REGIONE AUTONOMA FRIULI VENEZIA GIULIA
ISTITUTO DI RICOVERO E CURA A CARATTERE SCIENTIFICO
Burlo Garofolo di Trieste

E.C.M.

IRCBG 19135

Endometriosi alle porte del nuovo decennio

13/12/2019

Auditorium Museo Revoltella – Via Diaz,27 – Trieste

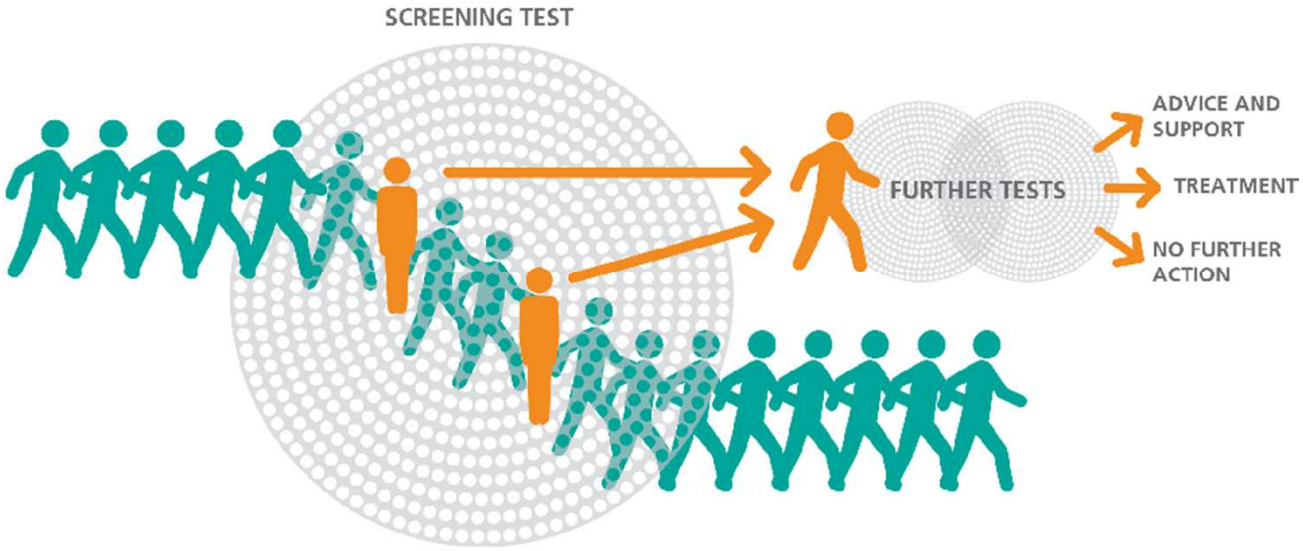
Programma:

08:30 – 08:40 **Saluti delle autorità**

Orario	Titolo
Prima sessione: IL PROBLEMA	***Discussant: F. Scrimin e F. Tomei***
08:40 – 09:00	**Epidemiologia dell'endometriosi -** L. Ronfani
09:00 – 09:20	**Il ruolo dell'Associazione Endometriosi FVG -** S. Manente
09:20 – 09:40	**Il dolore nell'endometriosi** – G. Di Lorenzo
09:40 – 10:00	**Fertilità ed endometriosi** – G. Zito
10:00 – 10:15	**L'esperto risponde: discussione con i partecipanti**
	10:15 – 10:30 COFFE BREAK
Seconda sessione: L'IDENTIFICAZIONE	***Discussant: M.Vanin e S. Facchin***
10:30 – 10:50	**Screening dell'endometriosi?** - A. Sartore
10:50 – 11:10	**Possibilità diagnostiche attuali nell'imaging –** F. Buonomo
11:10 – 11:30	**Prospettive diagnostiche nell'imaging –** S. Magnaldi
11:30 – 11:45	**L'esperto risponde: discussione con i partecipanti**

What is screening?

Process of identifying apparently healty people who may be **at increased risk** of a disease or condition



La parola *screening* in medicina indica un insieme di attività organizzate, rivolte a un'ampia quota della popolazione, per individuare precocemente la presenza di malattia in persone che non ne presentano ancora i sintomi. Identificare la patologia in una fase precoce permette possibilità di trattamento e guarigione (o comunque controllo) più alte. Per questo motivo, sia gli screening, sia le malattie da individuare e gli esami utilizzati, devono corrispondere a precise caratteristiche.

Quando lo screening è possibile

La malattia da individuare con lo screening deve essere **curabile** o, comunque, il suo decorso deve poter essere alterato grazie alla diagnosi precoce. Per una persona non c'è alcuna utilità nel ricevere una diagnosi anticipata della malattia se non si è in grado di migliorarne il decorso. Per questo gli screening condotti in Italia sono basati su solide prove scientifiche di efficacia e sono organizzati in "programmi di screening"

(…)

•rispettano le **prove scientifiche**. Tutti i passaggi all'interno degli screening sono effettuati secondo le indicazioni della ricerca scientifica, in base alla quale si determinano la popolazione su cui eseguire gli esami, gli esami da effettuare e gli iter terapeutici in caso di positività e l'intervallo tra due round successivi di screening.

How to create a screening knowing that:

- It has to be safe
- It has to be accepted
- It has the possibility to change the corse of the disease
- It has to have a sustainable cost for the community
- It has to be as reliable as possible

Numero Verde
800-219992

Per maggiori informazioni consulta
www.quellochenonsodime.it - www.ministerosalute.it

QUELLO CHE NON SO DI ME

Endometriosi
quello che non so di me.

Quello che non so di me...

Quello che SO DI ME è che soffro spesso di dolori mestruali, di un dolore al basso addome, di disturbi ciclici urinari o intestinali e di dolori durante i rapporti sessuali.

Quello che NON SO DI ME è che questi potrebbero essere i sintomi di una malattia molto diffusa ma poco nota: l'endometriosi.

Quello che non so di me...
lo posso conoscere.

Presta attenzione ai sintomi, consulta il tuo medico o il tuo ginecologo.

LINEE GUIDA
SULLA DIAGNOSI E TRATTAMENTO DELL'ENDOMETRIOSI

RACCOMANDAZIONI

Introduzione

L'endometriosi si riscontra nel 10% circa delle donne in età fertile. E' una malattia benigna cronica e ricorrente, caratterizzata dalla presenza e dalla proliferazione di tessuto endometriale al di fuori della cavità uterina. Il tessuto endometriosico è estrogeno-dipendente e va incontro a processi infiammatori acuti e cronici che coinvolgono più organi, non solo pelvici. L'ormono-dipendenza giustifica la regressione della malattia endometriosica con la menopausa o negli stati di amenorrea. La patologia ha un impatto notevole sulla qualità di vita, sia per l'aspetto sintomatologico (dismenorrea, dispareunia, dolore pelvico cronico, disuria, dischezia), sia per il potenziale impatto negativo sulla fertilità) (*Giudice, 2010*).

Is a screening possible for a disease such as endometriosis that

- Interests 10% of women

- Has a broad of different form of manifestation

- Is diagnosed only with histology

Diagnosis on the basis of symptoms alone can be difficult

- the presentation is so variable
- there is considerable overlap with other conditions such as irritable bowel syndrome and pelvic inflammatory disease

→ there is often a **delay of several years** between symptom onset and a definitive diagnosis

(Hadfield et al., 1996; Arruda et al., 2003; Husby et al., 2003)

Symptoms of endometriosis based on clinical and patient experience:

- severe dysmenorrhoea
- deep dyspareunia
- chronic pelvic pain
- ovulation pain
- cyclical or perimenstrual symptoms with or without abnormal bleeding
- infertility
- chronic fatigue
- nausea

However each of these symptoms can have other causes, and a significant proportion of affected women are asymptomatic

Original Research ajog.org

GYNECOLOGY

Spectrum of symptoms in women diagnosed with endometriosis during adolescence vs adulthood

Amy D. DiVasta, MD, MMSc; Allison F. Vitonis, SM; Marc R. Laufer, MD; Stacey A. Missmer, ScD

BACKGROUND: Endometriosis symptoms often start at a young age, and the time between symptom onset and endometriosis diagnosis can be several years. It is not clear whether the symptoms that are experienced by adolescents differ from adults. Better understanding may shorten the often lengthy delay in diagnosis.

OBJECTIVE: The purpose of the study was to further elucidate the symptom presentation of adolescents as compared with adults to determine whether differences existed, based on age at surgical diagnosis that could impact time to diagnosis.

STUDY DESIGN: This investigation was a cross-sectional study at enrollment within a longitudinal cohort of adolescents and women with endometriosis. The population-based cohort was recruited from 2 tertiary care centers and the surrounding communities. Participants included adolescents (diagnosed at ≤18 years old; n=295) and adults (diagnosed at >18 years old; n=107) with surgically confirmed endometriosis who were enrolled into The Women's Health Study: From Adolescence to Adulthood. Participants completed an expanded version of the World Endometriosis Research Foundation Endometriosis Phenome and Biobanking Harmonization Project standard clinical questionnaire that included items regarding menstrual history, associated symptoms, and pain. Chi-square or Fisher's exact tests were applied to categoric data; Wilcoxon rank sum tests were applied to continuous data.

RESULTS: Most participants (90%) experienced moderate-severe menstrual pain. On average, 3 doctors were seen before diagnosis, regardless of age at presentation (range, 0-25 years). Time from symptoms to diagnosis averaged 2 years for adolescents and 5 years for adults ($P<.001$). More adolescents (50%) than adults (33%) reported pain starting at menarche ($P=.002$) and nausea accompanying pain (69% vs 53%; $P=.01$). Noncyclic, general pelvic pain was prevalent. One-half of the participants reported relief of their general pelvic pain after a bowel movement. Pain interfered with work/school, daily activities, exercise, and sleep to a moderate-extreme degree; difficulties were similar by age at diagnosis.

CONCLUSIONS: Pelvic pain was severe and noncyclic and negatively impacted quality of life. At our tertiary care centers, symptoms of endometriosis did not differ between women surgically diagnosed during adolescence compared with those diagnosed as adults. Adolescents had more nausea and symptom onset at menarche. Multi-year delays in diagnosis were common. Clinicians should be aware of these alternate symptom patterns and include endometriosis in their differential diagnosis for both adolescent and young adult women who experience noncyclic pelvic pain and nausea.

Key words: adolescents, diagnosis, endometriosis, pelvic pain

Cite this article as: DiVasta AD, Vitonis AF, Laufer MR, et al. Spectrum of symptoms in women diagnosed with endometriosis during adolescence vs adulthood. Am J Obstet Gynecol 2018;218:324.e1-11.

Clinical Expert Series CME

Clinical Management of Endometriosis

Tommaso Falcone, MD, and Rebecca Flyckt, MD

(Obstet Gynecol 2018;0:1–15)

INCIDENCE AND EPIDEMIOLOGIC FACTORS

This enigmatic disease is influenced by multiple genetic, environmental, and epidemiologic factors. It affects 6–10% of reproductive-aged women and has been found in premenarchal and postmenopausal women. The average age at diagnosis is approximately 28 years. Several conditions show greater concordance with endometriosis. For example, endometriosis is present in 21–47% of women presenting with subfertility[2] and 71–87% of those with chronic pelvic pain.[3] Early menarche, short menstrual cycle

Management of women with endometriosis

Guideline of the European Society of Human Reproduction and Embryology

ESHRE Endometriosis Guideline Development Group

September 2013

Management of women with endometriosis

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7. PREVENTION OF ENDOMETRIOSIS

Introduction

Primary prevention is aimed at protecting healthy, asymptomatic women from developing endometriosis.

Since the cause of endometriosis is unknown, the potential of primary prevention is limited. One of the risk factors for endometriosis seems to be having a first-degree family member with the disease, although the specific genetic origin of this association is still unknown. The increased disease prevalence which has been found in first-degree relatives of women with endometriosis results in questions from patients and family members on how they can prevent the development of endometriosis. Therefore, we performed a literature search for interventions that could influence the development of endometriosis, although not specifically for women with increased risk for endometriosis. However, interventions for prevention of disease development could be beneficial for these women as well.

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Key question

IS THERE A ROLE FOR PRIMARY PREVENTION OF ENDOMETRIOSIS?

Recommendations

The usefulness of oral contraceptives for the primary prevention of endometriosis is uncertain (Vercellini, et al., 2011).	C

The usefulness of physical exercise for the primary prevention of endometriosis is uncertain (Vitonis, et al., 2010).	C

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SCREENING?

CONTENTS

Recommendations

The GDG recommends that clinicians should consider the diagnosis of endometriosis in the presence of gynecological symptoms such as: dysmenorrhea, non-cyclical pelvic pain, deep dyspareunia, infertility, fatigue in the presence of any of the above.	GPP
The GDG recommends that clinicians should consider the diagnosis of endometriosis in women of reproductive age with non-gynecological cyclical symptoms (dyschezia, dysuria, hematuria, rectal bleeding, shoulder pain).	GPP

BMJ

BMJ 2014;348:g1752 doi: 10.1136/bmj.g1752 (Published 19 March 2014)

CLINICAL REVIEW

Endometriosis

Martha Hickey *professor of obstetrics and gynaecology*[1], Karen Ballard *senior lecturer in women's health* [2], Cindy Farquhar *professor of obstetrics and gynaecology*[3]

Endometriosis should be suspected in women with persistent pelvic pain that interferes with normal life and that has poorly responded to hormonal suppression (combined oral contraceptive), or where there is dyspareunia, pain with bowel opening (not relieved by defecation as in irritable bowel syndrome) or pain on micturition, lower back pain that is not from other conditions such as urinary tract infection or musculoskeletal pain. Pelvic examination might reveal nodules, masses, and tenderness that can be suggestive of endometriosis

Transvaginal ultrasonography can identify ovarian endometriotic cysts

CA 125 levels, magnetic resonance imaging, and computed tomography are not recommended as initial investigations but might be of value as part of investigations before surgery

Cochrane Library

Cochrane Database of Systematic Reviews

Blood biomarkers for the non-invasive diagnosis of endometriosis (Review)

Nisenblat V, Bossuyt PMM, Shaikh R, Farquhar C, Jordan V, Scheffers CS, Mol BWJ, Johnson N, Hull ML.

Blood biomarkers for the non-invasive diagnosis of endometriosis.

Cochrane Database of Systematic Reviews 2016, Issue 5. Art. No.: CD012179.

DOI: 10.1002/14651858.CD012179.

Background

About 10% of reproductive-aged women suffer from endometriosis, a costly chronic disease causing pelvic pain and subfertility. Laparoscopy is the gold standard diagnostic test for endometriosis, but is expensive and carries surgical risks. Currently, there are no non-invasive or minimally invasive tests available in clinical practice to accurately diagnose endometriosis. Although other reviews have assessed the ability of blood tests to diagnose endometriosis, this is the first review to use Cochrane methods, providing an update on the rapidly expanding literature in this field.

Main results

We included 141 studies that involved 15,141 participants and evaluated 122 blood biomarkers. All the studies were of poor methodological quality. Studies evaluated the blood biomarkers either in a specific phase of the menstrual cycle or irrespective of the cycle phase, and they tested for them in serum, plasma or whole blood. Included women were a selected population with a high frequency of endometriosis (10% to 85%), in which surgery was indicated for endometriosis, infertility work-up or ovarian mass. Seventy studies

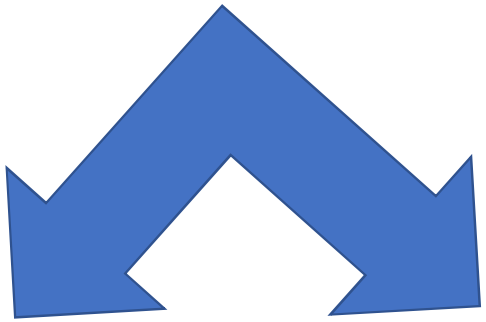
Authors' conclusions

Of the biomarkers that were subjected to meta-analysis, none consistently met the criteria for a replacement or triage diagnostic test. A subset of blood biomarkers could prove useful either for detecting pelvic endometriosis or for differentiating ovarian endometrioma from other benign ovarian masses, but there was insufficient evidence to draw meaningful conclusions. Overall, none of the biomarkers displayed enough accuracy to be used clinically outside a research setting. We also identified blood biomarkers that demonstrated no diagnostic value in endometriosis and recommend focusing research resources on evaluating other more clinically useful biomarkers.

Article

Case–control study to develop and validate a questionnaire for the secondary prevention of endometriosis

DISEGNO DELLO STUDIO



SVILUPPO DEL QUESTIONARIO

REVISIONE DELLA LETTERATURA PER IDENTIFICARE:

- ***FATTORI DI RISCHIO***
- ***SINTOMI***
- ***TRATTI FENOTIPICI***

STUDIO CASO-CONTROLLO

QUESTIONARIO

Clinica Ginecologica
Trieste

Paziente _____ Data _____

L'endometriosi è una malattia cronica, insidiosa, da molti misconosciuta; colpisce soprattutto le donne in età riproduttiva, ma anche le giovanissime.
Per molti aspetti è una malattia ancora incompresa, ma può avere importanti ripercussioni sulla qualità della vita delle donne affette.
Può rimanere silente per molti anni, fino a quando la donna scopre di non poter avere figli, o può manifestarsi con sintomi che spesso non vengono associati alla malattia.
Disporre di uno strumento per identificare le donne ad alto rischio è la chiave per arrivare ad una diagnosi precoce ed essere incisivi nel trattamento. È questo l'obiettivo del questionario.

La ringraziamo per il Suo tempo e raccomandiamo la massima attenzione nella compilazione.

Ha mai sentito parlare di endometriosi?

Si ☐
No ☐

Se si, come definirebbe la sua conoscenza della malattia?

Completa ☐
Parziale ☐

Conosce i sintomi di questa malattia?

Si ☐
No ☐

È a conoscenza del fatto che l'endometriosi può colpire anche donne molto giovani?

Si ☐
No ☐

ANAMNESI FISIOLOGICA

1. Indichi la sua età in anni compiuti:
____anni

2. Qual è il suo peso attuale?
____Kg

3. Quanto è alta?
____m

4. Il suo gruppo sanguigno è Rh + o -?

____

Non lo so ☐

5. Quante porzioni di frutta e/o verdura consuma in media nell'arco di una giornata?
____porzioni

6. Quante porzioni di carne rossa o prosciutti/insaccati consuma in media settimanalmente?
____porzioni

ANAMNESI FAMILIARE

7. Sua madre ha mai sofferto di endometriosi?

Sì ☐
No ☐

8a. Ha sorelle?

Sì ☐
No ☐

8b. Se sì, hanno mai sofferto di endometriosi?

Sì ☐
No ☐

ANAMNESI PATOLOGICA REMOTA

9a. È allergica a qualcosa?

Si ☐
No ☐

9b. Se sì, che tipo di allergia ha?

Allergia alimentare ☐ A_____
Allergia da contatto ☐ A_____
Allergia inalatoria ☐ A_____
Allergia farmacologica ☐ A _____

10. Ha mai sofferto di asma?

Si ☐
No ☐

11. Le è mai stata diagnosticata una delle seguenti patologie?
Se sì, specifichi quale e a quale età.

Si
Lupus eritematoso sistemico ☐ All'età di ____ anni
Artrite reumatoide ☐ All'età di ____ anni
Sindrome di Sjogren ☐ All'età di ____ anni
Sclerosi multipla ☐ All'età di ____ anni
Celiachia ☐ All'età di ____ anni
Tiroidite autoimmune ☐ All'età di ____ anni

No ☐

12. Ha mai sofferto di acne severa in adolescenza (ovvero brufoli o foruncoli in viso tali da spingerla a richiedere un consulto medico)?

Si ☐
No ☐

13. Ha mai sofferto di emicrania (ovvero attacchi di mal di testa ricorrenti che necessitano di ricorso a farmaci)?

Si ☐
No ☐

CARATTERISTICHE FENOTIPICHE

14. Come descriverebbe il suo colore naturale di capelli all'età di 18-20 anni?

- [ ] Rosso
- [ ] Biondo
- [ ] Marrone chiaro
- [ ] Marrone scuro
- [ ] Nero

15. Come descriverebbe il suo colore di occhi?

- [ ] Azzurro-grigi
- [ ] Verde-nocciola
- [ ] Marrone-nero

16. Come descriverebbe la sua carnagione?

- [ ] Molto chiara
- [ ] Chiara
- [ ] Media
- [ ] Scura
- [ ] Molto scura

17. Ha nei?

- [ ] Moltissimi
- [ ] Molti
- [ ] Pochi
- [ ] Nessuno

18. Ha lentiggini?

- [ ] Molte
- [ ] Poche
- [ ] Nessuna

19. Come descriverebbe la sensibilità della sua pelle al sole in seguito alla prima esposizione estiva?

- [ ] Alta
- [ ] Moderata
- [ ] Nessuna

Se le è stata diagnosticata l'endometriosi le domande seguenti si riferiscono al periodo PRECEDENTE all'inizio della terapia medica o chirurgica per tale patologia, ovvero al periodo di malattia. Se è attualmente incinta le domande seguenti si riferiscono al periodo PRECEDENTE la gravidanza.

SINTOMI GASTROINTESTINALI

20. Negli ultimi 3 mesi quanto spesso ha avuto fastidi o dolori in una qualsiasi parte dell'addome (escludendo i dolori pelvici mestruali)?

- ☐ Mai
- ☐ Meno di un giorno al mese
- ☐ 1 giorno al mese
- ☐ 2-3 gg al mese
- ☐ 1 giorno a settimana
- ☐ Più di 1 gg a settimana
- ☐ Ogni giorno

21. Negli ultimi 3 mesi quanto spesso è stata costipata (ovvero è andata in bagno meno di 3 volte a settimana?)

- ☐ Mai
- ☐ A volte
- ☐ La maggior parte delle volte
- ☐ Sempre

22. Negli ultimi 3 mesi quanto spesso ha avuto senso di gonfiore addominale o meteorismo?

- ☐ Mai
- ☐ Meno di un giorno al mese
- ☐ 1 giorno al mese
- ☐ 2-3 gg al mese
- ☐ 1 giorno a settimana
- ☐ Più di 1 gg a settimana
- ☐ Ogni giorno

23. Ha mai avuto difficoltà a trattenere le feci?

- ☐ Si
- ☐ No

24. Ha mai provato la sensazione di defecazione incompleta?

- ☐ Si
- ☐ No

SINTOMI URINARI

25. Ha mai avuto la sensazione di svuotamento non completo della vescica dopo la minzione?

- ☐ Mai
- ☐ 1 volta su 5
- ☐ Meno della metà delle volte
- ☐ Più della metà delle volte
- ☐ Quasi sempre

26. Le è mai capitato di tornare ad urinare entro 2 ore dalla precedente minzione?

- ☐ Si
- ☐ No

27. Ha mai avuto difficoltà nel rimandare la minzione?

- ☐ Mai
- ☐ 1 volta su 5
- ☐ Meno della metà delle volte
- ☐ Più della metà delle volte
- ☐ Quasi sempre

28. Quante volte si sveglia per urinare durante la notte?

- ☐ Mai
- ☐ 1 volta
- ☐ 2 volte
- ☐ 3 volte
- ☐ 4 volte
- ☐ 5 volte

Per le domande 29 e 30: in assenza di chiari sintomi di cistite batterica.

29. Ha mai avuto dolore o fastidio durante la minzione?

- ☐ Mai
- ☐ 1 volta su 5
- ☐ Meno della metà delle volte
- ☐ Più della metà delle volte
- ☐ Quasi sempre

30. Quanto spesso ha o ha avuto dolore una volta terminato di urinare?

- ☐ Mai
- ☐ 1 volta su 5
- ☐ Meno della metà delle volte
- ☐ Più della metà delle volte
- ☐ Quasi sempre

31. Quando ha le mestruazioni le sembra che urinare sia più doloroso rispetto a quando non ha le mestruazioni?

- ☐ Si
- ☐ No

ANAMNESI GINECOLOGICA

32. A quanti anni ha avuto la prima mestruazione?
____ anni

33a. Hai mai usato contraccettivi ormonali (pillola, cerotto, iniezioni)?

Si ☐
No ☐

33b. Se sì per quale motivo ha iniziato ad usarli?

Contraccezione ☐
Regolarizzazione del ciclo ☐
Dolori mestruali ☐
Acne/policistosi ovarica ☐
Sincronizzazione del ciclo per FIVET ☐
Altro (specificare) ☐

34a. Attualmente è incinta?

Si ☐
No ☐

34b. Ha mai avuto aborti?

Si ☐
No ☐

34c. Se si, che tipo di aborti?

Aborto spontaneo ☐
Interruzione Volontaria di Gravidanza ☐

34d. Se la gravidanza è andata a buon fine, indichi la modalità del parto:

Parto spontaneo ☐
Taglio cesareo ☐

35. Ha cicli regolari di norma (tra due mestruazioni successive passa sempre lo stesso periodo di tempo)?

Si ☐
No ☐

36. Qual è la durata media dei suoi cicli mestruali (quanti giorni passano tra l'inizio di una mestruazione e l'inizio di quella successiva)?

Meno di 28 giorni ☐
28-34 giorni ☐
Più di 34 giorni ☐
Ho il ciclo troppo irregolare per dirlo ☐

37. Come definirebbe di norma il suo flusso mestruale?

Scarso ☐
Moderato ☐
Abbondante ☐
Non saprei ☐

38. Quanti giorni dura il suo flusso mestruale? (si intende la durata del sanguinamento che richiede tamponi e assorbenti, non perdite per le quali è sufficiente il salvaslip)
____ giorni

È troppo irregolare per dirlo ☐

39. Come descriverebbe mediamente il dolore durante la mestruazione?

nessun dolore ☐
crampi lievi che non richiedono l'assunzione di farmaci ☐
crampi lievi che solo saltuariamente richiedono l'assunzione di farmaci ☐
crampi moderati che di solito richiedono l'assunzione di farmaci ☐
crampi gravi che necessitano sempre dell'assunzione di farmaci e di riposo assoluto ☐

40a. Il dolore durante la mestruazione (se non controllato da farmaci) le ha mai impedito di andare a scuola o al lavoro o di portare avanti le sue regolari attività quotidiane?

Si ☐
No ☐

40b. Se sì ogni quanto spesso le è capitato di dover restare a casa a causa del dolore?

Ad ogni mestruazione ☐
In più della metà delle mestruazioni ☐
In meno della metà delle mestruazioni ☐

Per le donne con diagnosi di endometriosi ci si riferisce al periodo di malattia.

41. Come descriveresti la defecazione durante la mestruazione?

Mai dolorosa ☐
Moderatamente dolorosa ☐
Molto dolorosa ☐

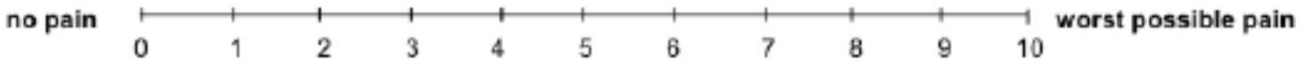
42a. Negli ultimi 3 mesi ha avuto rapporti sessuali?

Sì ☐
No, vada alla domanda 43 ☐

42b. Se sì, ha mai avuto dolore durante un rapporto sessuale?

Mai ☐
Occasionalmente (meno di 1 volta su 4) ☐
Spesso (circa metà delle volte) ☐
Sempre ☐

42c. Indica nella scala seguente (ove 0 sta per nessun dolore e 10 per il peggior dolore possibile) come descriveresti il dolore che hai provato durante i rapporti negli ultimi 3 mesi



43a. Ha mai sofferto di dolore pelvico per più di 6 mesi al di fuori della mestruazione (con dolore pelvico si intende un dolore dall'ombelico in giù)?

Sì ☐
No ☐

43b. Se sì quanto tempo è durato?

6 mesi-1 anno ☐
1-2 anni ☐
più di 2 anni ☐

STUDIO CASO- CONTROLLO

CASI n=51

Pazienti con diagnosi LPS di endometriosi afferite al centro PMA della Clinica Ginecologica di Trieste

CONTROLLI n=100

Pazienti nel I trimestre di gravidanza (concepimento spontaneo) afferite al centro di diagnosi prenatale della Clinica Ginecologica di Trieste senza storia suggestiva per endometriosi e senza evidenza ecografica di malattia endometriosica

Criteri di esclusione

Pazienti con patologie infiammatorie intestinali croniche

Pazienti straniere con difficoltà linguistiche

RISULTATI

	Cases (n = 51)			Controls (n = 100)				
	mean (sd)	median	IQR	mean (sd)	median	IQR	p*	
Age (years)	36.9 (4.5)	38	34-40	34.2 (4.7)	33	30-38	0.0006	
Weight (kg)	62.8 (10.6)	62	56-66	60.2 (7.8)	58	54-64	0.10	
Height (m)	1.67 (0.6)	1.66	1.63-1.71	1.65 (0.1)	1.65	1.60-1.69	0.15	

Variables significantly associated with endometriosis (bivariate analysis)

Variables	Cases (n = 51)	Controls (n = 100)	OR	95% CI	P
Age	36.9 ± 4.4	34.2 ± 4.7			0.006
Allergies					
Food	5(10%)	0 (0%)	23.8	1.3 – 439	0.033
Drugs	9 (18%)	4 (4%)	4.8	1.5 -15.6	0.009
Acne	15 (29%)	14 (14%)	2.5	1.1– 5.7	0.025
Hair color: red - blond	1(2%)	19(19%)	0.12	0.02 – 0.68	0.016
Abdominal pain > 2-3 day/month	34 (67%)	16 (16%)	10.1	4.8 – 23.1	0.000
Chronic constipation	15 (29%)	0 (0%)	85.4	5.0 – 1463.2	0.002
Meteorism > 1 day/week	18 (35%)	14 (14%)	3.3	1.5 – 7.3	0.003
Urgency in defecation	6 (12%)	0 (0%)	28.7	1.6 – 520.7	0.0023
Incomplete defecation	25 (49%)	26 (26%)	2.7	1.3 – 5.6	0.005
Urgency in urination > 1 time on 5	14 (27%)	7 (7%)	4.8	1.8 – 12.6	0.001
Dysuria > 1 time on 5					
During urination	11 (22%)	3 (3%)	7.9	2.3 – 27.6	0.001
At the end of urination	9 (18%)	2 (2%)	8.8	2.1 – 37.1	0.003
Painful urination during menstruation	15 (29%)	1 (1%)	41.25	5.2 – 323.6	0.000
Taking the pill for dysmenorrhea	19 (44%)	4 (6%)	17.8	5.3 – 59.8	0.000
Successful pregnancies	15 (29%)	49 (49%)	0.43	0.21 – 0.88	0.023
Heavy menstrual flow	27 (53%)	24 (24%)	3.8	1.8 – 8.0	0.000
Short cycle length	28 (55%)	28 (28%)	3.4	1.6 – 7.2	0.001
Cramps during the menstrual cycle which require the assumption of drugs	43 (68%)	20 (20%)	21.5	8.7 – 52.9	0.000
Dyspareunia (VAS ≥ 3)	36 (71%)	10 (10%)	20.3	8.5 – 48.6	0.000
Occasional (less than once every four intercourses)	13 (25%)	17 (17%)	4.5	1.8 – 11.3	0.001
Recurrent (about half the time)	14 (27%)	4 (4%)	19.0	5.7 – 63.3	0.000
Always	11 (22%)	0 (0%)	135.4	7.5 - 2436	0.001
Painful defecation	26 (51%)	2 (2%)	51.0	11.3 – 229.3	0.000
Pelvic pain that lasts longer than six months	18 (35%)	0 (0%)	111.0	6.5 – 1892.5	0.0001

Non statistical significant variables

associated with endometriosis

(bivariate analysis)

Variables	Cases (n = 51)	Controls (n = 100)	P
Weight (kg)	62.8 ± 10.6	60.2 ±7.8	0.10
Height (m)	1.67 ± 0.6	1.65 ± 0.1	0.15
Rhesus Factor	10/49 (20%)	14/94 (15%)	0.48
Portions fruit/vegetables	2.3 ± 1.1	2.5 ± 1.3	0.35
Portions meat/sausages	2.5 ± 1.3	2.7 ± 1.6	0.45
Mother affected	3/51 (6%)	3/100 (3%)	0.40
Sister affected	1/26 (4%)	2/56 (4%)	1.00
Asthma	3/51(6%)	10/100 (10%)	0.54
SLE	1/51(2%)	0/100 (0%)	0.33
Rheumatoid arthritis	0/51(0%)	1/100 (1%)	1.00
Coeliac disease	2/51 (4%)	3/100 (3%)	1.00
Autoimmune thyroiditis	7/51 (14%)	11/100 (11%)	0.61
Migraine	24/51 (47%)	37/100 (37%)	0.29
Eyes color			
Blue-gray	13/51 (25%)	33/100 (33%)	0.34
Green-hazelnut	16/51 (31%)	22/100 (22%)	0.61
Complexion			
Pale	6/51 (12%)	13/100 (13%)	0.92
Fair	20/51 (39%)	45/100 (45%)	0.95
Cutaneous nevus			
A lot	12/51 (24%)	11/100 (11%)	0.91
Many	16/51 (31%)	37/100 (37%)	0.55
Freckle			
Many	5/51 (10%)	10/100 (10%)	0.85
Sun sensitivity			
High	21/51 (41%)	40/100 (40%)	0.34
Incomplete emptying bladder>1-2 times	3/51 (6%)	0/100 (0%)	0.079
Urination within 2 h from previous	29/51(57%)	66/100 (66%)	0.29
Menarche early	Mean age 12.4 (sd 1.5)	Mean age 12.8 (sd 1.6)	0.075
Miscarriages	15/51 (29%)	36/100 (36%)	0.47
Spontaneous abortions	15/51 (29%)	26/100 (26%)	0.70
Regular cycle	43/51 (84%)	74/100 (74%)	0.21

Firth multivariate logistic model resulting from a stepdown procedure

Variables	Regression Coefficients	Odds Ratios	95% CI	P
Chronic pelvic pain	4.350162	77.5	3.4 – 1746.6	0.006
Dyspareunia (VAS ≥ 3)	2.731929	15.4	5.2 – 45.3	0.000
Painful defecation	2.619159	13.7	2.4 – 78.7	0.003
Acne	1.356307	2.4	1.2 – 13.1	0.029

Table 3 Characteristics of identified studies and measures

References	Population and country	Type of tool	Brief
Endometriosis studies			
Fornun et al. [17]	$N = 104$ Consecutive women with ≥2 years of subfertility undergoing laparoscopy and tubal hydrotubation United Kingdom	Patient-completed questionnaire	Diffe wit enc resp sym que
Fasciani et al. [18]	$N = 120$ Women referred for chronic pelvic pain or infertility or with clinical suspicion of endometriosis Mean age 36–38 years Italy	Endometriosis Index based on patient pain evaluation, physician consultation, and diagnostic evidence	Predi wo infi enc 38 Softv usi
Yeung et al. [19]	$N = 90$ Women attending a tertiary referral center reporting endometriosis-associated chronic pelvic pain (>6 months) Age range 13–55 years (mean age 28.9–30.4 years) United States	Predictive mathematical model for early stage endometriosis	Phys cha his life pre Final fac cor
Eskenazi et al. [20]	$N = 90$ Women scheduled to undergo laparoscopy or	Patient interviews and noninvasive diagnostic procedures	Predi dia san stru

Table 3 continued

References	Population and country	Type of tool	Brief description
Calhaz-Jorge et al. [21]	$N = 1079$; $N = 488$ with endometriosis; $N = 591$ without endometriosis Consecutive subfertile women undergoing diagnostic or therapeutic laparoscopy Mean age 31 years Portugal	Predictive mathematical model	Predictors of endometrios subfertile women sched laparoscopy using logist regression to evaluate w medical history could p presence of endometrio Standard interviewer-adm questionnaire collected demographic characteris medical history variable
Ballard et al. [22]	$N = 185$ Women undergoing laparoscopy for chronic pelvic pain Mean age 32 years United Kingdom	Patient-completed questionnaire	Investigation of whether dimensions of chronic p are useful in the diagno endometriosis 40 pain descriptors for thr aspects of pain: (1) des pain, (2) anatomical are and (3) intensity of pair
Hackethal et al. [23]	$N = 69$ Women presenting with suspected or known endometriosis Mean age 32.7 years Germany	Patient-completed questionnaire	Prospective, preoperative, 34-item questionnaire r history of endometriosis history, allergies and ot illnesses, family history pregnancy, hormone tre menstrual history, and analog scales for comm symptoms of endometri
Nnoaham et al. [24]	$N = 1396$ Women undergoing diagnostic laparoscopy for symptoms of dysmenorrhea, dyspareunia, nonmenstrual pelvic pain, menstrual dyschezia, or infertility Age range 18–45 years (mean age 31.0–32.4 years) 13 countries	Predictive symptom-based model	Multiple logistic regressio predict the likelihood o endometriosis on laparo women with pelvic pain infertility Variables included the W WHSS[a], as well as med obstetric, and family his intensity and frequency pain; and sociodemogra lifestyle, and physical a Independent validation w conducted via ROC cur

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REVIEW

Patient-completed or symptom-based screening tools for endometriosis: a scoping review

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Abstract

Purpose The objective of this review was to evaluate existing patient-completed screening questionnaires and/or symptom-based predictive models with respect to their potential for use as screening tools for endometriosis in adult women. Validated instruments were of particular interest.

Methods We conducted structured searches of PubMed and targeted searches of the gray literature to identify studies reporting on screening instruments used in endometriosis. Studies were screened according to inclusion and exclusion criteria that followed the PICOS (population, intervention, comparison, outcomes, study design) framework.

Results A total of 16 studies were identified, of which 10 described measures for endometriosis in general, 2 described measures for endometriosis at specific sites, and 4 described measures for deep-infiltrating endometriosis. Only 1 study evaluated a questionnaire that was solely patient-completed. Most measures required physician, imaging, or laboratory assessments in addition to patient-completed questionnaires, and several measures relied on complex scoring. Validation for use as a screening tool in adult women with potential endometriosis was lacking in all studies, as most studies focused on diagnosis versus screening.

Conclusions This literature review did not identify any fully validated, symptom-based, patient-reported questionnaires for endometriosis screening in adult women.

Keywords Endometriosis · Patient-reported · Screener · Self-administered · Symptoms

Introduction

Endometriosis is a painful, inflammatory condition characterized by the development of endometrial-like tissue outside the uterus [1]. Endometriotic lesions may occur at various anatomic sites, including the pelvic peritoneum and the ovary [2]. Deep-infiltrating endometriosis occurs in the pelvic structures below the surface of the peritoneum. More rarely, endometriosis lesions of the bladder, ureter, or extrapelvic sites may also occur [2].

An estimated 10% of women of reproductive age are affected by endometriosis [3]. Endometriosis causes considerable clinical, economic, and humanistic burden. Clinical symptoms include chronic pelvic pain, dysmen-

	Clinical utility	Assessment of performance and validation
ors that ir e the	Includes some core concepts, but a woman could screen "positive" for possible endometriosis by checking 3 of the nonsymptom items	Performance and validation not reported
it ible	Enables patients to self-evaluate and efficiently document endometriosis symptoms and to report alarming symptoms Information to evaluate its clinical utility is currently limited	Performance and validation not reported
os to of e., tin, l nea)	Potentially a useful measure to diagnose site-specific endometriosis, but utility for detecting endometriosis in the general population may be limited	Apareunia and nausea or abdominal bloating were particularly strong markers for rectovaginal disease with a predictive prevalence of 87 and 89%, respectively Validation not reported
ess d	Potentially a useful measure to diagnose site-specific endometriosis, but utility for detecting endometriosis in the general population may be limited	Excellent diagnostic accuracy for bladder endometriosis in a population with a high suspicion of bladder involvement Area under the ROC curve was 0.951, and the optimal cutoff was 9 (93% sensitivity, 88% specificity) Validation not reported
nen y or ing	Painful defecation during menses was the strongest predictor of posterior DIE No items evaluating dysmenorrhea correlated with the presence of posterior DIE Further validation would be required to evaluate clinical utility	Area under the ROC curve was 0.77, sensitivity was 74.5%, specificity was 68.7%, positive likelihood ratio was 2.4, and negative likelihood ratio was 0.4 Validation not reported
il		

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Original Article

A self-administered questionnaire to measure the painful symptoms of endometriosis: Results of a modified DELPHI survey of patients and physicians

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ABSTRACT

Purpose. – To develop a questionnaire based on patients' verbal descriptors, to measure the painful symptoms of endometriosis.

Methods. – We performed a two-round modified DELPHI procedure mixing endometriosis patients and physicians to select a set of statements to describe the painful symptoms of endometriosis. Each panelist rated each statement based on diagnosis validity and clarity. The clinicians were experts in endometriosis management selected from various geographic regions in France. Patients were women with surgically confirmed endometriosis who volunteered from a patient association and from the recruitment of the participating physicians. The first round questions were derived from words and phrases in narratives of pain by endometriosis patients.

Results. – Overall, 76 experts were invited, and of these 56 (74%), comprising 33 patients and 23 gynecologists, responded to the first round questionnaire, and 40 (71.4%) to the second round. Among the 48 statements assessed in the first-round questionnaire, 11 were selected after completion of the two round DELPHI procedure. After discussion and rewording of some items, a total of 21 questions were selected during a final face-to-face meeting. The content of the final questionnaire is organized according to four dimensions: (i) spontaneous pelvic pain and dysmenorrhea, (ii) dyspareunia, (iii) painful bowel symptoms, (iv) and other symptoms. We also provide an English (UK) version produced using several steps of translation and back-translation.

Conclusions. – The questionnaire has content validity to measure the subjective experiences of patients with painful endometriosis and can provide a solid basis on which to develop an efficient patient-centered outcome to measure the painful symptoms in therapeutic or in diagnostic studies of endometriosis.

TO IMPROVE THE MANAGEMENT OF ENDOMETRIOSIS

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BMC Women's Health

RESEARCH ARTICLE Open Access

The Endometriosis Impact Questionnaire (EIQ): a tool to measure the long-term impact of endometriosis on different aspects of women's lives

Maryam Moradi[1*], Melissa Parker[2], Anne Sneddon[3], Violeta Lopez[4] and David Ellwood[3]

Abstract

Background: Endometriosis is a chronic disease impacting on many aspects of a woman's life. Because of the chronic and recurring nature, many of the impacts of endometriosis could be missed using existing questionnaires which focus on recent events. Therefore, a questionnaire with a long-term perspective is necessary. This study aimed to develop and evaluate a questionnaire to measure the long-term impact of endometriosis on different aspects of women's lives.

Methods: Through a methodological design, phase 1 was qualitative and phase 2 was a cross-sectional study. The original 100 EIQ items were developed based on results from an earlier qualitative study and literature review. Through a process of assessing face and content validity this was reduced to 66 items. The psychometric properties of the final 63 item EIQ were evaluated through a web-based survey with data from 423 responders with a self-reported surgically-diagnosed endometriosis.

Results: Participants were aged 16-58 years. Exploratory factor analysis of a 66-item EIQ was established with 423 responders. The final 63-item EIQ contained six dimensions including: 33-item physical-psychosocial; 3-item fertility; 7-item sexual; 11-item employment; 6-item educational; and 3-item lifestyle. Cronbach's alpha of 0.99 for the whole 63-item EIQ, and 0.84 to 0.98 for the dimensions suggests a very good reliability. High positive correlations between the EIQ and the EHP-5 (altered recall period) indicated good evidence of concurrent validity. High intra-class correlations indicated very good test-retest reliability.

Conclusions: The EIQ, as a disease-specific questionnaire, could be used to provide a better understanding of the impact of endometriosis on different aspects of life, to better meet the needs of women. We recommend additional studies to establish validity evidence for the EIQ, including studies in other countries and languages.

Keywords: Endometriosis, questionnaire, psychometrics, reliability, validation study, quality of life

Developing symptom-based predictive models of endometriosis as a clinical screening tool: results from a multicenter study

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Objective: To generate and validate symptom-based models to predict endometriosis among symptomatic women prior to undergoing their first laparoscopy.
Design: Prospective, observational, two-phase study, in which women completed a 25-item questionnaire prior to surgery.
Setting: Nineteen hospitals in 13 countries.
Patient(s): Symptomatic women (n = 1,396) scheduled for laparoscopy without a previous surgical diagnosis of endometriosis.
Intervention(s): None.
Main Outcome Measure(s): Sensitivity and specificity of endometriosis diagnosis predicted by symptoms and patient characteristics from optimal models developed using multiple logistic regression analyses in one data set (phase I), and independently validated in a second data set (phase II) by receiver operating characteristic (ROC) curve analysis.
Result(s): Three hundred sixty (46.7%) women in phase I and 364 (58.2%) in phase II were diagnosed with endometriosis at laparoscopy. Menstrual dyschezia (pain on opening bowels) and a history of benign ovarian cysts most strongly predicted both any and stage III and IV endometriosis in both phases. Prediction of any-stage endometriosis, although improved by ultrasound scan evidence of cyst/nodules, was relatively poor (area under the curve [AUC] = 68.3). Stage III and IV disease was predicted with good accuracy (AUC = 84.9, sensitivity of 82.3% and specificity 75.8% at an optimal cut-off of 0.24).
Conclusion(s): Our symptom-based models predict any-stage endometriosis relatively poorly and stage III and IV disease with good accuracy. Predictive tools based on such models could help to prioritize women for surgical investigation in clinical practice and thus contribute to reducing time to diagnosis. We invite other researchers to validate the key models in additional populations. (Fertil Steril® 2012;98:692–701. ©2012 by American Society for Reproductive Medicine.)
Key Words: Endometriosis, predictive model, logistic regression

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CONCLUSIONI

Punti salienti

- E’ IL PRIMO STUDIO CHE HA COME OBIETTIVO PRIMARIO LA PREVENZIONE SECONDARIA DELL’ENDOMETRIOSI
- IL GRUPPO DI CONTROLLO E’ STATO VALUTATO CON ECOGRAFIA (ANCHE SE MANCA DI LPS)
- L’INTERVISTA E’ STATA CONDOTTA DA UN MEDICO PER OGNI SINGOLA PAZIENTE RECLUTATA (NON E’ UN SELF-ADMINISTERED QUESTIONNAIRE) E I DUE GRUPPI SONO RISULTATI OMOGENEI
- I RISULTATI INERENTI LA SINTOMATOLOGIA SONO IN LINEA CON I DATI DI LETTERATURA
- UTILIZZANDO I COEFFICIENTI DI REGRESSIONE DELL’ANALISI MULTIVARIATA E’ STATO INOLTRE POSSIBILE CREARE UN MODELLO IN GRADO DI IDENTIFICARE L’ENDOMETRIOSI CON UNA ***SENSIBILITA’ DEL 90,2% ED UNA SPECIFICITA’ DEL 75%***

IN QUESTO SENSO, QUINDI, IL NOSTRO QUESTIONARIO PUO’ RISPONDERE AI REQUISITI RICHIESTI AD UNO SCREENING, VISTI I POCHI FALSI NEGATIVI

CONCLUSIONI

- E’ IL PRIMO STUDIO AD ESSERE RIVOLTO ALLA POPOLAZIONE GENERALE CON L’OBIETTIVO DI IDENTIFICARE LE PAZIENTI AD ALTO RISCHIO DI ENDOMETRIOSI (PREVENZIONE SECONDARIA)
- I QUESTIONARI ATTUALMENTE PRESENTI IN LETTERATURA SONO PRINCIPALMENTE RIVOLTI A PREDIRE LO STADIO DELLA MALATTIA NELLE DONNE SINTOMATICHE, QUINDI A CREARE UN ORDINE DI PRIORITA’ CHIRURGICA
- LA BUONA PREDITTIVITA’ DEL QUESTIONARIO (FALSI NEGATIVI 10%, FALSI POSITIVI 25%) POTREBBE ESSERE IN GRADO DI UTILIZZARE GLI STRUMENTI DIAGNOSTICI IN MANIERA PIU’ CORRETTA E MIRATA, RIDUCENDO IL GAP TEMPORALE ESISTENTE TRA INSORGENZA DELLA MALATTIA E DIAGNOSI
- IN QUESTO SENSO, L’INDAGINE POTREBBE ESSERE RIVOLTA ANCHE ALLE ADOLESCENTI PER MIGLIORARE NON SOLO LA QUALITA’ DI VITA, MA ANCHE IL LORO POTENZIALE RIPRODUTTIVO