

The Indonesian Version of the Chapron's Screening Method for Endometriosis Diagnosis based on Questionnaire as a Tool for Better Endometriosis Screening in Indonesia

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Abstract

Objective: This study aims to translate, develop, and assess the validity and reliability of the Indonesian version of Professor Chapron's screening method for endometriosis diagnosis based on the questionnaire as a tool for better endometriosis screening in Indonesia.

Methods: Development of the questionnaire using 5 steps: translation, synthesis, back translation, expert committee review, and pretesting by involving language expert and subject expert. The analysis includes the validity and reliability of the questionnaire.

Results: A sample of 30 subjects was enrolled. The questionnaire was consist of 3 sections, including characteristic patient questions, yes or no questions (8 questions), and pain scale questions (5 questions). Of the 8 yes or no questions, 7 were valid ($r > 0.300$), and one question was not valid ($r < 0.300$). The yes or no questions were reliable (Cronbach's alpha 0.6968). All of the 6 pain scale questions were valid ($r > 0.300$) and reliable (Cronbach's alpha 0.790).

Conclusion: This study represent the Professor Chapron's questionnaire for endometriosis screening into another language (Bahasa) than the original. It showed that the questionnaire was reliable, and one question was not valid (removed from the questionnaire). The questionnaire can be used in Indonesia for screening method in Indonesia.

Keyword: screening; diagnosis; questionnaire; endometriosis; Indonesia

Versi Indonesia dari Kuesioner Chapron untuk Metode Skrining dalam Diagnosis Endometriosis sebagai Alat Skrining Endometriosis di Indonesia

Abstrak

Tujuan: Penelitian ini bertujuan untuk menerjemahkan, mengembangkan, dan menilai validitas dan reliabilitas versi bahasa Indonesia dari metode *Skrining Professor Chapron* berdasarkan kuesioner, sebagai alat untuk skrining endometriosis yang lebih baik di Indonesia.

Metode: Pengembangan kuesioner menggunakan 5 langkah: penerjemahan, sintesis, penerjemahan balik, telaah komite ahli, dan pra-uji dengan melibatkan ahli bahasa dan ahli subjek. Analisis yang dilakukan yaitu uji validitas dan reliabilitas kuesioner.

Hasil: Sampel penelitian sebanyak 30 orang. Kuesioner terdiri atas 3 bagian, yaitu pertanyaan karakteristik pasien, pertanyaan ya atau tidak (8 pertanyaan), dan pertanyaan skala nyeri (5 pertanyaan). Sebanyak 7 pertanyaan ya atau tidak, hasilnya valid ($r > 0,300$) dan 1 pertanyaan tidak valid ($r < 0,300$). Pertanyaan ya atau tidak hasilnya reliabel (Cronbach's alpha 0,6968). Semua pertanyaan skala nyeri hasilnya valid ($r > 0,300$) dan reliabel (Cronbach's alpha 0,7900).

Kesimpulan: Penelitian ini mengembangkan serta menilai validitas dan reliabilitas kuesioner Professor Chapron untuk skrining endometriosis dalam versi bahasa Indonesia. Kuesioner ini reliabel dengan 1 pertanyaan tidak valid (dihilangkan dari kuesioner). Kuesioner ini dapat digunakan di Indonesia untuk metode skrining endometriosis di Indonesia.

Kata kunci: diagnosis; endometriosis; Indonesia; kuesioner; skrining

Introduction

Endometriosis is a chronic-inflammatory condition in women in which endometrial-like tissue of the uterus is found outside the uterine cavity.¹⁻³ Women of reproductive age affected by endometriosis is about 10-15%, with 50% of infertile women affected.^{1, 2, 4} Endometriosis is a common gynecological disorder.³

The pathogenesis of endometriosis is still unknown.⁵ One of the most accepted theory is Sampson's theory of retrograde menstruation, which postulates that endometrial cells or fragments refluxed via the fallopian tubes during menstruation onto abdominopelvic structures, is supported by a substantial body of evidence. The chance of having endometriosis is causally related to the total amount of sloughed endometrial and refluxed blood.⁶ The endothelium is located abnormally or heterotopically, resulting in inflammation and scarring in the organ where endometriosis attaches, which then causes pain during menstruation due to high levels of prostaglandins caused by menstrual blood.⁵

The diagnosis of endometriosis is challenging.⁷ Symptoms of endometriosis is very diverse because it has a wide range of severity. Pain can vary depending on where the endometriosis tissue is located. In general, the pain is dysmenorrhea, but it can also be painful urination, painful bowel movements, or pain during sexual intercourse.³ Definitive diagnosis of endometriosis is made by histologic findings from laparoscopy. However, the limitation of laparoscopy is surgical risks and the delay in diagnosis because it takes time for the patient to decide to seek medical help, be referred to a gynaecology specialist, and get the courage to do the operation.²

The diagnosis of endometriosis is often delayed as long as 11 years. The delay will prolong the morbidity of endometriosis.¹

^{2, 4} Endometriosis can affect the quality of life, mental well-being, social activity, relationships, infertility, and severity of the disease.^{1, 3, 8} Furthermore, symptoms of endometriosis are associated with reduced productivity either in work or in school, which effect reduced of income. Endometriosis has also become a national economic burden because of the loss of productivity and healthcare costs. The longer the delay, the longer the burden. Therefore, endometriosis needs early recognition, diagnosis, and treatment.^{1, 8-10}

The diagnosis and management of endometriosis have undergone several changes in recent years, with increasing focus on clinical diagnosis and early medical management.² Currently, most guidelines recommend nonsurgical diagnosis based on clinical symptoms, physical examinations, and imaging to reduce delay in treatment.³ Early diagnosis should obtained from symptoms and physical examination that indicate endometriosis, without laparoscopic examination. After early diagnosis, the patients are then referred for radiological examination. The most common radiological examinations used for endometriosis are transvaginal sonography and magnetic resonance imaging (MRI).²

Indonesian women are more likely to put a delay in seeking treatment for endometriosis. They believe that menstrual discomfort is something to be tolerated. To prevent delayed diagnosis of endometriosis, a screening tool is needed for early recognition and early diagnosis. Chapron et al. made a questionnaire to screen for endometriosis. From the questionnaire, scoring is carried out to determine the level of risk of endometriosis. The study reported that it has good specificity and sensitivity for screening endometriosis.¹¹ The aim of this study was to translate and develop a questionnaire in the Indonesian version, so we can do the screening in Indonesia using the questionnaire in Bahasa.

In addition, the validity and reliability of the questionnaire were tested.

Method

This descriptive research was carried out by taking respondents from endometriosis patients who sought treatment at a tertiary referral Hospital in Bandung, Indonesia. Data was collected on 34 respondents who were diagnosed with endometriosis at the gynecology polyclinic in October 2024, using a purposive sampling technique. Uma Sekaran et al. stated the minimum sample size for testing the validity and reliability of the questionnaire is 30 respondents.¹² We excluded the patient with malignancy, was pregnant, and refused to provide consent. Diagnosis is made through history taking, physical examination and ultrasound examination (transabdominal and/or transvaginal) carried out by an obstetric and gynaecology specialist. All respondents provided written consent before conducting the research. The questionnaire was filled out by respondents via Google Forms.

This study was using a questionnaire created by Professor Chapron, which he tested in France for endometriosis screening. This study developed the questionnaire in Indonesian then tested it for validity and reliability. Validity demonstrates how closely the question relates to the study question or the outcome you wish to measure. Reliability indicates the extent of consistency in the measurement amongst respondents or the extent to which the question is understandable enough to avoid causing varying interpretations.

Development of the questionnaire using 5 steps: translation, synthesis, back translation, expert committee review, and pretesting. We involved a language expert and a subject expert in the development and translation of the questionnaire. The questionnaire consists of 3 question sections,

namely the characteristic patient questions, 8 yes or no questions, and 5 pain scale questions. The characteristic patient questions are age, highest level of education, occupation, height, weight, menarche, and obstetric history. The pain scale questions use Visual Analogue Score (VAS), which is used to measure pain intensity (scale 0-10).¹³ VAS is explained by using both pictures (pain expressions) and a description of the severity of the pain. Description of pain scale we describe to the respondents are pain scale 0: no pain, pain scale 2: pain does not bother you, pain scale 4: pain interferes with concentration, pain scale 8: pain that interferes with meeting basic daily needs -day (bathing, sleeping, eating), up to a pain scale of 10: pain that requires complete rest.

Statistical analysis was carried out using SPSS version 26.0.¹⁴ The yes or no questions were dichotomous items, so validity and reliability calculations were performed using the point biserial correlation coefficient. According to Friedenberg, in validity test, the minimum correlation coefficient is 0.300. The higher the correlation approaching 1.00, the better the consistency (validity). The questions that have a correlation coefficient of less than 0.300 were not valid and excluded from the questionnaire. Meanwhile the reliability test is said to be reliable if the result of the Kuder-Richardson reliability coefficient is more than 0.600.¹⁵

Statistical analysis of the pain scale questions, which are Likert data, uses Pearson's Product Moment correlation. The questionnaire is considered valid if the calculated Pearson Product Moment correlation coefficient value is greater than 0.300. Meanwhile, the reliability test is said to be reliable if the reliability coefficient value is more than 0.600.

Result

The questionnaire in this study used 3 parts

of questions, including characteristic patient questions, yes or no questions, and pain scale questions. The characteristics of the patient can be seen in Table 1. The questionnaire has gone through validity and reliability tests. Of the eight yes or no questions, seven questions were valid with a correlation coefficient of more than 0.300 (Table 1). One question was not valid with a correlation coefficient of 0.118 ($r < 0.300$), so it was removed from the questionnaire. The question that was removed was the question about whether the mother experienced bleeding when defecating. Fortunately, this question was not used in Chapron et al.’s scoring for endometriosis screening. In the reliability test, according to Friedenberg, the correlation of seven questions was reliable, with Kuder-Richardson reliability coefficient value of 0.6968.

Table 1 Characteristic patients

Characteristic	N (%)
Age	
<20 years	0 (0)
20-35 years	21 (61.8)
>35 years	13 (38.2)
BMI	
Underweight	4 (11.8)
Normal	18 (52.9)
Overweight	12 (32.3)
Education	
Elementary	1 (2.9)
Junior high school	5 (14.7)
High School	10 (29.4)
Bachelor	17 (50.0)
Master	1 (2.9)
Occupation	
Housewife	17 (50.0)
Employee	11 (32.4)
Healthcare provider	3 (8.8)
Entrepreneur	3 (8.8)
Primary infertility	6 (17.6)

Table 2 Validity test of yes or no questions

Variables	Question number	Total item correlation (r) perception level	Significancy	Conclusion
Question number	1	0.458	0.300	Valid
	2	0.307	0.300	Valid
	3	0.593	0.300	Valid
	4	0.118	0.300	Not Valid
	5	0.367	0.300	Valid
	6	0.478	0.300	Valid
	7	0.361	0.300	Valid
	8	0.345	0.300	Valid

Table 3 Validity test of pain scale questions

Question	Question number	Total item correlation (r) perception level	Significancy	Conclusion
Question number	1	0.686	0.300	Valid
	2	0.690	0.300	Valid
	3	0.847	0.300	Valid
	4	0.649	0.300	Valid
	5	0.805	0.300	Valid

Table 4 Yes or no questions

No	Questions
1.	Apakah ada riwayat endometriosis (kista coklat) dalam keluarga Anda?
2.	Apakah ibu pernah mengalami kehamilan? Jika tidak, Apakah ibu menggunakan KB/alat kontrasepsi (seperti suntik, pil, kondom, senggama terputus, alat kontrasepsi dalam rahim, atau steril)? Apakah ibu sudah menikah >1 tahun? Jika Ya, Apakah Anda secara rutin melakukan hubungan intim dengan pasangan Anda?
3.	Apakah jarak antara periode menstruasi Anda yang satu denganyang berikutnya kurang dari 28 hari (secara teratur)?
4.	Apakah Anda mengalami perdarahan saat buang air besar?
5.	Apakah Anda mengalami frekuensi buang air kecil yang tergolong sering saat menstruasi?
6.	Apakah warna urin (air kencing) Anda berubah menjadi merah saat menstruasi?
7.	Apakah Anda mengalami nyeri perut saat menstruasi yang cukup mengganggu aktivitas sehari-hari, sehingga tidak dapat bekerja atau bersekolah?
8.	Apakah Anda mengalami nyeri perut saat menstruasi yang begitu parah sehingga menyebabkan pingsan?

Table 5 Pain scale questions

No.	Questions
1.	Berapakah skala nyeri perut yang Anda rasakan saat menstruasi?
2.	Berapakah skala nyeri yang Anda rasakan saat berhubungan seksual?
3.	<i>Berapakah skala nyeri yang Anda rasakan saat buang air besar selama menstruasi?</i>
4.	<i>Berapakah skala nyeri atau sensasi terbakar yang Anda rasakan saat buang air kecil selama menstruasi?</i>
5.	<i>Berapakah skala nyeri panggul kronis (berkepanjangan) yang Anda rasakan meskipun saat tidak menstruasi?</i>

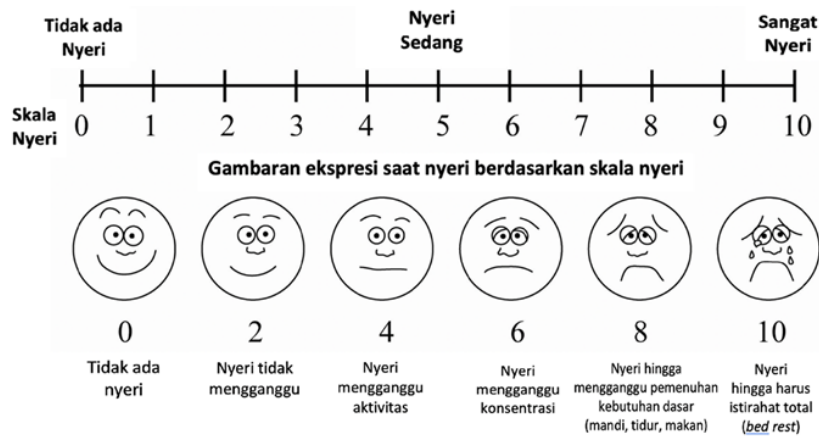


Figure 1 Explanation of pain scale

On the 5 pain scale questions, all questions were valid, with correlation coefficient >0.300 (table 3). The pain scale questions were also reliable with a Cronbach's Alpha value of 0.790, more than 0.600.

Based on the results of the validity and reliability tests, there were obtained 7 yes or no questions (Table 4), and 5 pain scale questions (Table 5). Explanation of the pain scale is done by explaining using both pictures and descriptions of the expression of pain that is felt (Figure 1).

Discussion

There are a lot of challenges in diagnosing endometriosis. Challenges in early diagnosis of endometriosis are the heterogeneity of endometriosis symptoms, unavailability of biomarkers for endometriosis, low sensitivity and specificity in clinical symptoms, and lack of public and physician attention to endometriosis. The common symptoms of endometriosis, such as pain, can be confused with other causes.²

Sampson postulated that endometriosis arises from endometrial tissue refluxing through the fallopian tubes during menstruation, followed by adhesion and implantation of the tissue, causing lesions in the organs it is attached to. Most women of reproductive age experience retrograde

menstruation, but the immune system often eliminates the endometrial tissue, stopping them from growing in ectopic locations. However, endometriosis develops when the immune system is unable to eliminate the fragments.^{16, 17} Progesterone resistance also plays a role in endometriosis by disrupting the control of uterine epithelial proliferation and preventing decidualization, significantly affects endometrial receptivity, which in turn affects implantation by changing the endometrium and influencing fertility.¹⁶

Endometrial tissue in the pelvic cavity during retrograde menstruation can cause ovarian and peritoneal illness, as well as inflammatory reactions, scarring, and fibrosis. The altered anatomy because of scarring and local inflammation, which affects oocytes and sperm motility, results in infertility.¹⁷ The inflammatory process, linked to macrophages and cytokine production, can impact ovulation, the quality of the embryo, and implantation.¹⁶

Symptoms of endometriosis is affected by cyclic changes.² The symptoms can vary and change over time.³ Endometriosis symptoms are often atypical and resemble symptoms caused by other gynecological, gastrointestinal, and urinary tract disorders. Therefore, the journey in diagnosing endometriosis is long and perplexing.¹⁸ Sometimes, endometriosis is found

accidentally in the surgery because the affected woman has no symptoms. The most common (90%) symptom of women with endometriosis is secondary dysmenorrhea, which is longer in duration and does not improve with non-steroid anti-inflammatory drugs (NSAID).³ The other common clinical presentations of endometriosis are dyspareunia, chronic pelvic pain, and infertility.² Endometriosis is found in 40-50% of women with chronic pelvic pain. As many as 30-40% of women with infertility suffer from endometriosis. Endometriosis alters the peritoneal environment and anatomy, which affects fertility. Difficulty in conceiving occurs in 30% of women with endometriosis.³ In deep endometriosis, endometrial tissue attaches to adjacent organs, causing symptoms depending on the organ it is attached to, such as painful bowel movement (dyschezia), bloody stool (hematochezia), dysuria, and hematuria. Symptoms begin during adolescence and diminish during menopause.³

Diagnosis of endometriosis is often delayed as long as 11 years.^{1, 2, 4} There are some barriers to the delayed diagnosis of endometriosis, including false belief, self-management of symptoms, and difficulty in diagnosing endometriosis. The perception that painful menstruation is normal, particularly during adolescence, contributes significantly to delays in diagnosing endometriosis.¹ One-third of young women with dysmenorrhea have endometriosis. They often do self-management of symptoms, delaying them from seeking medical advice. Physicians and non-gynaecology specialists also reported struggling to diagnose endometriosis symptoms because of the heterogeneity of endometriosis symptoms and the lack of appropriate guidelines for endometriosis.^{1, 19-21} Most women with endometriosis stated that they had seen a doctor 5 times or more before they were finally diagnosed with endometriosis and

then referred.²² We should make an effort to increase public awareness and to give enough knowledge and skills about clinical diagnosis of endometriosis to medical staff.

Routine laparoscopy as a diagnostic tool for endometriosis also causes delays in the diagnosis of endometriosis.¹⁸ Chapron et al. stated that laparoscopy for exploration should not be used to diagnose endometriosis. Instead diagnostic imaging can be used, such as transvaginal ultrasound and Magnetic Resonance Imaging (MRI). Then, medical treatment can be given to the affected women who do not desire immediate pregnancy, so that the affected women can get early treatment.¹⁰ However, referring all patients suspected of having endometriosis to do the diagnostic imaging is not possible. Early screening to select patients at higher risk of disease is necessary.²³

Endometriosis has a progressive nature, so early diagnosis can reduce morbidity, disease progression, adhesion formation, infertility, and pain. Early recognition should be done, so there is no delay in diagnosing endometriosis and early management can be given. It can reduce the morbidity of the affected women and reduce the national burden of endometriosis.¹⁸

There have been several studies examining screening tools to diagnose endometriosis. Chapron et al. created a scoring system through a questionnaire as a screening tool to sort out women at high risk of endometriosis, with high sensitivity and specificity.¹¹ Although there are many studies regarding screening tools for the diagnosis of endometriosis, there is still no routine screening for the clinical diagnosis of endometriosis.²⁴

Chapron et al. studied screening tools that are easy to use, and can be used even in first-level health care. The screening tool can recognize early high-risk women with endometriosis through a scoring system from the questionnaire.¹¹ Then, the high-

risk women were referred for imaging to further diagnose endometriosis. The sooner the diagnosis, the quicker the treatment, thus improving the quality of life of affected women.²⁵ We translate, develop, and test the validity and reliability of the Indonesian version of the questionnaire. In this research, a questionnaire asked about the symptoms commonly felt by endometriosis patients and the pain scale of the pain symptoms felt by the patient. With the help of linguists and subject experts, a questionnaire was developed and translated and then tested for validity and reliability, so that a valid and reliable questionnaire was formed after adjusting the questions in the questionnaire. We hope the Indonesian version of the questionnaire could be used as a screening tool for diagnosis in Indonesia.

The weakness of this study is that the respondents were taken from a small-scale research scope and in a short time. Further research is needed to assess the sensitivity and specificity of the Chapron et al.'s scoring from this Indonesian version questionnaire to assess the risk of endometriosis. This screening tool for diagnosing endometriosis using this questionnaire is expected to early recognize women with endometriosis when seeking treatment at first-level services, so that they can be diagnosed and treated early.

Conclusion

The diagnosis of endometriosis is challenging.⁷ The symptoms can be very diverse.³ Laparoscopy, as a definitive diagnosis, has some limitations, such as surgical risks and the delay in diagnosis.² The diagnosis of endometriosis is often delayed, so prolongs the morbidity of endometriosis.^{1,2,4} affect the quality of life, productivity, mental being, social activity, relationship, infertility, and severity of the disease.^{1, 3, 8} Therefore, endometriosis needs early recognition, diagnosis, and treatment.^{1, 8-10}

This study represents Professor Chapron's questionnaire for endometriosis screening in another language (Indonesian) than the original. It showed that the questionnaire was reliable, and one question was not valid (removed from the questionnaire). We hope this questionnaire can address the gap between the onset and diagnosis of endometriosis, which is usually delayed, through the early recognition of endometriosis. Being recognized sooner will lead to getting treatment quicker, so it will increase the quality of life and productivity of affected women, which will further decrease the national burden.

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