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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.

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Abstract

Study Objective To validate the PIPPA (Period ImPact and Pain Assessment) self-screening tool for menstrual disturbance in teenagers.

Design Cross-sectional study.

Setting Three Senior High Schools in the Australian Capital Territory (ACT), Australia.

Participants 1066 girls aged between 15 and 19 years

Interventions and Main Outcome Measures A quantitative paper survey collected self-reports of menstrual bleeding patterns, typical and atypical symptoms, morbidities and interference with daily activities. Multiple correspondence analysis (MCA) was used to examine associations between PIPPA questions. Generalised linear models compared total score and sub scores by validation criteria: pain, school absence and BMI. Receiver operating characteristic (ROC) curves were used to evaluate the predictiveness of menstrual disturbance indicators by total PIPPA score.

Results Reports of pain, interference and concern within the PIPPA items and between both the MDOT and PIPPA questionnaires were significantly correlated ($p< 0.0001$). The indicator 'missing school' was highly associated ($p<0.0001$) with pain and interference. Obesity (BMI ≥30) was associated with higher PIPPA scores as was underweight (BMI≤18.4). Where 0=no disturbance, 5=high disturbance, aggregated PIPPA scores found 75% scoring 0-2 (out of 5), 25% scoring 3-5 (257/1037). High scores of 4 or 5 (out of 5) were 7% (72/1037) and 3.7% (38/1037) respectively.

Conclusions PIPPA is a valid screening tool for pain related menstrual disturbance that effects functioning in young women. PIPPA subdomains of pain/interference have good validity relative to indicators of pain and interference and are responsive to age, BMI and school absence differences.

Keywords

adolescence, Dysmenorrhea, Menstruation, Menstrual Disturbance, Endometriosis, Diagnosis, Period Pain, Pelvic Pain

Introduction

For primary physicians and health care workers, the first challenge is to differentiate between normal period pain and pain-associated menstrual disturbance. The second is how to treat it. This requires knowledge regarding clinical indicators for menstrual disturbance, the potential causes of period and pelvic pain, and an understanding of the sequelae of not treating menstrual disturbance in young women.

Period pain, or dysmenorrhea, is cross cultural and seemingly reported in all countries researching the prevalence of period pain in adolescents and young women.[1] Severe pain is reported in many countries, however there is wide variation to measurement methodology.

Techniques used include the Numerical Rating Score (NRS), Visual Analogue Score (VAS), Multidimensional Scoring System (MSS); the terms ‘mild’, ‘moderate’, or ‘severe’; and cultural wording nuances such as ‘intense’, ‘very serious pain’[2], or ‘severe pain with symptoms’.[3] This variation in methodology may contribute to the wide differences reported by De Sanctis in 2016 where rates ranged from 0.9%[3] (Korea) to 59.8%[4] (Bangladesh) in relevant studies published between 2010-2015.

Similarly, measuring and comparing menstrual pain related reporting of school absenteeism amongst different countries and studies is problematic due to inconsistent measurement criteria for the frequency of absenteeism (never, sometimes, always, ‘most months’, ‘regularly’) or for the number of school days absent, with reported variability from 7.7% to 57.8%[1]. While it is hard to ascertain the full extent of pain and interference associated with menstrual disturbance in adolescents, there is enough long-standing research to confirm that it exists and is significant.[1,5–8] The development of a tool that identified the presence or absence of indicators for menstrual disturbance (regardless of how they are measured) would provide greater consistency and a clearer picture of the problem for individuals and population groups.

This study aimed to further develop knowledge obtained in the original MDOT study undertaken in 2005.[5] At that time, the main aim of the research team was to determine whether the presence of severe period pain and menstrual disturbance could be used as an indicator for symptomatic endometriosis. While the need for early detection of endometriosis, and a reduction in diagnostic delay remains a critical issue, research over the past 15 years has revealed a more complex and concerning picture among adolescents. It is now recognised that young women with dysmenorrhoea may progress to persistent pelvic pain, even within a year of menarche, particularly when pain is severe, prolonged and distressing.[9] Persistent pelvic pain represents a state of altered central pain processing [9–12] and is associated with additional symptoms including reduced quality of life, bladder sensitivity[12,13] myofascial pain or irritable bowel syndrome[14,15]. The presence or absence of these symptoms does not necessarily corelate with the presence of absence of endometriosis lesions, or with disease severity. [9,10,15]

The likelihood of developing persistent pelvic pain following dysmenorrhoea may not apply equally to all women. The development of an at-risk phenotypic profile would offer the opportunity for targeted early intervention and potentially pain prevention within the at risk group.[12] . It would also allow further investigation of factors that may contribute to the development of persistent pain such as dysmenorrhoea, the presence of endometriosis, antinociceptive capacity and maladaptation of the central pain regulatory system. [15] Consequently, identifying and addressing menstrual disturbance in teenagers is important for multiple reasons including:

- Severe pain and interference lead to school absenteeism, presenteeism and academic underperformance which have long term implications for life potential[16–20]
- Some girls with dysmenorrhoea may be at risk of developing persistent pelvic pain and sensitivity [9,11,12]
- Primary and secondary dysmenorrhoea incur an economic burden to women, families, workplaces and the health care system[21,22]
- Hormonal mood changes related to the menstrual cycle are common but the relationship between mood, severe pain and resultant disturbance is poorly understood and under-researched. It can be ‘normalised’ despite high impact and possibly be more deleterious for a young person whose wellbeing is already stressed by adolescence and is showing symptoms of anxiety and depression[12,20,23–26]

While approximately 70% of teenage girls report crampy pain with periods and consider their periods to be normal,[5] the challenge remains in determining criteria to identify girls with significant pain related menstrual disturbance.[6,27] The literature consistently highlights recurring factors that signpost adolescent menstrual disturbance or deviation from typical menstrual symptoms including severe period pain (equivalent to scoring 8-10 on NRS), interference with daily life activities, school absence and reporting of multiple other symptoms around menstruation.[1,6–8,10,18,28]

In our original Menstrual Disorder of Teenagers (MDOT) study of 1051 Australian teens aged 15-19 years conducted in 2005, we found significant menstrual disturbance in approximately 25% indicated by several criteria: severe pain, school absence, interference in daily activities, multiple menstrual symptoms, atypical bowel and bladder symptoms and the respondent being ‘sure there is something wrong with my periods’.[5]

The aim of this study was to evaluate the performance of the PIPPA screening tool (five indicators of menstrual disturbance identified from the 2005 MDOT study) relative to the responses obtained from the MDOT questionnaire.

Materials and Methods

Study design

The menstrual disorder of teenagers (MDOT) study Cohort 2 was replicated as close as possible to the original MDOT study conducted in 2005. Study methods have been previously published.[5] The design, setting, population, methods and outcome measures for MDOT 1 and MDOT 2 are shown together in Table 1.

Participants and setting

Three out of nine government senior high schools were selected based on enrolment size and location, with schools selected in the North, East and West across the Australian Capital Territory (ACT), Australia. A Study Information Letter was circulated to teachers and students at information sessions at the participating schools prior to data collection.

In both year cohorts, the data represent approximately one fifth of all girls in the Australian Capital Territory population aged 15-19 enrolled in senior high schools. In 2017 data collected by the Australian Bureau of Statistics, the population of the Australian Capital Territory (ACT) was 410,301, the median age 34.7 and the median wage was $62,618 (AUD). The ACT school retention rate is almost 90% making the school population representative for this age group. Only public schools were used in both cohorts.

Questionnaire

The 2005 MDOT study developed and piloted the six-page MDOT Questionnaire that collected data about menstrual characteristics, typical and atypical symptoms, interference, menstrual disturbance, awareness, and diagnosis of period problems. A mixture of question types included single and multiple response; 11 point (0-10) Numerical Rating Scales (NRS) for measuring pain, medication effectiveness and interference; true/false statements and one open ended question.

In 2016 the same questions were asked via the MDOT Questionnaire and one additional question was added about whether a diagnosis of endometriosis had been made and if so, was it by symptoms or through a laparoscopy. The PIPPA (Period ImPact and Pain

Assessment) five-item screening tool was also administered in the 2016 questionnaire booklet preceding the six-page MDOT questionnaire.

PIPPA tool development

From the MDOT study data collected in 2005, several items emerged as indicators of menstrual disturbance. These were school absence with periods, severe period pain, high interference of menstruation on lifestyle activities, five or more menstrual related symptoms, atypical bowel and/or bladder symptoms and respondents who were 'sure that there was something wrong with their periods'. In consideration of the target population (teenage women) and user ease and simplicity for self-screening, the PIPPA screening tool was developed with dichotomous Yes/No responses. A recall period of 6 months was used to capture consistently problematic periods rather than a single painful period. The final five PIPPA items included two questions relating to pain (severity and atypical symptoms), two questions relating to interference on life activities (including school absence) and one question relating to the perception that something was wrong. Prior to ethics approval, the PIPPA questions were revised through a survey committee process for face validity and tested for ease of completion through a public outpatient clinic for period and pelvic pain.

Procedure

From a designated location, class teachers collected a pack containing questionnaire booklets and a handout with further information about menstrual pain and helpful contacts and websites. The consent forms were a loose leaf in the questionnaire booklet and each questionnaire and consent form had matching numbers. Participants were asked to complete their consent form prior to completing their questionnaire. The consent process was witnessed by other students or their teacher/supervisor. The consent forms were then collected, which de-identified the questionnaires, and put into an envelope and then sealed. The participants then completed their questionnaire booklets and were able to collect a period information sheet when they handed back their questionnaire. The questionnaire booklets, envelope with consent forms and any remaining information sheets and unused questionnaires were returned by teachers to the distribution point which was either the teacher staff room or school office area and monitored by the research team. One of the researchers was also circulating in case there were any queries from teachers or students. In two of the high schools, we conducted data collection at the same time point for all girls and at one high school we collected data in all English classes over two days which captured most girls and had proven to be successful in the 2005 MDOT study data collection.

Ethics

The study was approved by the ACT Health Human Research Ethics Committee (Protocol Number: ETHLR.15.133) and the ACT Government Education Directorate.

Statistical analysis

Questionnaire data were analysed using SPSS (version 23) and R software (version 3.3.5). The frequencies for responses to each question in the PIPPA questionnaire and the distribution of the total PIPPA scores were examined. A p-value less than 0.05 was considered statistically significant.

Multiple correspondence analysis (MCA) was used to examine the associations between the PIPPA questions. MCA is a multivariate technique which uses latent components to reduce the dimensionality of categorical data, and it is commonly used to analyse survey data.

Receiver operating characteristic (ROC) curves were used to examine the sensitivity and specificity of predictiveness of severe pain, school absence and self-reported diagnostics of endometriosis by the total PIPPA scores.

Self-reports of both height and weight were used to calculate BMI data for the 2016 MDOT/PIPPA cohort which was correlated with PIPPA total scores.

Results

The PIPPA questionnaire was completed by n=1060 respondents aged 15-19 years which represented 99.4% of girls who completed the MDOT questionnaire (n=1066).

Five respondents out of 1060 answered ‘No’ to ‘Have you had your first period yet?’ The overall participation rate for MDOT/PIPPA 2016 across the three colleges was 67% which was similar to the 71% rate in the 2005 MDOT cohort. The participation rate represents the total number of girls who completed a questionnaire out of the total number of girls enrolled in the three high schools used.

Distributions from the data collected in the first MDOT study in 2005 were found to be consistent with those from the second MDOT study, meaning that the indicators identified in the original study were still relevant as indicators of menstrual disturbance (Table 2).

Response frequencies to each PIPPA question and total PIPPA scores

Table 3 lists the frequencies for each individual question. Frequencies ranged from 44.2% for ‘regular severe period pain’ down to 13.7% for regular school absence.

For n=1037 respondents who answered all questions, the number of girls who scored 0, 1, 2, 3, 4, or 5 out of total possible 5 were 30.5%, 25.9%, 18.8%, 14.2%, 6.9%, 3.7% respectively (Table 3).

Multiple Correspondence Analysis

Figure 1A shows the loading plot with varimax rotation and Figure 1B lists the loading scores from two components from the MCA analysis. Questions one, two and four clustered together in component one which explained 33.79% of the total variation and is expressed as representing the pain and interference dimension. Questions three and five clustered in component two which explained 24.35% of the total variance and represents another dimension for atypical symptoms and concern.

Sensitivity and specificity

Figure 1C, 1D, 1E show Receiver Operating Characteristics (ROC) for predicting: MDOT diagnosis of endometriosis based on self-reports (p6q7k) (n=7); MDOT school absence (p1q8); MDOT NRS severe pain scores (p2Q12, ≥8) respectively, based on total PIPPA scores. Area Under the Curve (AUC) were 0.789, 0.813, 0.855, for diagnosis of endometriosis, school absence and severe pain, respectively.

BMI and total PIPPA scores

BMI ranged from 13.6-40 (n=903) with the mean BMI 21.5. When compared with total PIPPA scores obesity (BMI ≥30, n=26) was associated with higher PIPPA scores as were the underweight (BMI≤18.4, n=136) but to a lesser degree producing a ‘J’ curve (Figure 2).

Self-reported diagnosis of endometriosis

In the 2016 cohort, 92% (978/1060) women said ‘No’ to ‘have you ever been diagnosed with…endometriosis’, 5% (52/1060) answered ‘Don’t know’. Less than 1% (7/1060) women reported ‘Yes’ to a diagnosis, <1% (8/1060) said ‘Yes’ to a diagnosis based on symptoms and <1% (5/1060) answered ‘Yes’ through ‘an operation (Laparoscopy) to look inside your abdomen’.

Discussion

To our knowledge the Period ImPact and Pain Assessment (PIPPA) screening tool is the first tool to identify those girls with dysmenorrhea that require first-line treatment of significant menstrual disturbance using a method that has been statistically evaluated against an established questionnaire.[29]

This large population-based study 5-item screening tool captured young women who were experiencing significant pain related menstrual disturbance affecting every-day functioning. Our aim, to identify girls with severe pain (dysmenorrhoea), interference, atypical symptoms, school absence and high concern was achieved.

Of the 1060 teenagers aged 15-19 years who completed the PIPPA tool, 25% of respondents scored 3-5/5 indicating some level of menstrual disturbance. The overall rate of severe menstrual disturbance was 10.6% (110/1037) and included those girls who scored 4 (n=72, 6.9%) and 5 (n=38, 3.7%) out of 5 on PIPPA. This group represents girls most in need of urgent assessment and pain management to reduce the impact of pain, and the risk of developing persistent pelvic pain conditions. The PIPPA severe menstrual disturbance group (10.6% scoring 4-5/5) is highly consistent with the approximate 10% of girls who reported severe pain and school absence, severe pain and seeing doctor, referral to a specialist, two or more atypical symptoms and were 'sure that there is something wrong with period' in the original MDOT study.[5]

It also appears that total PIPPA scores may be more sensitive to other variables such as body weight (measured as Body Mass Index) as body weight has been reported to affect menstrual characteristics and morbidity.[30,31]

Four of the five indicators for menstrual disturbance identified through MDOT/PIPPA are consistently seen in other reported literature over a long period of time[6–8,20,27], however, girls' level of concern about their periods has not been widely researched and girls being 'sure there is something wrong with my period' not typically given credence.

While measurement of single menstrual aspects may highlight various period problems, a tool that detects multiple characteristics to give an overall picture of menstrual disturbance is likely to be more helpful in distinguishing degree of disturbance and priorities for intervention.[27] The strength of PIPPA is that the scoring system provides a tool that clinicians can use to detect young women who may benefit from medical intervention or support. Using PIPPA scores for a whole cohort may also provide a better indication of menstrual disturbance in a population rather than trying to compare individual aspects such as pain and interference that are measured differently across studies.

PIPPA scores for menstrual disturbance of 3-5/5, indicate that 25% of the cohort identified as having pain and interference significant enough to warrant intervention and could be at a higher risk of developing other pain conditions and persistent pelvic pain without timely intervention.[9,11,12] Ongoing research recognises relationships between severe period pain and other pelvic pain conditions including, but not limited to, myofascial pain (pelvic muscle overactivation and spasm) Irritable Bowel Syndrome (IBS), Painful Bladder Syndrome (PBS)[9,12,14,32,33]. Altered flora of the vagina, bladder and bowel could also be a contributor to pelvic irritability and symptoms.[34]

There is justifiable ongoing concern regarding the average delay in diagnosis of endometriosis averaging 6-12 years and highly symptomatic or invasive disease that usually has a high impact on women’s lives across all age groups.[14,35–37] However there is also concern that focussing only on endometriosis forms an incomplete picture of an individual’s pain as it may miss other comorbid exacerbators to period pain and contributors to persistent pelvic pain.[33] This brings risk of overtreating endometriosis with unnecessary procedures and misdiagnosis and undertreatment of comorbidities, further prolonging exposure to symptoms. Symptomatic comorbidities with dysmenorrhoea highlighted in a study by Evans et al, were not corelated to the presence or absence of endometriosis lesions at laparoscopy which supports the case for properly identifying and treating all contributors.[10]

Regarding endometriosis specifically, determining the estimated specificity and sensitivity for a diagnosis of endometriosis based on PIPPA score would need objective measures such as a laparoscopy done on all participants to determine the presence or absence of disease. Also, PIPPA items are symptom based which means that those young women who may have symptomatic endometriosis but are well managed on hormonal suppression of their menstrual cycle (eg through COCP use) may score lower for menstrual disturbance at the time of screening. Likewise, young women with asymptomatic endometriosis will not be detected as it is thought that this group are less likely to have painful periods/menstrual disturbance, however research in this area is lacking. While PIPPA may detect menstrual disturbance, this is only one aspect of endometriosis symptomatology. Equally, menstrual disturbance and pelvic pain overlay multiple possible pathology.

The potential of the PIPPA tool is that it could be used to assist young people in distinguishing normal period pain from menstrual disturbance (based on pain, atypical symptoms, interference, and concern). This could then facilitate initial self-management and encourage discussions with primary health providers. The PIPPA tool was completed by more than 1000 15-19 year old women, however, self-scoring and acting on those scores was not evaluated. Further research into the resultant trajectory of care, patient outcomes and large-scale effectiveness of using the PIPPA tool needs to be conducted.

PIPPA assesses menstrual pain and interference, thereby 'value-adding' to the overall 'vital signs' of assessment of menstruation in young women for non-pain related menstrual disturbance such as amenorrhoea, oligomenorrhoea, and dysfunctional uterine bleeding suggested by ACOG (2015).[38]

The absence of other menstrual disturbance screening tools for comparison and validation may be a limitation. For this reason, the first MDOT study was replicated and the PIPPA tool was validated against the original six-page MDOT questionnaire which generated the original findings that the indicators were drawn from. Reported results for the same five indicators were consistent in the second MDOT cohort, although, all indicators except school absence had increased with statistical significance (p value range 0.05 to <0.0001).[29] (Table 2).

There are some other limitations to this study. The PIPPA questionnaire was tested in young women aged 15-19 years, but further testing is required to check ease of completion and validity in younger menstruating girls from age eight years and onwards. Broader testing for applicability in the adult population (>19yrs) would also be useful. In this study we did not test or establish whether the use of Yes/No dichotomous answers was more challenging in complex cases. Only public schools were used in both the 2005 and 2016 cohorts which may partly ameliorate a 'best-case scenario' due to the higher economic status of the Australian Capital Territory, further testing in other locations or private schools may detect further differences.

A paper copy of PIPPA was tested during this study to replicate the original MDOT study, but an electronic version may be of value given the high use of electronic media by this age group. Not only is electronic data collection and scoring more convenient but internet-based availability of the tool would also provide access for young women in remote and rural locations (with access to the internet) to screen themselves and self-manage initially. Access to online supportive information post self-screening could guide conversations with their primary carers regarding symptom management and the need to travel to primary/secondary/tertiary health care if needed.

Our planned use of electronic PIPPA self-screening is to include menstrual health education and initial self-management strategies via a website for young women. For those girls scoring three, four or five out of five on PIPPA the website includes first line treatment guidelines for primary health professionals such as school nurses and general practitioners. If menstrual disturbance is identified, ongoing decisions around treatment and investigation should be based on individual assessment and consultation with the young woman and her carers (depending on age). Equally, low scorers of PIPPA who present with concerns should be individually assessed.

A streamlined low intervention pathway of self-care and primary health care will help minimise risk of over diagnosis from PIPPA screening. Under diagnosis is more likely if women are asymptomatic. Either way, screening adolescents early for menstrual disturbance is more comprehensive and likely to be more beneficial as it will address both primary and secondary dysmenorrhoea, reduce risk for development of persistent pain states, and facilitates diagnosis and treatment of underlying pathology.

For example, low cost and minimally invasive measures such as regular exercise and/or exercise before a period or non-steroidal anti-inflammatories (NSAIDs) to manage high prostaglandin response, referral to a pelvic physiotherapist for myofascial pain, improving gut/vaginal/bladder flora or recognizing bladder irritation and changing the diet could alleviate some painful symptoms and avoid unnecessary interventions.[16,34,39] Optimal outcomes from a comprehensive approach includes consideration and management of PMDD, depression, anxiety and mental health issues.[12,23–26]

Menstrual education and screening in schools has optimal reach for young women and is both desired by young women (and young men) to address unmet information needs and can facilitate early identification of problems.[4,40–42] However, early awareness strategies can reach further with the use of social media and internet sites that can facilitate early self-screening and self-management if (links to) tools and information are readily available and accessible.[41,42]

Recommendation for research in the field of dysmenorrhoea is to increase consistency among studies and currently, an 11 point (0-10) numeric rating scale (NRS) is commonly used, and recommended,[43] to measure pain with 8-10/10 being considered ‘severe pain’. For measuring school absence related to period pain a 5-point Likert scale for school absence with never/rarely/sometimes/often/always is recommended as currently, wording is variable and makes comparison between studies difficult. Further investigation on optimal measures to provide universal consistency (in different languages) and assist comparison would be of value.

The brevity of PIPPA facilitates language translation (5 questions only) but further testing of application across cultures and for generalisability to other groups and settings is required. Although, indicators such as severe pain, interference and school absence are widely reported in many countries.[1]

The absence of a robust screening tool for pain related menstrual disturbance creates a considerable gap for consistent identification and intervention in best practice primary health care. The development of the PIPPA tool is a positive step towards tackling the issue of menstrual disturbance in young women. While this early validation testing of PIPPA is promising, further widespread testing in similar and different populations and settings will further reveal its full worth as a screening tool for menstrual disturbance. Further reporting will explore PIPPA in adult women and the links to surgical findings at laparoscopy.

At a minimum, a tool that addresses the question of menstrual normality in young women, facilitates health seeking behaviour and drives first line treatment of menstrual disturbance and comorbid conditions to minimise impact, is a game changer.

Conclusion

The PIPPA screening tool was found to be a valid measure of symptomatic pain related menstrual disturbance in young women. Further research is required to measure the impact of early screening on reducing menstrual morbidity; diagnostic delay for endometriosis; identifying comorbid pain conditions and improving long term health outcomes for young women. Further research is required to track how self-screening users of PIPPA interpret scoring and what action they take.

Declaration of Competing Interest

None declared.

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Contribution of Authorship

Study conceived and designed by MP, AK, BS, AS. Data collection by MP; Analysis by MP, BS, JW, article written by MP and edited by AK, BS,JW, AS.

Details of ethics approval

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Table legends

Table 1. Design, setting, population, methods and outcome measures for MDOT 1 and MDOT 2 studies

	MDOT 1	MDOT 2
Year	2005	2016
Cohort size (total N=2117)	N=1051	N=1066
Population (age group)	15-19	15-19
Setting: Canberra ACT	4 Senior High Schools	3 Senior High Schools
Cross sectional study	Yes	Yes
Survey used	MDOT questionnaire	MDOT questionnaire PIPPA questionnaire (within one booklet)
Data collection	En masse year groups; English classes;	English classes; pastoral care type classes
Outcome measures	Menstrual characteristics Typical and atypical symptoms Interference Menstrual disturbance Diagnosis of period problem	Menstrual characteristics Typical and atypical symptoms Interference Menstrual disturbance Diagnosis of period problem Diagnosis of endometriosis (new question) PIPPA score

Table 2. Comparison between the MDOT (Menstrual Disorder of Teenagers) 2005 and 2016 cohorts of the five indicators for menstrual disturbance reported from MDOT questionnaire (indicators used to develop PIPPA)

Indicators for menstrual disturbance	2005 (N=1051)		2016 (N=1066)		p value
	Respondents	Response	Respondents	Response	
Severe pain (scoring 8-10; 0=no pain, 10=worst pain)	1039	21%	1049	24.30%	0.035
School absence (Yes/No)	1019	25.70%	1024	27.60%	0.175
Interference*	1037	20.20%	1049	24.70%	0.008
Reported no. of menstrual symptoms (average)	1040	4.34	1066	5.34	<0.0001
Sure there is something wrong with my period (True/False)	1039	9.70%	1048	10.60%	0.045

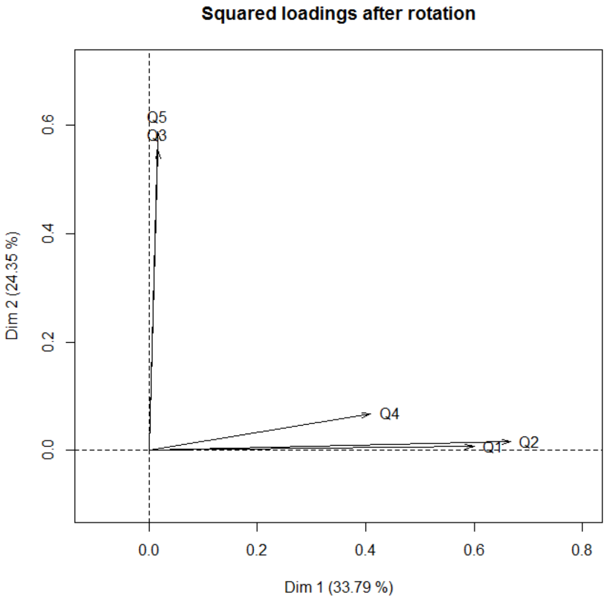
Table 3. Response frequencies to each PIPPA question and total PIPPA scores for cohort (N=1066)

Question No	PIPPA questions *Over the past 6 months have you*	Total Responses	Yes	%(se)
1	had regular severe period pain?	1051	471	44.2(1.53)
2	had significant interference to your daily activities because of your period?	1054	380	35.7(1.48)
3	experienced bowel or bladder pain?	1049	380	35.7(1.48)
4	regularly missed school or work because of your period?	1054	146	13.7(1.06)
5	felt sure there is something wrong with your periods?	1051	238	22.3(1.28)
	Total PIPPA scores for cohort (out of 5[a])	**Frequency**		**%(se)**
	0	316		30.5(1.43)
	1	269		25.9(1.36)
	2	195		18.8(1.21)
	3	147		14.2(1.08)
	4	72		6.9(0.79)
	5	38		3.7(0.59)
		1037		**100**
	Missing	29		
	Total	1066		

[a]0=no menstrual disturbance; 5=high menstrual disturbance

Figure legends

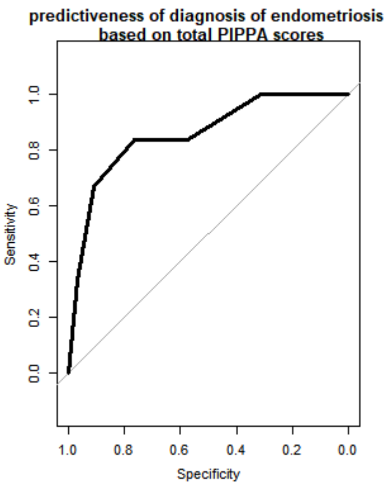
A



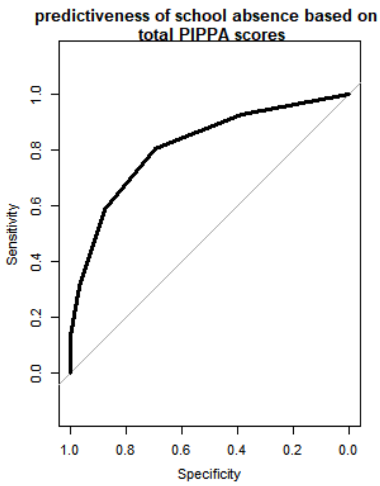
B

PIPPA	Component 1	Component 2
Q1	**0.600**	0.007
Q2	**0.667**	0.016
Q3	0.017	**0.555**
Q4	**0.409**	0.068
Q5	0.017	**0.589**

C



D



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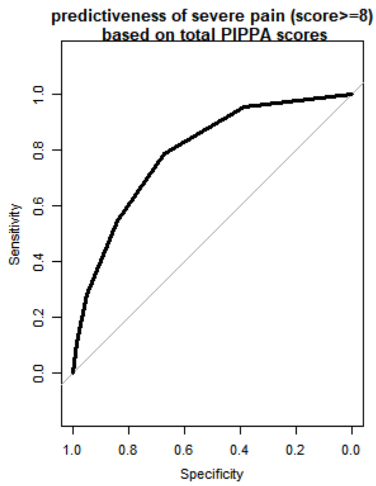

1C ROC curve: predictiveness of self-diagnosis of endometriosis based on total PIPPA scores (AUC=0.789)

1D ROC curve: predictiveness of school absence based on total PIPPA scores (AUC=0.813)

1E ROC curve: predictiveness of severe pain (NRS score≥8) based on total PIPPA scores (AUC=0.855)

Figure 1. MCA loading plot (A) and factor loading table (B); three ROC figures with AUC for total PIPPA scores and predictiveness of a diagnosis of endometriosis (C), school absence (D) and pain severity (E)

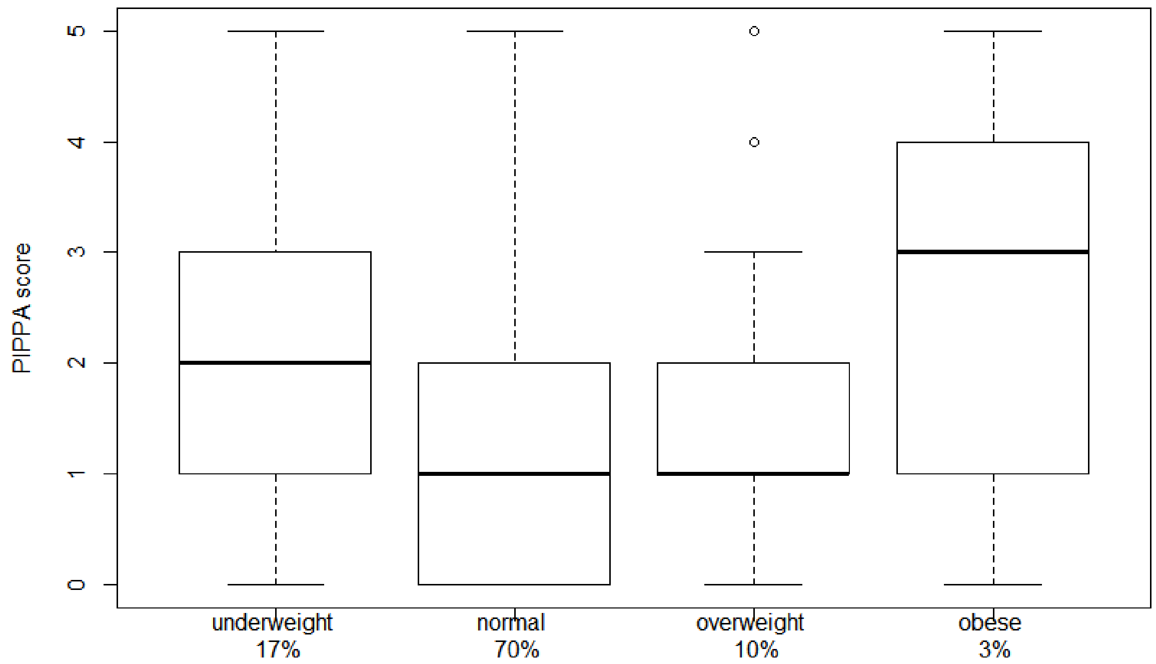

Figure 2. Relationship between total PIPPA scores and Body Mass Index (BMI) groupings (N=903)