

Clinical assessment of the impact of pelvic pain on women

K. Jane Chalmers^{a,*}, Mark J. Catley^a, Susan F. Evans^b, G. Lorimer Moseley^a

Abstract

We aimed to develop a questionnaire that assesses the impact of pelvic pain on women, regardless of diagnosis, that has high utility, sound psychometric performance, easy scoring, and high reliability. Two studies, with 3 separate cohorts, were undertaken. Both studies were completed online. Studies included women with self-reported pelvic pain. Women were eligible to participate regardless of whether their pelvic pain was undiagnosed, self-diagnosed, or diagnosed by a clinician. Study 1 used a 3-round “patient-as-expert” Delphi technique. These rounds defined the 10 aspects of life with the self-reported greatest impact on the lives of women with pelvic pain, which formed the questionnaire. Study 2 used Rasch analysis to assess the psychometric properties of the resultant 10-item questionnaire. To assess its reliability, a subgroup completed the questionnaire 3 times over a 3-week period. In study 1, 443 women with pelvic pain participated. The resultant 10-item questionnaire consisted of 8 Likert questions and 2 supplemental, nonscored questions. In study 2, 1203 women with pelvic pain completed the questionnaire. Rasch analysis showed that the questionnaire targeted the pelvic pain population well, had appropriate Likert categories, constituted a unidimensional scale, and showed internal consistency. Twenty-seven women with pelvic pain completed the reliability trial. Test–retest reliability was high (intraclass correlation coefficient 0.91, $P < 0.001$). The resultant Pelvic Pain Impact Questionnaire assesses the life impact of pelvic pain. It uses patient-generated language, is easily administered and scored, has very strong psychometric properties, and it is suitable for research and clinical settings across primary, secondary, and tertiary care.

Keywords: Pelvic pain, Impact, Questionnaire, Endometriosis, Vulvodynia, Quality of life, Rasch, Measurement

1. Introduction

Pelvic pain is very common in women—up to 1 in 4 women have persistent pelvic pain,^{43,44} and almost every woman has experienced pain during menstruation (dysmenorrhoea).²³ Diagnosis of pelvic pain varies between clinicians, and between clinical and research settings, in part because the mechanisms underlying pelvic pain vary and are often not well understood, and because many women have multiple conditions. Not surprisingly, the highest treatment priority for pelvic pain is usually pain relief.³⁸ However, recent assertions that it is the impact of pain on one’s physical, social, and psychological well-being that requires better assessment³ adds weight to established recommendations to better assess the impact of pelvic pain on sufferers as part of primary care.⁸ Indeed, the strong negative association between pain intensity and quality of life in people with pelvic pain is attributed to its impact on meaningful activities, relationships, and intimacy.^{24,28}

Currently, there is no recognised method of assessing pelvic pain impact. Clinical tests generally focus on physiological problems but correlate poorly with a patient’s well-being and level of function.¹⁹ Health-related quality of life tools encompass some aspects of impact²² but are time-consuming to complete and score, and do not touch on pelvic pain-specific areas of impact, such as intimacy. Health-related quality of life tools specific for pelvic pain conditions are available but they too are often too time-consuming for primary care (eg, Endometriosis Health Profile [EHP]-30).¹⁶ More importantly, such tools rely on accurate diagnosis, which is problematic, and require the patient to have only 1 pelvic pain condition, which is rarely the case.²⁰ For example, women with endometriosis commonly have comorbid diagnoses and symptoms of dysmenorrhoea,²⁷ painful ovulation,¹² and bladder pain syndrome.³⁴ Remarkably, consumers themselves seem to have been excluded in the development of these condition-specific questionnaires.^{6,10} That patients and clinicians have distinctly different views on what determines quality of life^{5,15} points to the importance of considering the patient’s perspective in assessment development.

Pelvic pain is associated with unique areas of impact on life. Grace and Zondervan^{17,18} identified pelvic pain-specific aspects of impact including problems with sitting, limitations in social activities, limitations in sexual activities and intimacy, and limitations on their interaction with their physical and social environment (including family). These studies, however, failed to produce a clinical tool that could investigate and measure these areas of impact. We aimed to fill this substantial gap in the literature by developing a questionnaire for assessing the impact of pelvic pain in women. Our objectives were to prioritise the patient’s perspective on impact rather than the clinician or researcher’s, to ensure that the questionnaire was easy to

Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.

^a Sansom Institute for Health Research, University of South Australia, Adelaide, Australia, ^b Pelvic Pain SA, Adelaide, Australia

*Corresponding author. Address: School of Science and Health, Western Sydney University, Locked Bag 1797, Penrith, New South Wales, Australia 2751. Tel.: +61 2 4620 3851. E-mail address: k.jane.chalmers@gmail.com (K. J. Chalmers).

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal’s Web site (www.painjournalonline.com).

PAIN 0 (2017) 1–7

© 2016 International Association for the Study of Pain

<http://dx.doi.org/10.1097/j.pain.0000000000000789>

understand, use, and score, and was not too burdensome for use in primary care. We then set out to fully interrogate its psychometric properties.

2. Materials and methods

We undertook 2 studies involving 3 separate cohorts of women with pelvic pain. All participants were directed to the studies through word of mouth, clinicians, or online methods (Appendix 1, available online at <http://links.lww.com/PAIN/A367>). Women were included in the study, whether their pelvic pain was undiagnosed, self-diagnosed, or diagnosed by a clinician. Participants were excluded if they reported not having pelvic pain. Pelvic pain was defined using the International Association for the Study of Pain definition: pain perceived in structures related to the pelvis of women,³⁰ including the lower abdomen, pelvis, vulva, anus, or sacral regions. Each participant provided informed consent and the studies were approved by the University of South Australia Human Research Ethics Committee.

2.1. Study 1: development of the Pelvic Pain Impact Questionnaire

We used a patient-as-expert eDelphi technique to develop the Pelvic Pain Impact Questionnaire (PPIQ) (Appendix 1, available online at <http://links.lww.com/PAIN/A367>). There were 3 rounds (Appendix 2, available online at <http://links.lww.com/PAIN/A367>). For the first round, we developed a bank of 52 statements across 9 subdivisions (daily activities, leisure activities, working life, self-care, sleep, energy, appetite, mood, and spiritual life) (Appendix 3, available online at <http://links.lww.com/PAIN/A367>). These statements and subdivisions were based on the basis of published literature^{1,16,17,21,22,28,31} and discussions with experts in the pelvic pain field. Participants checked the box next to the statements that they felt applied to their lives. There was also an open-response option that enabled participants to nominate additional aspects of their lives that were not reflected in the statements.

The results from the first round of the eDelphi were reviewed, and a list of the 25 most common aspects of life that are impacted by women's pelvic pain was generated (Appendix 4, available online at <http://links.lww.com/PAIN/A367>). Statements that were not ticked by any participant in round 1 were rejected. Some of the related statements were collated to cover an aspect of life; for example, all sport-related statements were collated into 1 sports statement that included a list of examples. For rounds 2 and 3 of the survey, we used a 100-point allocation approach to weight the statements (Appendix 4, available online at <http://links.lww.com/PAIN/A367>). The top 10 aspects obtained in round 3 formed the PPIQ.

Each included aspect was added to the sentence structure "In the past month, how much has your pelvic pain affected..." to form questions. A 5-question Likert scale with the following categories was attached to each question: "Not at all" (0); "A little bit" (1); "Somewhat" (2); "Quite a bit" (3); and "A great deal" (4). The Likert category labels of each question were presented without numbers for clarity and to avoid patients confusing the scale with a pain numerical rating scale. This scale was chosen as it has demonstrated utility in quality of life questionnaires¹¹ and is easy for participants to understand. The month time frame was used based on other impact questionnaires and that some pelvic pains fluctuate greatly over the menstrual cycle.³⁵

2.2. Study 2: psychometric assessment of the Pelvic Pain Impact Questionnaire

In stage 1 of study 2, the PPIQ was administered to a second cohort of women with pelvic pain and the following demographic data were collected: diagnosis/diagnoses, age, and duration of pelvic pain. Rasch analysis was used to assess the functioning of the questionnaire. In stage 2, the PPIQ was then administered to a third cohort of women with pelvic pain and the following demographic data were also collected: diagnosis or diagnoses and treatments or medications accessed during administration stage. Participants were required to complete the PPIQ on the same day and at the same time of day once per week for 3 consecutive weeks. Intraclass correlations were used to assess the test-retest reliability of the PPIQ over the 3 weeks.

2.2.1. Rasch analysis

We used Rasch analysis to determine the psychometric properties of the PPIQ. Rasch analysis is based on a probabilistic model that uses the level of endorsement of questions to investigate the integrity of the questionnaire. Participants are said to have "endorsed" a question if they have selected a response of 1 or above on a question. We used Rasch analysis to assess whether 2 main assumptions were met: first, that a participant who is greatly impacted by pelvic pain will have a greater probability of endorsing any PPIQ question than a participant who is less impacted; and second, that the probability of any participants endorsing a question indicative of high impact is less than that of any participant endorsing a question indicative of lower impact. Rasch analysis assesses whether the tool targets the sample appropriately, whether it forms a unidimensional scale, and whether scores can be used as an interval level measurement. For more detail on the Rasch analysis see Appendix 1 (available online at <http://links.lww.com/PAIN/A367>). For a comprehensive overview see Bond and Fox (2013).⁷

Unidimensionality was assessed by a principal components analysis of residuals and an analysis of the question outfit and infit statistics was. Outfit (outlier-sensitive) statistics are more sensitive to unexpected behavior by participants on questions far from the participant's measure level, and infit (information-weighted) statistics are more sensitive to unexpected behavior affecting responses to items near the participant's measure level.²⁵ Internal consistency of the PPIQ was assessed by the person reliability index, the Rasch equivalent of Cronbach alpha. We determined, a priori, that values above 0.7 and 0.85 would be used to indicate the appropriateness of the scale for group and individual use, respectively.³⁹ Bias was assessed using a Mantel chi-squared test. Question bias occurs when characteristics other than the variable of interest change the functioning of the scale (ie, 2 persons for whom pelvic pain has a similar true impact endorse a question differently because of some other characteristic). We assessed whether the participant's age (≤ 35 , > 35 years); duration of symptoms (0-12 months, > 12 months); or diagnosis biased the functioning of the scale. If bias was apparent in a small subset of participants, a sensitivity analysis was conducted. Three random samples of equal size to the bias subset were drawn from the larger sample and compared.

2.2.2. Test-retest reliability

Participants in stage 2 of study 2 were required to complete the PPIQ on the same day and at the same time of day once per week for 3 consecutive weeks. Intraclass correlations were used to assess the test-retest reliability of the PPIQ over the 3 weeks.

3. Results

3.1. Study 1: development of the Pelvic Pain Impact Questionnaire

Four hundred forty-three women volunteered to take part in the eDelphi study. Fifty-four were excluded because they reported no pelvic pain.

After the first round of the eDelphi, 25 prominent aspects of life that participants judged as being impacted by their pelvic pain were identified (Appendix 4, available online at <http://links.lww.com/PAIN/A367>). One hundred thirty-three participants from round 1 agreed to participate in round 2, and of these, 79 agreed to participate in round 3.

Over rounds 2 and 3, intimacy, mood, sleep, and physical activity were the most commonly and fully endorsed aspects. No participants in either round designated all 100 points to “My pelvic pain does not affect any of these aspects of my life”; that is, all participants responded that their pelvic pain impacted at least 1 aspect of their life—none reported “zero impact”. The average scores of each of the 25 aspects across rounds 2 and 3 were calculated, and the 10 most endorsed aspects were identified. These 10 aspects captured over 73% of the total available points in the last 2 rounds of the eDelphi and were used to form the PPIQ. However, 2 of the questions were deemed to be potentially relevant to only a subset of responders; question 9 (“During your last period, how much did your pelvic pain affect your ability to use tampons?”) and 10 (“In the past month, how much has your pelvic pain affected your levels of intimacy or sexual relationships?”) were included as supplementary questions that did not contribute to the overall PPIQ score. In summary, the PPIQ contained 8 summative questions (with a possible total score of 32) and 2 supplementary questions (Appendix 5, available online at <http://links.lww.com/PAIN/A368>).

3.2. Study 2: psychometric properties of the Pelvic Pain Impact Questionnaire

3.2.1. Rasch analysis

One thousand two hundred three women (mean age 33.1 ± 8.6 years) completed the PPIQ (Table 1). Most women (56%) reported their pelvic pain to have a duration of longer than 10 years. Forty-three (4%) participants registered a maximum score (32) and 21 (2%) registered a minimum score (0) on the PPIQ suggesting negligible ceiling and floor effects of the scale. Data for these participants were excluded from the analysis because extreme scores correspond to infinite measures and are not directly estimable using the Rasch process. Full data from 1139 participants were included in the Rasch analysis.

The targeting of the PPIQ to the sample is shown in person-question distribution map in Figure 1, and the average question endorsability thresholds are listed in Table 2. The distribution map indicates that the sample was slightly loaded toward higher levels of impact in comparison with the average question thresholds. The average participant level of impact was 0.84 (1.39) logits (range: -3.71 to -3.90 logits), in comparison with the default question impact level average of 0 (0.53) logits (range: -0.73 to -1.13 logits). Question 1 (In the past month, how much has your pelvic pain affected your energy levels?) was the easiest to endorse (ie, responses were toward the “A great deal” Likert anchor) and question 5 (In the past month, how much has your pelvic pain affected your ability to sit for longer than 20 minutes?) was the most difficult to endorse (ie, responses were toward the “Not at all” Likert anchor).

The average category thresholds were not disordered suggesting the Likert categories functioned as intended and that the participants were able to discriminate between each category.

Table 1

The diagnostic categories of women participating in the 3 separate studies.

Diagnosis	Percentage of participants, n (%)		
	eDelphi study	Rasch study	Reliability study
Endometriosis	76 (28)	995 (83)	12 (46)
Dysmenorrhoea	58 (21)	12 (1)	7 (27)
Tight pelvic floor	74 (27)	17 (1)	7 (27)
Vulvodynia	40 (15)	33 (3)	6 (23)
Ovarian cysts	36 (13)	25 (2)	6 (23)
Interstitial cystitis	22 (8)	10 (1)	4 (15)
Painful ovulation	29 (11)	2 (0.2)	4 (15)
Pudendal neuralgia	35 (13)	11 (1)	4 (15)
Vestibulodynia	24 (9)	3 (0.2)	4 (15)
Pelvic congestion syndrome	5 (2)	0	3 (12)
Candida (thrush)	12 (4)	0	3 (12)
Adenomyosis	18 (7)	11 (1)	2 (8)
Other	98 (36)	68 (6)	5 (19)
No diagnosis	—	16 (1)	3 (12)

Women participating in the eDelphi and Reliability studies could select more than 1 diagnosis; therefore, total percentage does not equal 100. However, in the Rasch study, participants were required to provide a primary diagnosis, and any secondary diagnoses (not listed here).

Table 2 summarises the fit statistics for the 8 questions. Three questions demonstrated excessive fit statistics. Question 8 (“In the past month, how much has your pelvic pain affected your ability to wear certain clothes?”) showed slightly excessive positive infit and outfit indicating a potential threat to the validity of the scale. Analysis of the question characteristic curves for question 8 suggested that the slight misfit was due to a small number of participants who had low scores overall and had scored this question higher. Although not a threat to validity, question 1 (“In the past month, how much has your pelvic pain affected your energy levels?”) and question 6 (“In the past month, how much has your pelvic pain affected your ability to perform and function normally at home/work/school/university?”) showed slightly excessive negative infit and outfit, meaning they performed better than the model predicted.

Visual inspection of the principal components analysis of residuals correlation matrix revealed no meaningful patterns and a second dimension eigenvalue of 1.7, suggesting the PPIQ constitutes a unidimensional scale.³² Assessment of local dependence did not identify any large correlations between questions suggesting none of the questions are redundant.

Eighty-seven participants (7%) displayed excessive fit statistics (>2 logits). Analysis of these data showed no significant associations with age but an association with diagnosis and duration. Because of the nature of the sample, participants were grouped according to their diagnosis as endometriosis, vulvodynia, or “other,” encompassing all other pelvic pain diagnoses. There were more participants in the misfitting group reporting pelvic pain for less than 12 months and were diagnosed as having vulvodynia or “other” than the remainder of the same. Visual analysis of the response strings of the misfitting participants typically identified persons with high scores overall but low scores on 1 or 2 individual questions. Less commonly, persons with low scores overall scored high on individual questions.

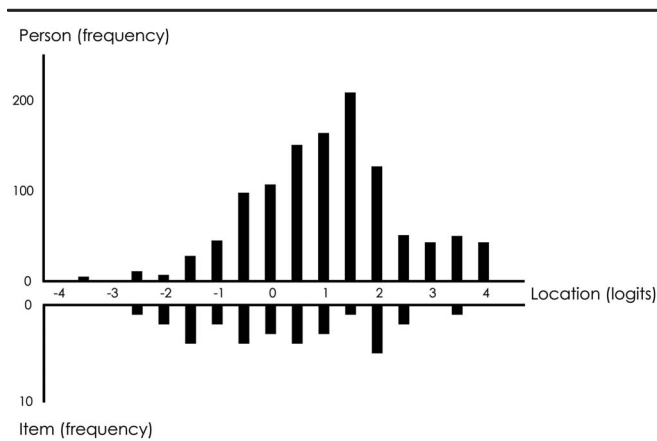


Figure 1. Person-item distribution map for the Pelvic Pain Impact Questionnaire. Persons less affected by pelvic pain and items easier to endorse are located on the left side of the logit scale (ie, <0 logits); Persons more affected by pelvic pain and items harder to endorse are located to the right of the logit scale (ie, >0 logits). Average item endorsability mean is set at 0 logits by default.

A person reliability of 0.87 indicated that the PPIQ is suitable for individual use³⁹; however, diagnosis appears to bias the response to some questions. Participants with vulvodynia ($n = 36$) found it significantly easier to endorse question 2 (“In the past month, how much has your pelvic pain affected your mood?”), 5 (“In the past month, how much has your pelvic pain affected your ability to sit for longer than 20 minutes?”), and 8 (“In the past month, how much has your pelvic pain affected your ability to wear certain clothes?”) than those with endometriosis ($n = 995$). Participants with vulvodynia also found it significantly harder to endorse question 1 (“In the past month, how much has your pelvic pain affected your energy levels?”), 3 (“In the past month, how much has your pelvic pain affected your sleep?”), and 4 (“In the past month, how much has your pelvic pain affected your stomach and intestinal function?”) than those with endometriosis (Fig. 2). A sensitivity analysis was conducted and these findings were replicated in the smaller samples, supporting the original finding (Fig. 2). No significant differences were observed between those with endometriosis and “other” pelvic pain-related conditions ($n = 172$).

In addition, no significant differences were observed between younger ($n = 763$) and older ($n = 440$) persons. Neither were significant differences observed between those participants who had experienced pelvic pain for less than 12 months ($n = 36$) and

those who had experienced pelvic pain for greater than 12 months ($n = 1103$).

3.2.2. Test-retest reliability

Twenty-six women (mean age 32.8 ± 10.5 years) completed the PPIQ 3 times (Table 1). Participants reported that the PPIQ took approximately 5 minutes to complete. Although every attempt was made to ensure participants completed the PPIQ exactly 7 days apart, 1 participant completed the PPIQ the second time 14 days after completing it the first time. The remainder completed the PPIQ between 7 and 9 days after the last completion. Test-retest reliability at each of the time points was good (intraclass correlation coefficient 0.87–0.94), and the overall test-retest reliability was also good (intraclass correlation coefficient 0.91; confidence interval: 0.83–0.96; $P < 0.001$; Fig. 3).

4. Discussion

We aimed to develop and fully test a questionnaire for assessing the impact of pelvic pain, prioritising the patient’s perspective on impact rather than the clinician or researcher’s, the questionnaire’s ease of use and scoring, and agreeability for patients. The resultant PPIQ (Appendix 5, available online at <http://links.lww.com/PAIN/A368>) consists of 8 Likert scale questions, with an additional 2 supplementary questions. The 8 questions can be converted to a score from 0 to 4 and summed to provide a total “impact score” with a range of 0 to 32. The questionnaire is suitable for both individual and group use. There are 2 questions that are exempt from scoring on the questionnaire. Question 9, regarding the use of tampons, is excluded from the tallied score because it only applies to the subgroup of women with pelvic pain who use tampons (Rasch analysis showed >35% missing data on this item). Hormone use, menopause, pregnancy, hysterectomy, amenorrhea (such as that seen in high-end athletes),²⁶ religious, medical, or ideological reasons are all potential explanations for not using tampons. Question 9 is therefore considered an “if applicable” question. Question 10, regarding sexual relationships and intimacy, is excluded from the tallied score because it did not function similarly to the other questions. This would occur if enough participants did not answer the question truthfully. There was also much (>10%) missing data on this question, probably because some participants were not sexually active, making this question redundant, or were reluctant to discuss the impact of their pelvic pain on their sexual relationships. Again, this question has been removed from the tallied portion of the PPIQ and added as an “if applicable” question at the end of the questionnaire.

Our study shows that the PPIQ is suitable for use across varying types of pelvic pain and that not all women respond to the questions in the same manner. Secondary analyses revealed that women who reported suffering from only vulvodynia found it harder to endorse the questions regarding their sleep and stomach/intestinal function than women who reported only suffering from endometriosis did. They also found it much easier to endorse the question regarding their levels of sexual relationships/intimacy and sitting for longer than 20 minutes than women with endometriosis did. This is unsurprising given the differences in presentation of the 2 conditions: the signs and symptoms of vulvodynia are localised to the vulva and occur in response to mechanical provocation. In contrast, endometriosis involves the uterus and other organs within the pelvic and abdominal cavities. Potential pathology-driven pain in endometriosis would not cease on lying down, which may explain why

Table 2
The average question endorsability thresholds for each item.

Item	Measure, Logits	SE	Score	Infit, mnsq	Outfit, mnsq
5	1.13	0.04	2247	1.3	1.3
3	0.28	0.04	2912	0.9	0.9
8	0.22	0.04	2956	1.4	1.5
6	−0.05	0.04	3154	0.6	0.6
7	−0.15	0.04	3228	0.9	0.9
4	−0.27	0.04	3311	1.3	1.4
2	−0.43	0.04	3416	0.8	0.8
1	−0.73	0.04	3604	0.6	0.6

Items are listed from most difficult to endorse (highest measure) to easiest to endorse (lowest measure). mnsq, mean square. Mean square fit statistics >1.4 or <0.6 were deemed to underfit or overfit the Rasch model respectively (see Appendix 1).

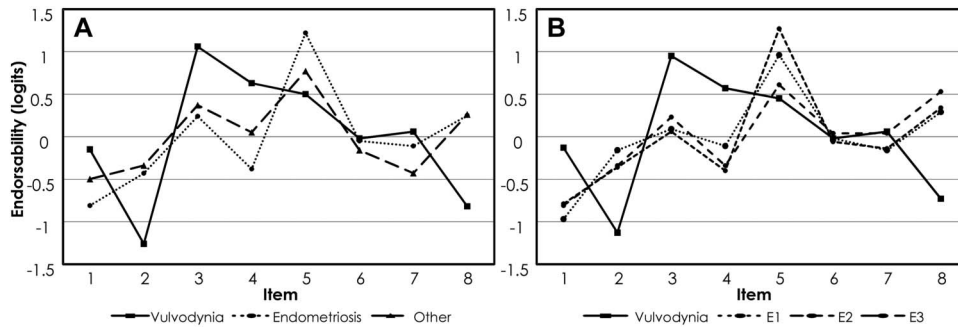


Figure 2. Item bias due to diagnosis. Part (A) compares the diagnoses across the sample (n = 1203). Part (B) compares the item responses of respondents diagnosed as having vulvodynia to 3 random samples (E1, E2, E3) of respondents diagnosed as having endometriosis (n = 36 in each group). Negative endorsability values indicate easier to endorse items and positive endorsability values indicate harder to endorse items.

those with endometriosis reported an impact of their pelvic pain on sleeping. On the contrary, provocation of vulvodynia pain is unlikely while in a horizontal position, meaning vulvodynia is less likely to impact on sleep. The impact of vulvodynia-related pelvic pain is more likely to involve activities that involve vulva pressure or touch, such as during sexual relationships/intimacy and with sitting for longer than 20 minutes. Previous tools suggest that women with endometriosis do commonly report problems with mobility,²¹ which does not differentiate between the act of sitting down or standing up, and that of remaining in a seated position. Our findings suggest that it is the actions of moving between sitting and standing, rather than sitting per se, that is impacted in women with endometriosis, but it is the act of remaining seated that is impacted in women with vulvodynia. Of course, our findings do not elucidate what it is about moving between sitting and standing that is difficult—perhaps it relates to changes in intra-abdominal pressure,³³ movement of the pelvic and abdominal organs, or contraction of pelvic and abdominal muscles—but highlights that the problem does not lie in sitting itself.

Overall, women found it easiest to endorse the question relating to their energy levels. Previous literature assessing energy levels in women with endometriosis has found that this is a commonly reported issue.^{4,13,37} The same issue faces those with other chronic pain conditions, including low back pain,¹⁴ fibromyalgia,² and osteoarthritis.⁴² Fatigue in chronic pain conditions could be explained by several factors; some commonly purported factors include psychological impacts, disruptions to the immune system,⁹ and central sensitisation.²⁹ Fatigue, like pain, thirst, and hunger, can be conceptualised as “survival perceptions” because they are powerful motivators of behaviour,⁴¹ and that fatigue and pain often occur together has led to some proposals of a shared biology or neurological substrate.³³ Of course, fatigue is likely when sleep is poor, and it is also

important to note that sleep disturbances were commonly reported in our cohort.

This study had clear strengths. The PPIQ was developed using a rigorous method with the consideration of patients-as-experts on impact, a focus on utility for the patient and clinician, and the substantial sample size for each study. Our approach has yielded a questionnaire that is tailored to the specific concerns of the population, is presented in their own language, and is highly usable across busy and resource-limited settings. Moreover, using a contemporary analytical approach—the Rasch—we have a high level of confidence in its psychometric properties. That the PPIQ is reliable (notwithstanding the debate that exists about the interpretation of intra-class correlation coefficients)⁴⁰ suggests it should detect change in impact with, for example treatment. This clearly needs to be tested in a fresh cohort. The PPIQ has sufficient utility and meaning to guide subjective examination and treatment—patient responses to individual questions may require further exploration and thus help clinicians prioritise management strategies. For example, if a patient reports that their ability to sleep is impacted by their pelvic pain, a clinician could clarify what it is about their sleep that is impacted (eg, getting to sleep, staying asleep, duration of sleep, or quality of sleep) and provide appropriate advice.

This study also has limitations. Participants were from many countries around the world, but they were all English speaking and had access to a computer and the internet, which reflects cultural specificity—some questions may be less relevant to women of other cultural and linguistic groups than they are to the study population. Also relevant is the predominance of women who reported a diagnosis of endometriosis. This is likely to reflect the population—many women with pelvic pain have received a diagnosis of endometriosis—but it also limits our ability to compare PPIQ results between diagnostic groups or clusters. The reported rates of endometriosis were highest in the Rasch analysis study, in which women provided only their primary diagnosis. In the other 2 studies, they had an option of selecting any relevant diagnoses. This is again likely to reflect the higher prevalence of endometriosis than of other pelvic pain conditions, but it limits our ability to expand the Rasch analysis results to women with multiple conditions, especially women who do not necessarily have a single primary diagnosis. It is likely that these women reporting endometriosis also have other pelvic pain conditions²⁰; but our findings suggest that many women do view endometriosis as their primary diagnosis over other comorbid pelvic pain conditions. Because of the high rates of endometriosis and vulvodynia reported in these studies, it will be important for future research to investigate the use of the PPIQ in women who

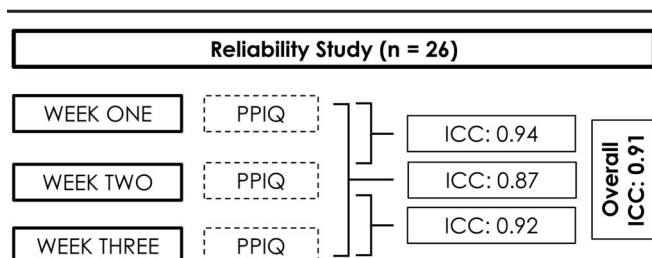


Figure 3. Results of the Reliability study over 3 weeks. The week-to-week intraclass correlations are presented followed by the overall intraclass correlation coefficient.

have diagnoses other than endometriosis or vulvodynia. These limitations notwithstanding, the PPIQ seems appropriate for further investigations into the massive problem of pelvic pain in women, for example, into its utility for detecting change in impact, predicting outcome or response to treatment, and subgrouping and modification for other languages and cultures. Given that pelvic pain affects 10% to 16% of men,³⁶ there is clear impetus to develop a similar tool for use in men. There are clearly some items that would not apply—for example, questions on tampon use—but others may. Nonetheless, we would recommend a process similar to ours—of prioritising the patient experience in development—so as to ensure a valid capture of the highest impact areas.

The PPIQ for women has high utility and excellent psychometric properties. It assesses the impact that pelvic pain has on a woman's life and is appropriate for use in clinical practice, across primary, secondary, and tertiary care settings, and also in research.

Conflict of interest statement

S. F. Evans has been a consultant for Pfizer and Bayer. She receives royalties from sales of *Endometriosis and Pelvic Pain* and receives research funding from The Anaesthesia and Pain Medicine Foundation. G. L. Moseley receives author royalties for *Explain Pain*; *Explain Pain Handbook: Protectometer*; *Painful Yarns: Metaphors and Stories to help understand the biology of pain*; *The Graded Motor Imagery Handbook*; and *Explain Pain Supercharged*. He receives speaker fees for lectures on pain and rehabilitation. He has received support from Pfizer, Kaiser Permanente, Results Physiotherapy, Agile Physiotherapy, The International Olympic Committee, and The Port Adelaide Football Club. The remaining authors have no conflicts of interest to declare.

K. J. Chalmers is supported by a Research Grant from The Pelvic Pain Foundation of Australia and the Gould Experimental Science Grant from the University of South Australia. S. F. Evans is a gynaecologist in private medical practice. G. L. Moseley is supported by a Principal Research Fellowship from the National Health and Medical Research Council of Australia ID 1061279.

This study has been previously presented as a free paper at the Australian Society for Psychosocial Obstetrics and Gynaecology 41st Annual Scientific Meeting 2015 (Melbourne, Australia) and the Australian Pain Society 35th Annual Scientific Meeting 2015 (Brisbane, Australia).

Appendix A. Supplemental Digital Content

Supplemental Digital Content associated with this article can be found online at <http://links.lww.com/PAIN/A367> and <http://links.lww.com/PAIN/A368>.

Article history:

Received 27 June 2016

Received in revised form 21 November 2016

Accepted 28 November 2016

Available online 8 December 2016

References

- Arnold LD, Bachmann GA, Kelly S, Rosen R, Rhoads GG. Vulvodynia: characteristics and associations with co-morbidities and quality of life. *Obstet Gynecol* 2006;107:617.
- Arnold LM, Crofford LJ, Mease PJ, Burgess SM, Palmer SC, Abetz L, Martin SA. Patient perspectives on the impact of fibromyalgia. *Patient Educ Couns* 2008;73:114–20.
- Ballantyne JC, Sullivan MD. Intensity of chronic pain—the wrong metric?. *New Engl J Med* 2015;373:2098–9.
- Ballweg ML. Impact of endometriosis on women's health: comparative historical data show that the earlier the onset, the more severe the disease. *Best Pract Res Clin Obstet Gynaecol* 2004;18:201–18.
- Black N. *Health services research methods: a guide to best practice*. London, United Kingdom: BMJ Books, 2000.
- Bodner C, Garratt A, Ratcliffe J, Macdonald L, Penney G. Measuring health-related quality of life outcomes in women with endometriosis—results of the Gynaecology Audit Project in Scotland. *Health Bull* 1997;55:109–17.
- Bond TG, Fox CM. *Applying the Rasch model: fundamental measurement in the human sciences*. Oxford, United Kingdom: Psychology Press, 2013.
- Brown R, Vyas S. Pelvic pain. *BMJ* 2015;351:h5637.
- Clauw D, Chrousos G. Chronic pain and fatigue syndromes: overlapping clinical and neuroendocrine features and potential pathogenic mechanisms. *Neuroimmunomodulation* 1997;4:134–53.
- Colwell HH, Mathias SD, Pasta DJ, Henning JM, Steege JF. A health-related quality-of-life instrument for symptomatic patients with endometriosis: a validation study. *Am J Obstetrics Gynecol* 1998;179:47–55.
- Cummins RA. *Comprehensive Quality of Life Scale: adult (ComQol-A5): manual*. Geelong, Australia: Centre for Australia-Asia Studies, Deakin University, 1997.
- Denny E. Women's experience of endometriosis. *J Adv Nurs* 2004;46:641–8.
- Denny E, Mann CH. A clinical overview of endometriosis: a misunderstood disease. *Br J Nurs* 2007;16:1112–16.
- Fishbain DA, Cutler R, Cole B, Lewis J, Smets E, Rosomoff H, Rosomoff RS. Are patients with chronic low back pain or chronic neck pain fatigued? *Pain Med* 2004;5:187–95.
- Fitzpatrick R, Davey C, Buxton M, Jones D. *Patient-assessed outcome measures*. Health services research methods. London: BMJ Publishing Group, 1998.
- Gao X, Yeh Y-C, Outley J, Simon J, Botteman M, Spalding J. Health-related quality of life burden of women with endometriosis: a literature review. *Curr Med Res Opin* 2006;22:1787–97.
- Grace V, Zondervan K. Chronic pelvic pain in women in New Zealand: comparative well-being, comorbidity, and impact on work and other activities. *Health Care Women Int* 2006;27:585–99.
- Grace VM, Zondervan KT. Chronic pelvic pain in New Zealand: prevalence, pain severity, diagnoses and use of the health services. *Aust N Z J Public Health* 2004;28:369–75.
- Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. *Ann Intern Med* 1993;118:622–9.
- Howard FM. Chronic pelvic pain. *Obstet Gynecol* 2003;101:594–611.
- Jones G, Jenkinson C, Kennedy S. The impact of endometriosis upon quality of life: a qualitative analysis. *J Psychosom Obstet Gynecol* 2004;25:123–33.
- Jones GMA, Kennedy SMD, Barnard A, Wong JP, Jenkinson CD. Development of an endometriosis quality-of-life instrument: the Endometriosis Health Profile-30. *Obstet Gynecol* 2001;98:258–64.
- Latthe P, Latthe M, Say L, Gülmezoglu M, Khan KS. WHO systematic review of prevalence of chronic pelvic pain: a neglected reproductive health morbidity. *BMC Public Health* 2006;6:177.
- Laursen BS, Bajaj P, Olesen AS, Delmar C, Arendt-Nielsen L. Health related quality of life and quantitative pain measurement in females with chronic non-malignant pain. *Eur J Pain* 2005;9:267.
- Linacre JM. *A user's guide to WINSTEPS MINISTEP Rasch-model computer programs*. Chicago: Winsteps.com, 2006.
- Loucks AB. Effects of exercise training on the menstrual cycle: existence and mechanisms. *Med Sci Sports Exerc* 1990;22:275–80.
- Mahmood T, Templeton A, Thomson L, Fraser C. Menstrual symptoms in women with pelvic endometriosis. *Br J Obstet Gynaecol* 1991;98:558–63.
- Mathias SDM, Kuppermann MPMPH, Liberman RFM, Lipschutz RCM, Steege JFM. Chronic pelvic pain: prevalence, health-related quality of life, and economic correlates. *Obstet Gynecol* 1996;87:321–7.
- Meeus M, Nijs J. Central sensitization: a biopsychosocial explanation for chronic widespread pain in patients with fibromyalgia and chronic fatigue syndrome. *Clin Rheumatol* 2007;26:465–73.
- Merskey H, Bogduk N. *Classification of chronic pain: descriptions of chronic pain syndromes and definitions of pain terms*. Seattle: IASP Press, 2011.
- Ponte M, Klemperer E, Sahay A, Chren MM. Effects of vulvodynia on quality of life. *J Am Acad Dermatol* 2009;60:70–6.
- Raiche G. Critical Eigenvalues sizes in standardized residual principal components analysis. *Rasch Meas Trans* 2005;19:1012.
- Raison V. Neurobiology of depression, fibromyalgia and neuropathic pain. *Front Biosci* 2009;14:5291–338.

- [34] Ratner V. Interstitial cystitis: a chronic inflammatory bladder condition. *World J Urol* 2001;19:157–9.
- [35] Riley JL III, Robinson ME, Wise EA, Price D. A meta-analytic review of pain perception across the menstrual cycle. *PAIN* 1999;81:225–35.
- [36] Schaeffer A. Epidemiology and evaluation of chronic pelvic pain syndrome in men. *Int J Antimicrob Agents* 2008;31:108–11.
- [37] Sinaii N, Cleary SD, Ballweg M, Nieman LK, Stratton P. High rates of autoimmune and endocrine disorders, fibromyalgia, chronic fatigue syndrome and atopic diseases among women with endometriosis: a survey analysis. *Hum Reprod* 2002;17:2715–24.
- [38] Sullivan MD, Ballantyne J. Must we reduce pain intensity to treat chronic pain? *PAIN* 2016;157:65–9.
- [39] Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: what is it and why use it? When should it be applied, and what should one look for in a Rasch paper? *Arthritis Rheum* 2007;57:1358–62.
- [40] Weir JP. Quantifying test-retest reliability using the intraclass correlation coefficient and the SEM. *J Strength Cond Res* 2005;19:231–40.
- [41] Williams MT, Gerlach Y, Moseley L. The “survival perceptions”: time to put some Bacon on our plates? *J Physiother* 2012;58:73–5.
- [42] Zautra AJ, Fasman R, Parish BP, Davis MC. Daily fatigue in women with osteoarthritis, rheumatoid arthritis, and fibromyalgia. *PAIN* 2007;128:128–35.
- [43] Zondervan K, Barlow DH. Epidemiology of chronic pelvic pain. *Baillieres Best Pract Res Clin Obstet Gynaecol* 2000;14:403–14.
- [44] Zondervan KT, Yudkin PL, Vessey MP, Jenkinson CP, Dawes MG, Barlow DH, Kennedy SH. The community prevalence of chronic pelvic pain in women and associated illness behaviour. *Br J Gen Pract* 2001;51:541–7.