved online educational tool for young people seeking information about dysmenorrhea and endometriosis. Adapting *me* to include an online service and improve health navigation through mobile health is currently under review.

The menstrual disorders of teenagers (MDOT) study aimed to determine typical menstrual patterns and disturbance in a large population of Australian teenagers.²⁰ In concordance with audit data from the *me* program, Parker *et al.* (2010) revealed approximately 25% of the sample had marked menstrual disturbance, 21% experienced severe pain (whereas 13% experienced distressing pain in the *me* data), 26% reported school absence (whereas 27% reported school absence in the *me* data).²⁰ Similarly, survey studies report a prevalence of dysmenorrhoea in 25–93% of adolescents, school absence in 20–31% and interference with normal life activity in 24–66%.^{17–21} A limited number of studies report adolescent awareness and knowledge of endometriosis. Shadbolt *et al.* (2013) conducted an online survey with females aged 16–25.⁷ The study revealed 33% of participants aged 16–18 had heard of endometriosis. Similar observations were noted in our present study, 32% of students being aware of endometriosis in Canterbury and 18% in Hawkes Bay in 2015. Motivation bias to complete an online survey about endometriosis may be higher for those who had already heard of endometriosis. We do not fully understand the reasons for the higher incidence of distressing menstrual symptoms, school absence and awareness of endometriosis in the Marlborough region compared to other areas. However, Marlborough has a smaller population than other regions where the *me* program is delivered.

To our knowledge no other studies have captured data revealing earlier presentation of endometriosis in a geographical region of consistent endometriosis education in secondary schools. Therefore, this study is unique and provides a pivotal platform to base further research and implementation for menstrual health and endometriosis education programs globally. Further longitudinal research to track participants’ pathways from education of menstrual health and endometriosis to potentially presenting at tertiary care is required to verify our findings – specifically a prospective cohort study design would be required to provide definitive verification of whether this type of program impacts on presentations for clinical assessment.

International data report that only 5.6–33% of young females suffering from dysmenorrhoea seek medical care, despite the significant impact on their lives.^{17–21} Education programs that discuss menstrual health and raise awareness of endometriosis may increase investigation of symptoms, reduce the burden of disease physically, socially, psychologically, economically and clinically. Further, they are potentially crucial to protecting future fertility by promoting early intervention.

Several key indicators may identify a subgroup of adolescents suffering from considerable menstrual disturbance that may reflect underlying pathology, such as endometriosis, and warrant further investigation from a specialist doctor for effective management.^{20,21,30} These factors include moderate to severe menstrual pain, multiple menstrual symptoms, chronic pelvic pain, school absence and high interference with life activities.^{20,22,26} Ignoring these key indicators can result in long-term consequences for these young women, including the development of persistent pelvic pain.²² This study shows that it is possible to identify such a group while empowering adolescent females, and their wider community, with accurate and acceptable education and tools to seek care for menstrual symptoms that are not normal, to raise awareness of endometriosis and we presume thereby to minimise menstrual morbidity.

An unrecognised and under-reported number of girls and young women miss school and have a compromised quality of life due to menstrual dysfunction. Dysmenorrhoea has an important impact on adolescent females' lives and a broader burden on family, community and society. In the absence of any screening tool for endometriosis, education in identifying abnormal menstrual symptoms and improving health-seeking behaviours is imperative. To attain better access to multidisciplinary treatment for endometriosis, multipronged action from health professionals, government, health decision makers, researchers and individuals should be considered to prevent the emotional, physical and financial harm caused by endometriosis and pelvic pain.

CONCLUSION

We have demonstrated strong suggestive evidence for the first time that consistent delivery of a menstrual health and endometriosis program in secondary schools increases awareness of endometriosis and may promote timely presentation of young women to specialised healthcare services. This might also promote earlier intervention. Further research is required to verify whether this does indeed result in early presentation and whether this may improve short-term and long-term outcomes of importance to women.

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REFERENCES

1. Nnoaham KE, Hummelshoj L, Webster P *et al.* World Endometriosis Research Foundation Global Study of Women's Health Consortium Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril* 2011; **96**(2): 366–373.
2. Adamson GD. Endometriosis classification: an update. *Curr Opin Obstet Gynecol* 2011; **23**(4): 213–220.
3. Gao X, Yeh YC, Outley J *et al.* Health-related quality of life burden of women with endometriosis: a literature review. *Curr Med Res Opin* 2006; **22**(9): 1787–1797.
4. Ballard K, Lowton K, Wright J. What's the delay? a qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertil Steril* 2006; **86**(5): 1296–1301.
5. Seear K. The etiquette of endometriosis: stigmatisation, menstrual concealment and the diagnostic delay. *Soc Sci Med* 2009; **69**(8): 1220–1227.
6. Laufer MR, Sanfilippo J, Rose G. Adolescent endometriosis: diagnosis and treatment approaches. *J Pediatr Adolesc Gynecol* 2003; **16**(3): S3–S11.
7. Shadbolt NA, Parker MA, Orthia LA. Communicating endometriosis with young women to decrease diagnosis time. *Health Promot J Austr* 2013; **24**(2): 151–154.
8. Fourquet J, Báez L, Figueroa M *et al.* Quantification of the impact of endometriosis symptoms on health-related quality of life and work productivity. *Fertil Steril* 2011; **96**(1): 107–112.
9. Young K, Fisher J, Kirkman M. Women's experiences of endometriosis: a systematic review and synthesis of qualitative research. *J Fam Plann Reprod Health Care* 2014; **0**: 1–10. doi:10.1136/jfprhc-2013-100853
10. Denny E. Women's experience of endometriosis. *J Adv Nurs* 2004; **46**(6): 641–648.
11. Simoens S, Dunselman G, Dirksen C *et al.* The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012; **27**(5): 1292–1299.
12. Kennedy S, Bergqvist A, Chapron C *et al.* on behalf of the ESHRE Special Interest Group for Endometriosis and Endometrium Guideline Development Group. *Hum Reprod* 2005; **20**(10): 2698–2704.
13. Moradi M, Parker M, Sneddon A *et al.* Impact of endometriosis on women's lives: a qualitative study. *BMC Womens Health* 2014; **14**(1): 123.
14. Unger CA, Laufer MR. Progression of endometriosis in non-medically managed adolescents: a case series. *J Pediatr Adolesc Gynecol* 2011; **24**(2): e21–e23.
15. Johnson NP, Hummelshoj L. for The World Endometriosis Society Montpellier Consortium. Consensus on current management of endometriosis. *Hum Reprod* 2013; **28**(6): 1552–1568.
16. Dunselman GA, Vermeulen N, Becker C *et al.* ESHRE guideline: management of women with endometriosis. *Hum Reprod* 2014; **29**(3): 400–412.
17. Ortiz MI, Rangel-Flores E, Carrillo-Alarcón LC, Veras-Godoy HA. Prevalence and impact of primary dysmenorrhoea among Mexican high school students. *Int J Gynaecol Obstet* 2009; **107**(3): 240–243.
18. Nwankwo TO, Aniebue UU, Aniebue PN. Menstrual disorders in adolescent school girls in Enugu, Nigeria. *J Pediatr Adolesc Gynecol* 2010; **23**(6): 358–363.

19. Agarwal A, Venkat A. Questionnaire study on menstrual disorders in adolescent girls in Singapore. *J Pediatr Adolesc Gynecol* 2009; **22**(6): 365–371.
20. 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): 185–192.
21. Pitangui AC, Gomes MR, Lima AS *et al*. Menstruation disturbances: prevalence, characteristics, and effects on the activities of daily living among adolescent girls from Brazil. *J Pediatr Adolesc Gynecol* 2013; **26**(3): 148–152.
22. Hardi G, Evans S, Craigie M. A possible link between dysmenorrhoea and the development of chronic pelvic pain. *Aust N Z J Obstet Gynaecol* 2014 Dec 1; **54**(6): 593–596.
23. Lafer MR, Goitein L, Bush M *et al*. Prevalence of endometriosis in adolescent girls with chronic pelvic pain not responding to conventional therapy. *J Pediatr Adolesc Gynecol* 1997; **10**(4): 199–202.
24. Reese KA, Reddy S, Rock JA. Endometriosis in an adolescent population: the Emory experience. *J Pediatr Adolesc Gynecol* 1996; **9**(3): 125–128.
25. Dorn LD, Negriff S, Huang B *et al*. Menstrual symptoms in adolescent girls: association with smoking, depressive symptoms, and anxiety. *J Adolesc Health* 2009; **44**(3): 237–243.
26. Azurah AG, Sancu L, Moore E, Grover S. The quality of life of adolescents with menstrual problems. *J Pediatr Adolesc Gynecol* 2013; **26**(2): 102–108.
27. World Health Organization. *Health education: Theoretical Concepts, Effective Strategies and Core Competencies: A Foundation Document to Guide Capacity Development of Health Educators*. Cairo: Regional Office for the Eastern Mediterranean, 2012.
28. Centers for Disease Control and Prevention. Introduction to program evaluation for public health programs, 2006.
29. Ettel G, Nathanson I, Ettel D *et al*. How do adolescents access health information? And do they ask their physicians? *Perm J* 2012; **16**(1): 35–38.
30. Steenberg CK, Tanbo TG, Qvigstad E. Endometriosis in adolescence: predictive markers and management. *Acta Obstet Gynecol Scand* 2013; **92**(5): 491–495.