

Where is the 'me' ?
20+ un-fun facts
about endometriosis

Yves Jacquemyn

UN-FUN fact 1: It hurts!


Ledenplatform Help ons groeien! Doe een vrije gift Word lid Word vrijwilliger

Endometriose Patiënt Endo Stories VZW Blog In de pers Webshop Events

ONZE MISSIE IS SIMPEL

Geef endometriose een gezicht en een stem

LEES ONZE ENDO STORIES
DOOR OP EEN FOTO TE KLIKKEN



<https://behindendo.be/>

MEHR ALS NUR BAUCHSCHMERZEN

Die Schmerzen können sich von „üblichen“
Regelschmerzen erheblich unter-
scheiden und auf den ganzen Körper auswirken.



Kopfschmerzen und Schwindel; chronische Erschöpfung
und Depressionen



Blasenbeschwerden; Darmbeschwerden; Blähungen;
vegetative Begleiterscheinungen, etwa Übelkeit,
Erbrechen, Magenbeschwerden



Schmierblutungen und/oder starke Blutungen;
Schmerzen um den Eisprung; Unterbauchschmerzen



Rückenschmerzen; Ausstrahlung der Schmerzen in die
unteren Extremitäten

UN-FUN fact 1: It hurts!

- Hoeveel pijn is normaal?
- Hou een pijndagboek bij
- Meer dan enkel buik-pijn

And yes : pain is 'gendered'

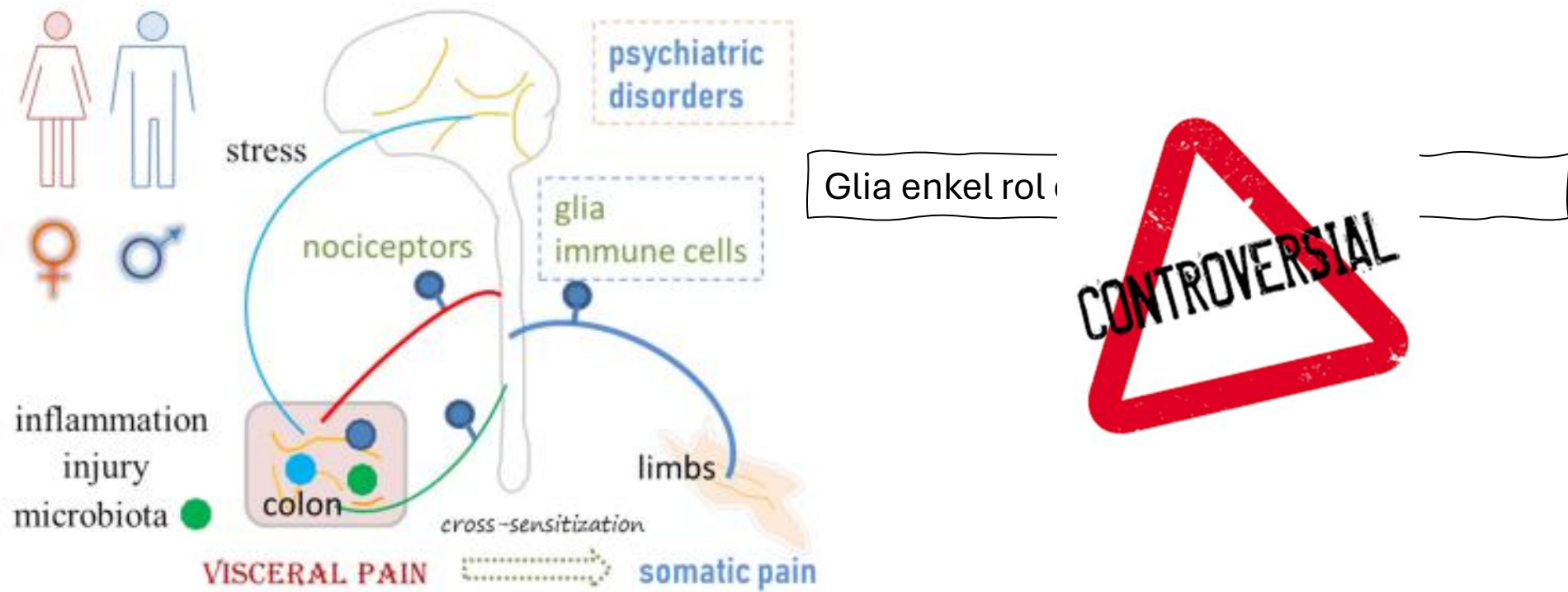


Figure 1. Visceral pain emanates from or is associated with inflammation, injury, gut microbiota imbalance, stress, psychiatric disorders, and somatic pain. Neuroplasticity in the peripheral and central nervous systems, including changes in the properties of neurons, glial cells and immune cells, plays a role in visceral pain and associated comorbidities.

Sex Differences in Visceral Pain and Comorbidities: Clinical Outcomes, Preclinical Models, and Cellular and Molecular Mechanisms

Namrata Tiwari ^{1,2} and Liya Y. Qiao ^{1,2,*}

Mogil JS, Parisien M, Esfahani SJ, Diatchenko L. Sex differences in mechanisms of pain hypersensitivity. *Neurosci Biobehav Rev.* 2024 Aug;163:105749. doi: 10.1016/j.neubiorev.2024.105749. Epub 2024 Jun

3. PMID: 38838876.

♂ & ♀ reageren niet gelijk op pijnmedicatie

- ♀ 30% meer morfine nodig voor zelfde analgesie
- M+ meer effectief in folliculaire dan luteale fase
- Andere copingmechanismen
- Andere activatie μ -opioid receptoren in CZS
- ♂ met hypogonadisme > M+ nodig, kan met testosteron \rightarrow worden

♂ meer MOR in PAG-RVM
Significant minder ♀ krijgen adequate pijnstilling met gelijke pijn scores

Geslacht arts geen invloed

MOR μ opioid receptor
PAG periaqueductal gray matter
RVM rostroventrale medulla

ANNALS OF MEDICINE
2024, VOL. 56, NO. 1, 2329259
<https://doi.org/10.1080/07853890.2024.2329259>

REVIEW ARTICLE

OPEN ACCESS [Check for updates](#)

The role of gonadal hormones in regulating opioid antinociception

Qi Xu, Lin Jin, LuYang Wang, YingYing Tang, Hui Wu, Qing Chen and LiHong Sun

Department of Anesthesiology, Women's Hospital, School of Medicine, Zhejiang University, Hangzhou, Zhejiang Province, China

Graf J, Simoes E, Kranz A, Weinert K, Abele H. The Importance of Gender-Sensitive Health Care in the Context of Pain, Emergency and Vaccination: A Narrative Review. Int J Environ Res Public Health. 2023 Dec 21;21(1):13. doi: 10.3390/ijerph21010013. PMID:

38276801; PMCID: PMC10815689.

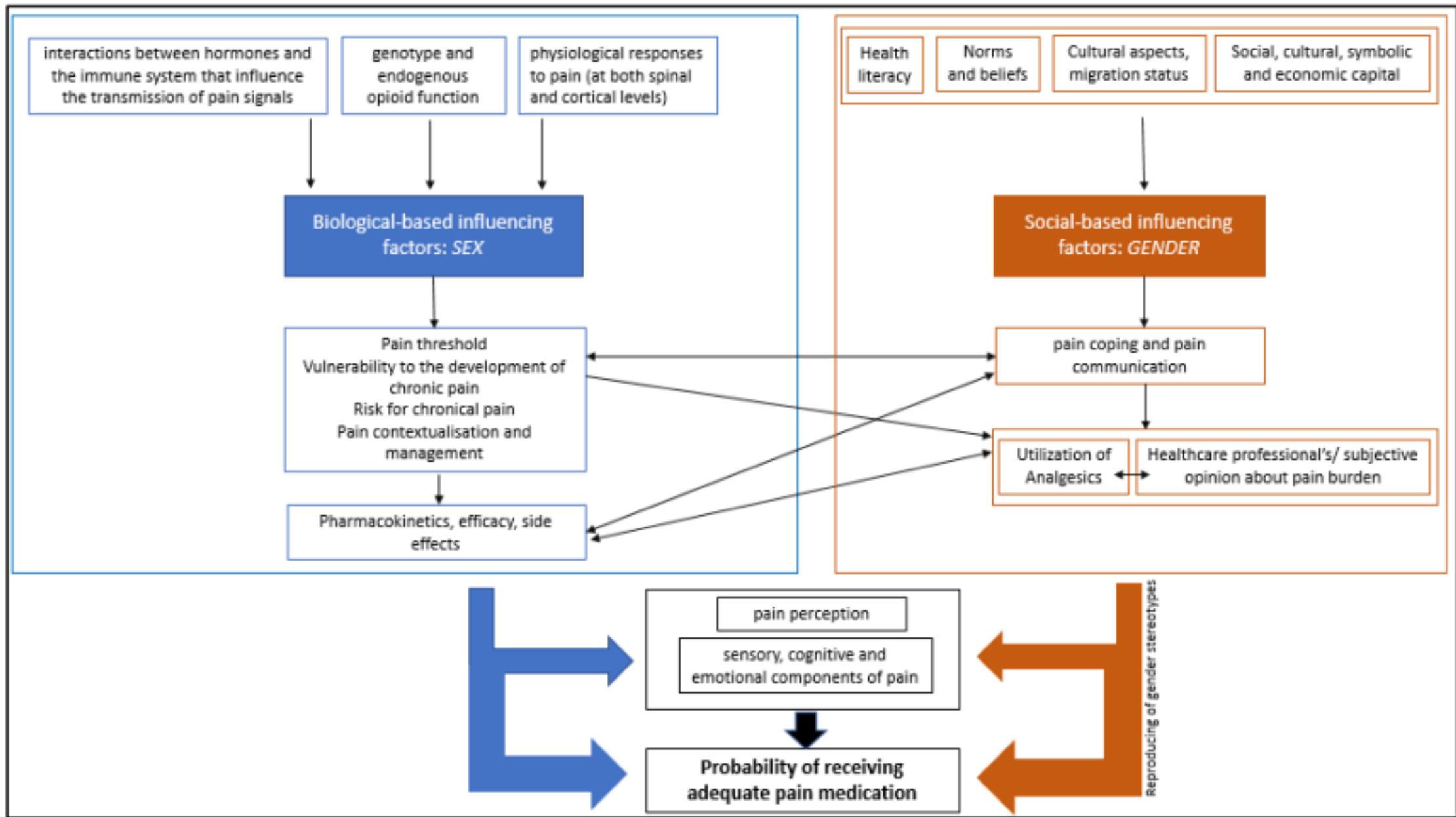


Figure 1. Simplified representation of sex and gender effects on pain care.

UN-FUN fact 2: more than pain and subfertility

Review

Endometriosis is a chronic systemic disease: clinical challenges and novel innovations



Hugh S Taylor, Alexander M Kotlyar, Valerie A Flores

Endometriosis is a common disease affecting 5–10% of women of reproductive age globally. However, despite its [Lancet 2021; 397: 839–52](#)

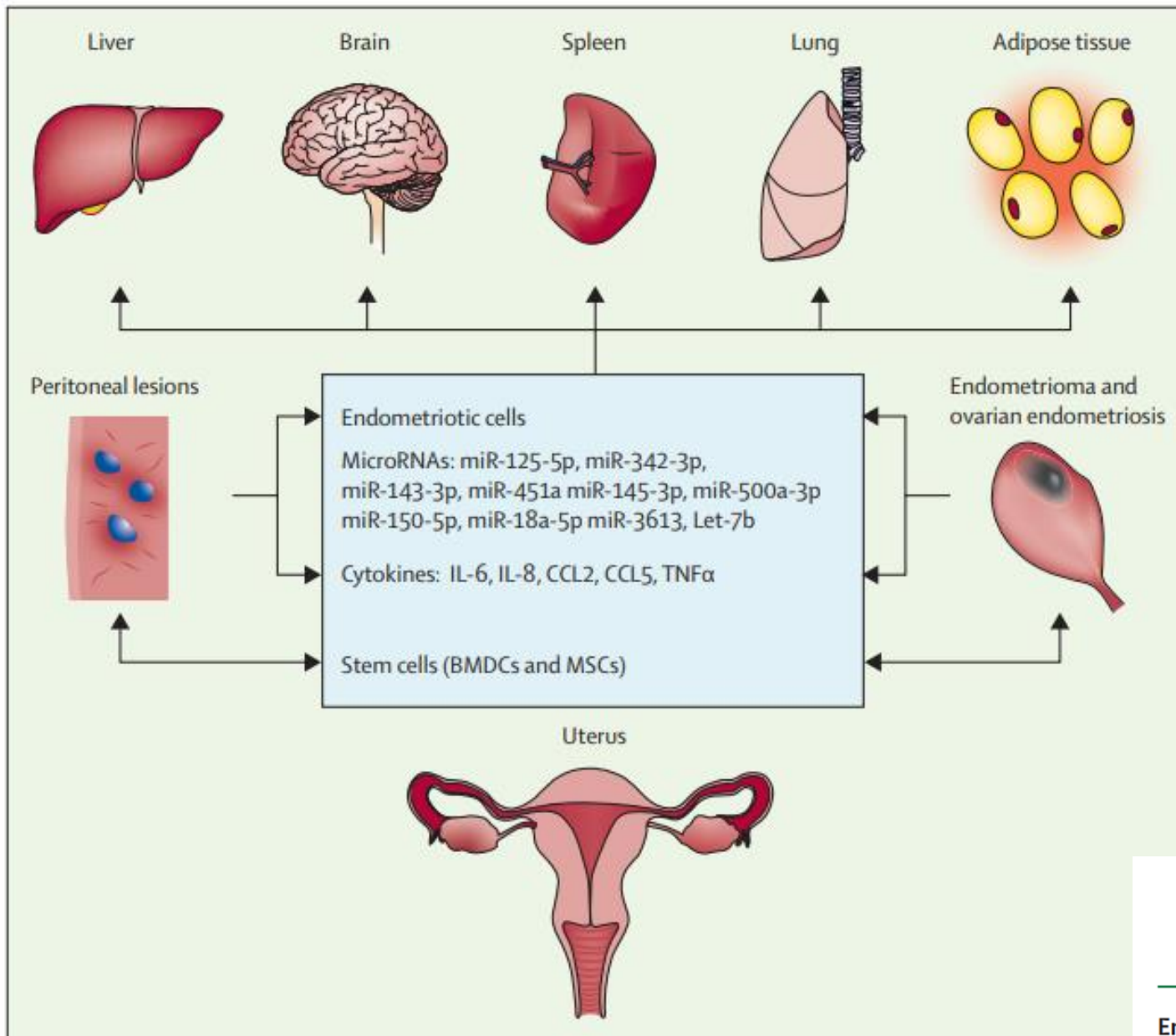


Figure 1: Circulating factors involved in the pathogenesis of endometriosis

TNF α =tumour necrosis factor alpha. BMDCs=bone marrow-derived cells. MSCs=mesenchymal stem cells.

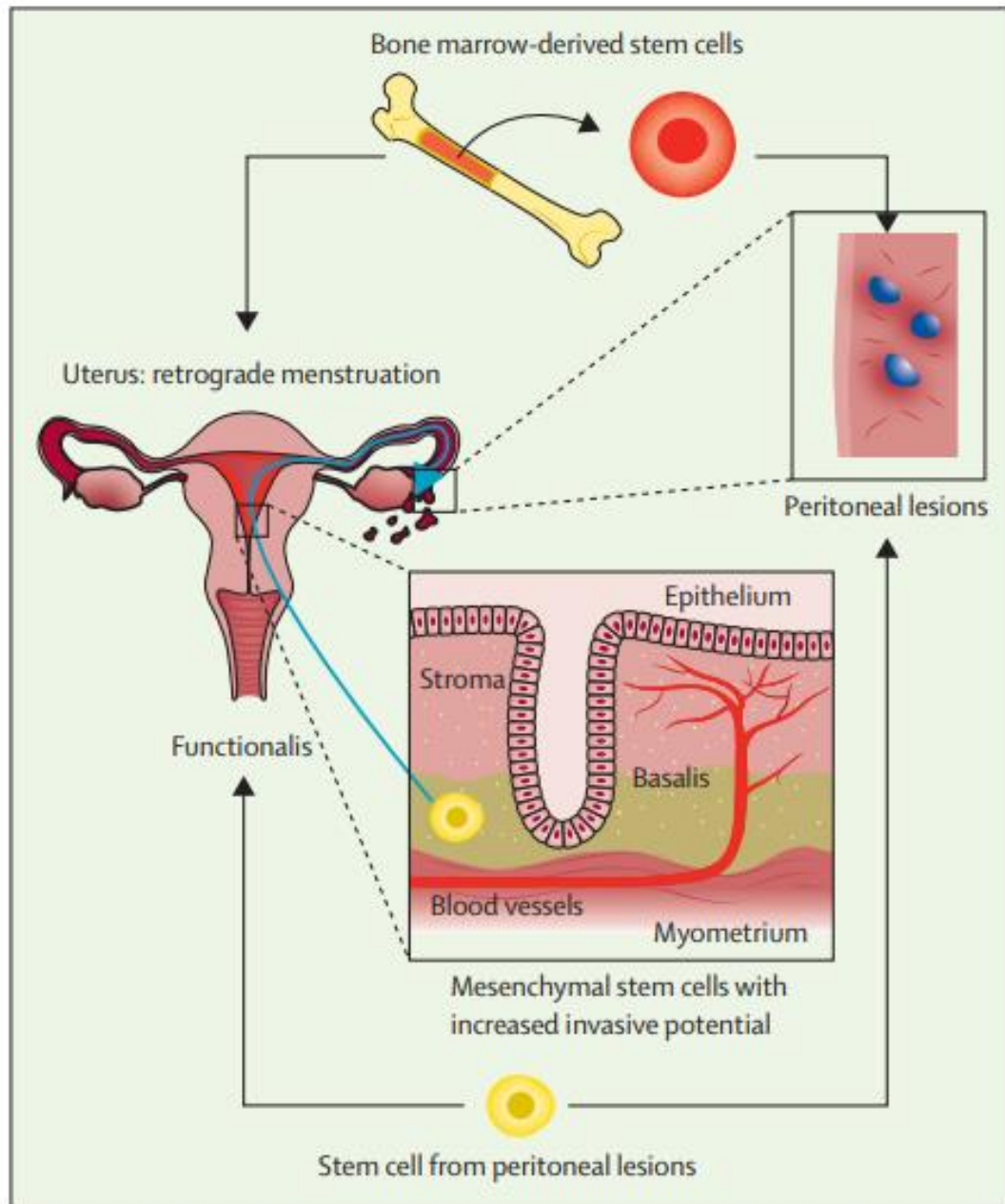


Figure 2: Stem-cell trafficking in endometriosis

Panel: Clinical diagnosis of endometriosis

Symptomatology, history, and proposed mechanisms

- Cyclic pelvic pain (cyclic dysuria and cyclic dyschezia) as a result of increased prostaglandin production and proinflammatory cytokine production
- Deep dyspareunia and progressive dysmenorrhoea influenced by lesion location and depth of invasion
- Chronic pelvic pain (especially with a history of dysmenorrhoea during adolescence) and non-menstrual pelvic pain resulting from pain sensitisation and immune-mediated sensory nerve innervation of lesions
- Infertility as a result of inflammation and adverse effect on oocytes; aberrant gene expression in the endometrium and altered stem-cell trafficking; adhesive disease distorting anatomy and impairing oocyte release and transport

Review

Endometriosis is a chronic systemic disease: clinical challenges and novel innovations



Hugh S Taylor, Alexander M Kotlyar, Valerie A Flores


Endometriosis is a common disease affecting 5–10% of women of reproductive age globally. However, despite its *Lancet* 2021; 397: 839–52

Low body-mass index and altered metabolism as a result of induction of hepatic (anorexigenic) gene expression; microRNA-mediated changes in adipocyte (metabolic) gene expression

Systemic inflammation as a result of estradiol-mediated increased prostaglandin E2, aberrant microRNA expression, aberrant immune cell function, and increased production of inflammatory cytokines

Mood disorders (eg, depression and anxiety) resulting from altered gene expression in regions of the brain associated with anxiety and depression; decreased volume in areas of the brain associated with emotional and sensory nerve processing

Review

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Physical examination findings*


- Tender nodules along the uterosacral ligaments or posterior cul-de-sac (especially before menses)
- Pain or induration without nodules in the rectovaginal septum
- Uterine or adnexal fixation or fullness

Imaging

- Transvaginal ultrasound and pelvic MRI for assessment of endometriomas, fibroids, adenomyosis (can be coexisting), or other adnexal masses

*A normal examination does not exclude endometriosis.

Review 

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Endometriosis is a common disease affecting 5–10% of women of reproductive age globally. However, despite its Lancet 2021; 397: 839–52

UN-FUN fact 2: more than pain and
subfertility

Chronische systemische
Inflammatoire
Zielte

~rheuma, Crohn...

UN-FUN fact 3: it is not LOCAL

The lesion



The 'me'

UN-FUN fact 3: it is not LOCAL

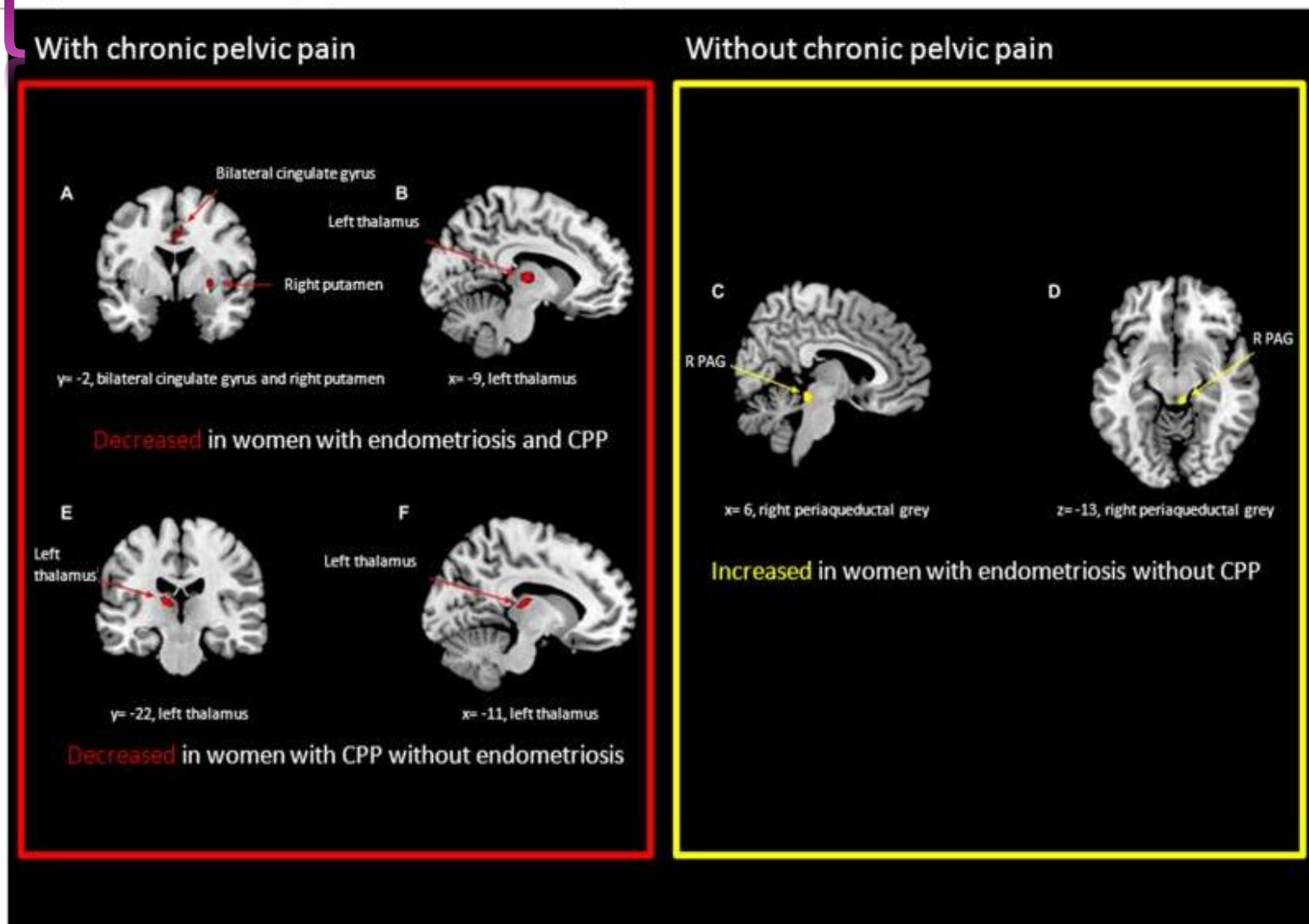
- Central sensitisation!

Pijn: centraal

Alle CPP: kleinere thalamus

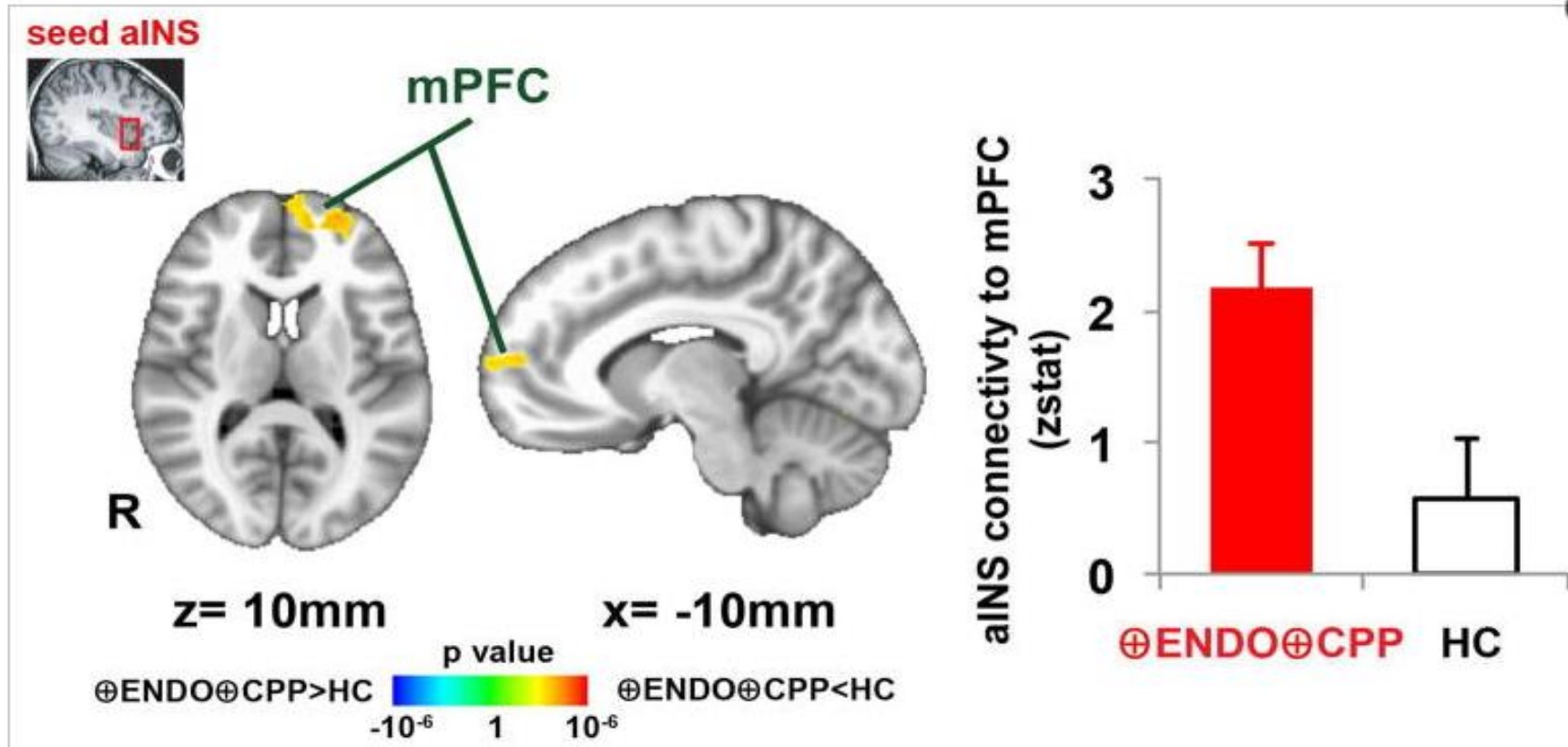
CPP + endometriose:
Kleinere cingulatus, insula putamen

Endometriose ZONDER CPP
Toename peri aquaductale grijze stof (inhibitie descenderende pijn banen?)



Adapted from [As-Sanie et al. \(2012\)](#) with permission. The figure has been reproduced with permission of the International Association for the Study of Pain[®] (IASP). The figure may *not* be reproduced for any other purpose without permission. Regional grey matter changes in women with and without endometriosis and chronic pelvic pain compared with healthy pain-free controls. Red regions represent areas in which grey matter decreased, while yellow regions represent where grey matter increased.

Meer connecties



Greater connectivity between anterior insula and medial prefrontal cortex (mPFC) in women with endometriosis and chronic pelvic pain (\oplus Endo \oplus CPP, n=16).

[Pain](#). Author manuscript; available in PMC 2017 Jan 1.
Published in final edited form as:
[J Pain](#). 2016 Jan; 17(1): 1–13.
Published online 2015 Oct
9. doi: [10.1016/j.jpain.2015.09.008](#)
PMCID: PMC4698023
NIHMSID: NIHMS729108
Functional connectivity is associated with altered brain chemistry in women with endometriosis-associated chronic pelvic pain
[Sawsan As-Sanie](#),^a [Jieun Kim](#),^{b,1} [Tobias Schmidt-Wilcke](#),^{c,2} [Pia C. Sundgren](#),^d [Daniel J. Clauw](#),^e [Vitaly Napadow](#),^b and [Richard E. Harris](#)^c

UN-FUN fact 4: it is also a sociocultural construct

Reproductive BioMedicine and Society Online (2022) 14, 20–27



www.sciencedirect.com
www.rbmsociety.com



SYMPOSIUM: RISK, INNOVATION AND IGNORANCE PRODUCTION
ORIGINAL ARTICLE

The missed disease? Endometriosis as an example of 'undone science'

Nicky Hudson

Centre for Reproduction Research, De Montfort University, Leicester, UK



Nicky Hudson is a medical sociologist with particular expertise in social and cultural significance of reproduction, infertility and assisted reproductive technology. Her work also focuses on the sociology of chronic illness. Uniting these themes is an emphasis on questions of individual-biomedicine-society relations. She has received funding for her work from the Economic and Social Research Council, the Wellcome Trust, Foundation for Sociology of Health and Illness, and the National Institute for Health Research. Her research is characterized by a strong commitment to interdisciplinary collaboration, social translation and impact. She leads the Centre for Reproduction Research, an interdisciplinary centre of expertise dedicated to the production of scholarship on the social, cultural and political aspects of human reproduction, based at the Faculty of Health and Life Sciences at De Montfort University (UK).

and misrecognition of particular conditions is historically situated, illustrating how gendered frameworks have operated to delegitimize certain bodies and symptoms (Greenhalgh, 2001; Kempner, 2014; Nettleton, 2004). Fibroids, polycystic ovary syndrome, fibromyalgia and migraines (Kempner, 2014) are further examples of conditions in which painful and disabling symptoms (mostly amongst women) have been systematically and historically dismissed, ignored or delegitimized. Sharing characteristics with endometriosis, these examples of 'missed' diseases collectively draw our attention to the ways that practices of ignorance are entwined by and with practices of oppression and exclusion (Tuana, 2004), helping to contextualize contemporary complexities of diagnosis, and struggles for recognition and legitimacy in relation to expert knowledge.

The systematic non-production of knowledge about women's health, in particular, can be located within a historical context of (white) androcentric biomedicine, setting the scene for an understanding of contemporary forms of ignorance. Whilst non-production of knowledge is not exclusive to women's health, feminist scholars have drawn our attention to the systematic failure of scientific thought to account for women as agents and subjects, and for their experiences to be included in determining the definition of problems given attention by science (Fox Keller, 1982; Haraway, 1988; Harding, 1989; Vostral 2018), and this work has been an exceptionally rich source of reflections about silence and its significances, exemplifying the character of ignorance in a range of arenas (Gross and McGoey, 2015).

Significantly, for the theorization of ignorance, endometriosis is a phenomenon which has come to be defined by a lack of scientific knowledge and consensus. The ambiguity that exists around it has become the defining feature of the condition, folded into scientific consensus statements and treatment schemas. Thinking about

Lived experience

Applying an ignorance lens to the case of endometriosis adds further evidence of the ways in which women's experiences of illness have been, and continue to be, ignored. Scholars have illustrated how ignorance is not a motionless state but is an 'active accomplishment' (Gross and McGoey, 2015: 5) in which a range of stakeholders may participate in knowledge production, non-knowledge production and a

UN-FUN fact 4: it is also a sociocultural construct

- En dat is de reden dat het 7-10 jaar duurt voor de diagnose wordt gesteld

Fun (?) fact 1: it is not a cisgender female condition

ENDOMETRIOSIS In Transgender Men

Physical Impact:

- Chronic pain,
- fatigue,
- irregular menstruation

Psychological Impact:

- Anxiety,
- depression,
- stress



trans-mannen

Social Impact:

- Stigmatization,
- isolation

Healthcare Barriers:

- Delayed diagnosis,
- inadequate care

Quality of Life:

- Reduced physical and mental well-being

trans-vrouwen

Cis-mannen

ENDOMETRIOSIS IN MEN

LITERATURE REVIEWS & EMERGING RESEARCH ABOUT ENDOMETRIOSIS IN MEN, BOYS, AND PERSONS AMAB WITHOUT ANEUPLOID FEATURES.

Case Report
Endometriosis in a Man as a Rare Source of Abdominal Pain:
A Case Report and Review of the Literature

Christina Bai,¹ Thomas Williams,² and Michael Felonyo³

Case Report

Introduction

Case Report

Conclusion

Learn More

Endometriosis in Men, Boys without Aneuploid Features

Endometriosis in men without aneuploid features has been recognized for more than half a century. In most reported cases, it's traditionally reported that these cases developed in connection with hormonal treatments for prostate cancer. In reality, there are also several cases in which no known hormonal treatments were taken. A caveat has to be mentioned, though, as one of the cases the male patient was consuming high doses of certain traditional Chinese medicines, and so this factor could have exerted some exogenous phytoestrogenic, or even xenoestrogenic, effects.

<https://endomarch.org/endometriosis-in-men-boys-without-aneuploid-features/>

And Yes pain is gendered part 2

- Endometriose is beschreven bij cis-mannen en endometrium is aangetroffen in de prostaat bij trans- vrouwen, ook bestaat endometriose bij congenitale agenese van de uterus zoals Mayer-Rokitansky-Küster-Hauser syndroom

Enorme negatie van endometriose als Oorzaak pijn bij trans♂

- **Hoewel endometriose voornamelijk bij cisgender vrouwen voorkomt, erkent men dat er mensen zijn met endometriose die transgender zijn, niet menstrueren, geen baarmoeder hebben of zich niet identificeren met de gendertermen die in de literatuur worden gebruikt; voortaan verwijzen we naar de populatie personen met endometriose met genderneutrale termen, tenzij we verwijzen naar specifieke studies die uitsluitend vrouwen omvatten**

Pascoal E, Wessels JM, Aas-Eng MK, Abrao MS, Condous G, Jurkovic D, Espada M, Exacoustos C, Ferrero S, Guerriero S, Hudelist G, Malzoni M, Reid S, Tang S, Tomassetti C, Singh SS, Van den Bosch T, Leonardi M. Strengths and limitations of diagnostic tools for endometriosis and relevance in diagnostic test accuracy research. *Ultrasound Obstet Gynecol.* 2022 Sep;60(3):309-327. doi: 10.1002/uog.24892. PMID: 35229963.

Gender bevestigende hormoontherapie

Trans♀

- Oestrogeen: ↗ pijn
- Anti-androgeen: ↗ pijn
- Trans ♀ > pijn dan cis♀ of cis ♂

Trans♂

- Testosteron
- Mindel
- Kleine
- Soms : ns ↘



Anger JT, Case LK, Baranowski AP, Berger A, Craft RM, Damitz LA, Gabriel R, Harrison T, Kaptein K, Lee S, Murphy AZ, Said E, Smith SA, Thomas DA, Valdés Hernández MDC, Trasvina V, Wesselmann U, Yaksh TL. Pain mechanisms in the transgender individual: a review. *Front Pain Res (Lausanne)*. 2024 Mar 27;5:1241015. doi: 10.3389/fpain.2024.1241015. PMID: 38601924; PMCID: PMC11004280.

Boerner KE, Keogh E, Inkster AM, Nahman-Averbuch H, Oberlander TF. A developmental framework for understanding the influence of sex and gender on health: Pediatric pain as an exemplar. *Neurosci Biobehav Rev*. 2024 Mar;158:105546. doi: 10.1016/j.neubiorev.2024.105546. Epub 2024 Jan 24. PMID: 38272336.

Trans♀

- Chronic pelvic pain 51-72%
- Meer pijn
 - Hoofdpijn

Cis ♀

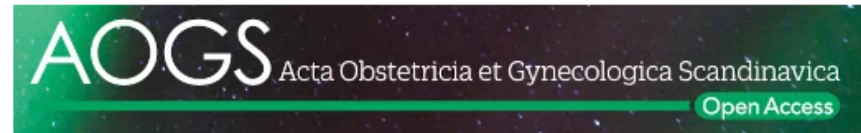
- Chronic pelvic pain 27%
- Minder pijn

UN-FUN fact 5: adolescents suffer

Dysmenorrhea and Endometriosis in the Adolescent

Committee Opinion ⓘ | Number 760 | December 2018

UN-FUN fact 6: menopause is not the end



COMMENTARY | Open Access | CC BY-NC-ND

Endometriosis and menopause—management strategies based on clinical scenarios

Ivika Jakson Angelica Lindén Hirschberg, Sebastian B. Gidlöf

First published: 26 April 2023 | <https://doi.org/10.1111/aogs.14583> | Citations: 5

SECTIONS

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Abstract

Endometriosis is largely considered a premenopausal disease with symptoms often improving during menopausal transition. However, 2%–4% of postmenopausal women are affected by endometriosis symptoms. At the same time, many peri- and postmenopausal women experience menopausal symptoms and inquire about treatment. Because of the estrogen-dependent nature of endometriosis, treatment with












UN-FUN fact 7: CT, MRI, US can not exclude

Ultrasound Obstet Gynecol 2022; 60: 309–327

Published online in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/uog.24892

State-of-the-Art Review

Strengths and limitations of diagnostic tools for endometriosis and relevance in diagnostic test accuracy research

E. PASCOAL^{1*} , J. M. WESSELS^{1,2},
M. K. AAS-ENG^{3,4} , M. S. ABRAO^{5,6} ,
G. CONDOUS⁷, D. JURKOVIC⁸ ,
M. ESPADA^{9,10} , C. EXACOUSTOS¹¹ ,
S. FERRERO¹² , S. GUERRIERO¹³ ,
G. HUDELIST^{14,15} , M. MALZONI¹⁶,
S. REID¹⁷, S. TANG¹⁸, C. TOMASSETTI¹⁹,
S. S. SINGH²⁰, T. VAN DEN BOSCH²¹  and
M. LEONARDI^{1,10,22} 



Ultrasound

- High specificity and sensitivity for OE
- Overall high accuracy in detecting DE and POD obliteration
- Dynamic nature for organ mobility
- Allows anatomic mapping
- Opportunity to provide visual evidence to patients
- High tolerability
- Cost-effective
- Limited ability to detect SE
- Detection of DE requires highly trained sonographers/sonologists
- Outcomes are operator-dependent
- Examination may be considered invasive and painful

SE: Sn, 65–79%;
Sp, 91–95%⁷¹
OE: Sn, 93%; Sp, 96%⁷¹
DE: Sn, 79%; Sp, 94%⁷¹

MRI

- Images obtained appear the same to all viewers
- Overall high accuracy in detecting DE and extrapelvic endometriosis
- Allows anatomic mapping
- Opportunity to provide visual evidence to patients
- Static assessment
- Limited ability to detect SE
- Variable imaging protocols reported in literature
- Low accuracy in defining bowel depth of invasion
- Requires specific training endometriosis
- No consensus on how to describe findings
- High cost compared with ultrasound

SE: Sn, 79%; Sp, 72%⁷¹
OE: Sn, 95%; Sp, 91%⁷¹
DE: Sn, 94%; Sp, 77%⁷¹

See fact 8

Laparoscopy

- Overall high accuracy, considered gold standard
- Allows concomitant diagnosis and treatment
- Opportunity to provide visual evidence to patients
- Significant placebo effect
- Invasive, carries surgical risk
- Diagnostic accuracy dependent on surgical experience
- Visual diagnosis challenged by heterogeneous lesion appearance, inaccessible lesions

Sn, 90–94%^{49,51,141,144};
Sp, 40–79%^{51,144}

UN-FUN fact 8: can be missed on laparoscopy

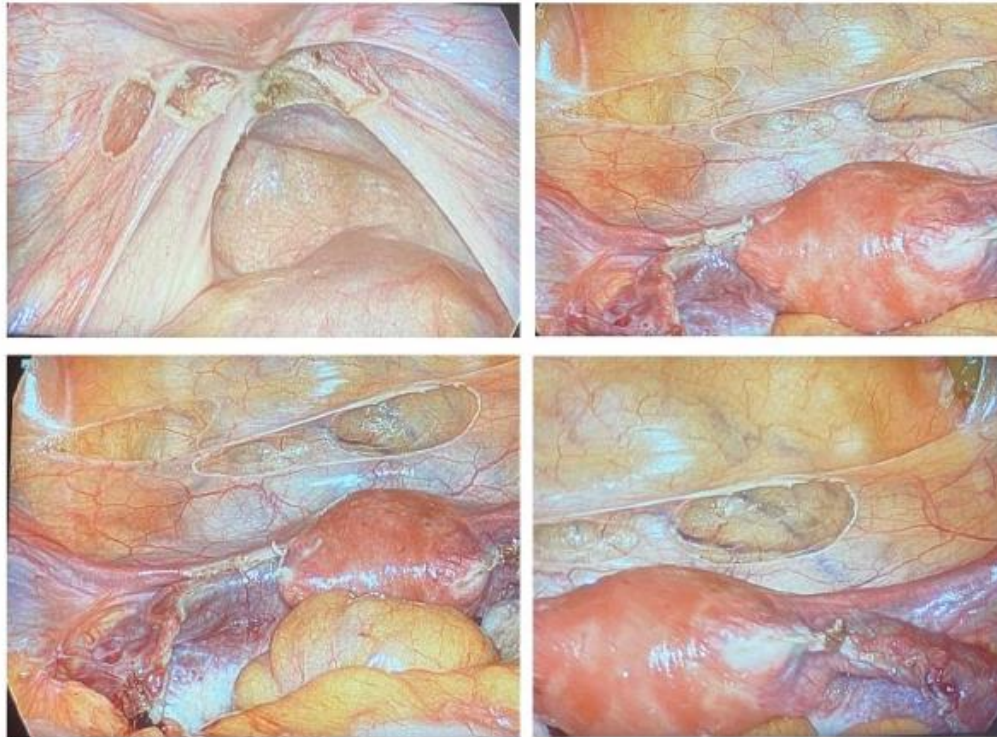


Figure 1. This patient presented with a primary complaint of pelvic pain. Video laparoscopic findings did not reveal any obvious evidence of endometriosis. To rule out endometriosis and decrease the chance of missing endometriosis, as demonstrated above, multiple biopsies were taken from the most common sites of endometriosis away from tubes and ovaries.

Summary

- **High Prevalence of Occult Endometriosis:** Studies indicate that a significant proportion of patients with chronic pelvic pain and negative visual findings during laparoscopy may still have microscopic endometriosis ¹.
- **Importance of Histologic Confirmation:** Visual diagnosis alone is not always reliable. Histologic confirmation is necessary to accurately diagnose endometriosis, as visual inspection can miss microscopic lesions. This is particularly important in early-stage disease where visual diagnosis is less accurate ^{2 3}.
- **Blind Biopsies from Normal-Appearing Peritoneum:** Blind biopsies can reveal endometriosis in normal-appearing peritoneum, supporting their value in diagnosing cases where no clear lesions are visible ⁴.

In conclusion, blind biopsies during laparoscopy are valuable for diagnosing endometriosis, especially when no clear lesions are visible. They help in identifying occult microscopic endometriosis, thereby improving diagnostic accuracy and ensuring appropriate treatment.



shift + enter to add a new line

 Share chat

Ask a follow-up question...



References

selec

- 1 [Prevalence of occult microscopic endometriosis in clinically negative peritoneum during laparoscopy for chronic pelvic pain.](#)

International journal of gynaecology and obstetrics: the official organ of the International Federation of Gynaecology and Obstetrics, AL Gubbels et al, 2020

- 2 [Endometriosis: correlation between histologic and visual findings at laparoscopy.](#)

American journal of obstetrics and gynecology, AJ Walter et al, 2001

- 3 [Diagnosis of pelvic endometriosis with use of macroscopic versus histologic findings.](#)

Fertility and sterility, GL Marchino et al, 2005

- 4 [Visible and non-visible endometriosis at laparoscopy in fertile and infertile women and in patients with chronic pelvic pain: a prospective study.](#)

UN-FUN fact 8: can be missed on laparoscopy

- Een gouden standaard die eerder van aluminium is

UN-FUN fact 9: local lesions \neq 'I have symptomatic endometriosis'

Summary

- The prevalence of asymptomatic endometriosis varies widely across different studies and populations, ranging from 10% to 45.3%.
- A systematic review estimated that approximately 23% of asymptomatic women have endometriosis.
- Specific populations, such as infertile women and those undergoing sterilization, also show significant rates of asymptomatic endometriosis.

These findings suggest that a substantial proportion of endometriosis cases are asymptomatic, highlighting the importance of considering endometriosis even in the absence of typical symptoms.

Moen MH, Stokstad T. A long-term follow-up study of women with asymptomatic endometriosis diagnosed incidentally at sterilization. *Fertil Steril*. 2002 Oct;78(4):773-6. doi: 10.1016/s0015-0282(02)03336-8. PMID: 12372455.

Tissot M, Lecoindre L, Faller E, Afors K, Akladios C, Audebert A. Clinical presentation of endometriosis identified at interval laparoscopic tubal sterilization: Prospective series of 465 cases. *J Gynecol Obstet Hum Reprod*. 2017 Oct;46(8):647-650. doi: 10.1016/j.jogoh.2017.05.003. Epub 2017 May 17. PMID: 28526518.

Chu KK, Chen FP, Chang SD. Prevalence of endometriosis among women undergoing laparoscopic procedures. *Diagn Ther Endosc*. 1995;2(1):35-7. doi: 10.1155/DTE.2.35. PMID: 18493379; PMCID: PMC2362508.



<https://evidencehunt.com/>

UN-FUN fact 9: local lesions ≠ ‘i have symptomatic endometriosis’

FERTILITY AND STERILITY®
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Published by Elsevier Science Inc.
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A long-term follow-up study of women with asymptomatic endometriosis diagnosed incidentally at sterilization

Mette Haase Moen, M.D, Ph.D., and Trine Stokstad, M.D.

Department of Obstetrics and Gynecology, St. Olav's University Hospital, Trondheim, Norway

TABLE 1

Pain and surgery reported by women with and without endometriosis.

	Endometriosis <i>n</i> =32 (%)	Non-endometriosis <i>n</i> =127 (%)	<i>P</i>
Dysmenorrhea ^a	9/16 (56)	44/61 (72)	NS
Premenstrual pain ^a	6/16 (38)	26/61 (43)	NS
Dyspareunia	7 (22)	34 (28)	NS
Pelvic pain present	2 (6)	28 (22)	<.05
Consulted a doctor for pelvic pain	8 (25)	34 (27)	NS
Hospitalized for pelvic pain	5 (16)	22 (17)	NS
Laparoscopy for pain	1 ^b (3)	5 ^c (4)	NS
Hysterectomy, cancer	—	2 (2)	—
Hysterectomy, benign	6 ^d (19)	12 ^e (9)	NS

Note: Analyses performed by the χ^2 test. NS = not significant.

^a In women still menstruating or on sequential HRT.

^b Endometriosis reconfirmed.

^c Endometriosis found in one case, the other four cases were normal.

^d Adenomyosis found in one case, and endometriosis reconfirmed in two.

^e Adenomyosis found in two cases, no endometriosis diagnosed.

Moen. *Asymptomatic endometriosis. Fertil Steril* 2002.

Meer pijn ZONDER endometriose

with little clinical significance. The possibility of such lesions progressing to cause pain or tissue damage is unlikely, and there is probably no need to try to eradicate the endometriotic spots that are found incidentally. This conclusion has previously been reported (20). A dilemma appears when

UN-FUN fact 9: NO local lesions ≠ 'i have NO endometriosis'

- Zie ook UN FUN fact 8

Conclusions The majority of pelvic pain symptoms did not differ significantly between women with and those without sonographic evidence of endometriosis,

indicating that endometriosis may not always be the source of pelvic pain, even if present. This highlights the need to rule out other causes of pain in symptomatic endometriosis patients before considering surgical procedures, and to provide appropriate patient counseling. ©

Ultrasound Obstet Gynecol 2025

Published online in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/uog.29150.

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Impact of deep or ovarian endometriosis on pelvic pain and quality of life: prospective cross-sectional ultrasound study

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¹EGA Institute for Women's Health, Faculty of Population Health Sciences, University College London Hospital, London, UK;

²Department of Gynaecology, Oslo University Hospital, Oslo, Norway

UN-FUN fact 10: surgery is less useful than thought



**Cochrane
Library**

Cochrane Database of Systematic Reviews

Laparoscopic surgery for endometriosis (Review)

Bafort C, Beebeejaun Y, Tomassetti C, Bosteels J, Duffy JMN

Bafort C, Beebeejaun Y, Tomassetti C, Bosteels J, Duffy JMN.
Laparoscopic surgery for endometriosis.
Cochrane Database of Systematic Reviews 2020, Issue 10. Art. No.: CD011031.
DOI: [10.1002/14651858.CD011031.pub3](https://doi.org/10.1002/14651858.CD011031.pub3).

UN-FUN fact 10: surgery is less useful than thought

Authors' conclusions

Compared to diagnostic laparoscopy only, it is uncertain whether laparoscopic surgery reduces overall pain associated with minimal to severe endometriosis. No data were reported on live birth. There is moderate quality evidence that laparoscopic surgery increases viable intrauterine pregnancy rates confirmed by ultrasound compared to diagnostic laparoscopy only. No studies were found that looked at live birth for any of the comparisons. Further research is needed considering the management of different subtypes of endometriosis and comparing laparoscopic interventions with lifestyle and medical interventions. There was insufficient evidence on adverse events to allow any conclusions to be drawn regarding safety.

UN-FUN fact 11: early detection apps seem crap

Hoge PPW in selecte groep: al
verwezen voor vermoeden
endometriose!

N = 25

Android apps assessment results (Par

App's Name	N
Luna-endometriosis	Y
Endometrix	N
EndoCoach	N
Endometriosis Support	N
Nezhat-Endometriosis Advisor	N
frendo-Endometriosis Tracker	N
Endometriosis Treatment	N
Phendo	Y
AAGL endo classification	N
manage my pain	N
Diseases Dictionary	N
All diseases treatments	N
Assessment score (%)	1

Table 9

iOS apps assessment results (Part 1).

App's name
Luna for Health
Endometrix
EndoWheel
Nezhat-Endometriosis Advisor
Frendo
Living With Endometriosis
She's Well
Symptom & Mood Tracker
Peppy Health
AAGL endo classification
Visana Health
SORA: Virtual Health Clinic
ENdi: Track Your Endometriosis
Question Assessment score (%)

Scientific African 21 (2023) e01833

Contents lists available at ScienceDirect

Scientific African

journal homepage: www.elsevier.com/locate/sciaf



Mobile applications for endometriosis management
functionalities: Analysis and potential

Karima Moumane ^{a,*}, Ali Idri ^{a,b}

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^b Mohammed VI Polytechnic University, Ben Guerir, Morocco

New Chat

- Sources
- Total Clinical & Biomed Research ⓘ
 - NICE Guidelines

Elaborate mode ⓘ

Off On

Precision mode ⓘ

Off On

Using both Precision mode and Elaborate mode optimizes accuracy at the cost of speed.

Filters ⤴️

Published since ⓘ

All years ▾

Study types ⓘ

Randomized trial Meta-analysis

Systematic review

Clinical intervention Rodent study

Protocol Other

Impact factor ⓘ

Off High

Sample size ≥ ⓘ

Your question

apps to screen for endometriosis

Evidencehunt

Available Apps to Screen for Endometriosis

Several digital tools and apps have been developed to aid in the screening and management of endometriosis. Below is a summary of the most relevant apps based on the studies provided:

1. Endometriosis Risk Advisor (EndoRA)

- **Study Type:** Retrospective cross-sectional study
- **Population:** 293 patients with chronic pelvic pain and/or unexplained infertility, no prior diagnosis of endometriosis
- **Key Findings:**
 - **Sensitivity:** 93.1%
 - **Specificity:** 5.9%
 - **Positive Predictive Value:** 94.1%
 - **Negative Predictive Value:** 5.0%
- **Conclusion:** The EndoRA app shows high sensitivity and positive predictive value, making it a valuable non-invasive screening tool for identifying individuals at high risk for endometriosis. However, its low specificity indicates a high rate of false positives ⓘ.

2. Flo Health Symptom Checkers

- **Study Type:** Clinical vignettes study
- **Population:** Simulated users with reproductive health conditions including endometriosis
- **Key Findings:**
 - **Sensitivity for Endometriosis:** 81.8%
 - **Specificity for Endometriosis:** 84.6%
 - **Positive Predictive Value for Endometriosis:** 81.8%
 - **Negative Predictive Value for Endometriosis:** 84.6%

References select all

- 1 [Use of the Free Endometriosis Risk Advisor App as a Non-Invasive Screening Test for Endometriosis in Patients with Chronic Pelvic Pain and/or Unexplained Infertility.](#)
Journal of clinical medicine, C Nezhath et al, 2023
- 2 [Assessment of a Digital Symptom Checker Tool's Accuracy in Suggesting Reproductive Health Conditions: Clinical Vignettes Study.](#)
JMIR mHealth and uHealth, K Peven et al, 2023
- 3 [Influence of App-Based Self-Management on the Quality of Life of Women With Endometriosis.](#)
Cureus, N Rohloff et al, 2024

Other References

- [Endometriosis Predictive Models Based on Self-Assessment Questionnaire, Evidence from Clinical Examination or Imaging Findings: A Narrative Review.](#)
Journal of clinical medicine, F Gkrozou et al, 2024
- [Patient-completed or symptom-based screening tools for endometriosis: a scoping review.](#)
Archives of gynecology and obstetrics, E Surrey et al, 2017

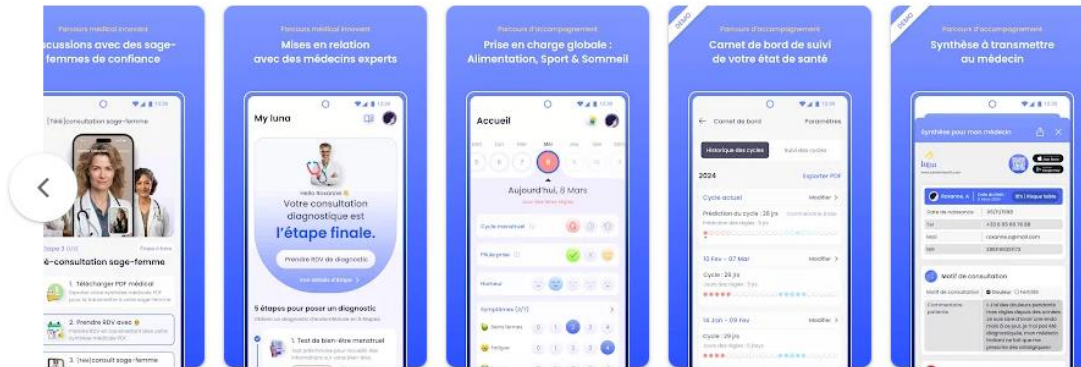
Export

Luna for Health - Endométriose

HDSI
In-app aankopen

10K+ Downloads
PEGI 3

Installeren Delen Aan verlanglijstje toevoegen



App-support

No studies found

Over deze app →

Luna, uw bondgenoot bij het diagnosticeren en behandelen van uw endometriose.

Ontdek Luna, uw gezondheidsapplicatie die u helpt endometriose te diagnosticeren en te ondersteunen in 5 eenvoudige stappen. Zorg goed voor jezelf en leer je gezondheid beter begrijpen!

Veel vager wordt het niet....

This consensus study highlighted six symptoms and related consequences commonly associated with endometriosis: menstrual pain, pain during sexual intercourse, cyclic pain during defecation, cyclic pain, infertility, and frequent doctor/health care visits for abdominal/pelvic pain. Recognising a broad range

BJOG: An International Journal of Obstetrics & Gynaecology

WILEY

BJOG An International Journal of Obstetrics and Gynaecology

RESEARCH ARTICLE **OPEN ACCESS**

Consensus on Symptom Selection for Endometriosis Questionnaires: A Modified e-Delphi Study

Tong Zhu¹ | Henrik Marschall¹ | Karina E. Hansen¹ | Andrew W. Horne² | Lucky Saraswat³ | Krina T. Zondervan⁴ | Stacey A. Missmer⁵ | Lone Hummelshoj⁶ | Atilla Bokor⁷ | Camilla S. Østrup¹ | Anna Melgaard¹ | Dorte Rytter¹

¹Department of Public Health, Aarhus University, Aarhus, Denmark | ²Centre for Reproductive Health, Institute of Regeneration and Repair, University of Edinburgh, Edinburgh, UK | ³Aberdeen Royal Infirmary, University of Aberdeen, Aberdeen, UK | ⁴Oxford Endometriosis CaRe Centre, Nuffield Department of Women's and Reproductive Health, University of Oxford, Oxford, UK | ⁵Department of Obstetrics Gynecology and Reproductive Biology, Michigan State University, East Lansing, Michigan, USA | ⁶Endometriosis.org, London, UK | ⁷Department of Obstetrics and Gynecology, Semmelweis University, Budapest, Hungary

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Received: 4 September 2024 | Revised: 5 December 2024 | Accepted: 29 December 2024

Wel zinvol voor QoL en zelf management

Cureus
Part of SPRINGER NATURE

Open Access Original Article

Influence of App-Based Self-Management on the Quality of Life of Women With Endometriosis

Nadine Rohloff¹, Teresa Götz¹, Sarah S. Kortekamp¹, Nicole R. Heinze¹, Charlotte Weber¹, Sebastian D. Schäfer²

1. Science, Endo Health GmbH, Chemnitz, DEU 2. Gynecology and Obstetrics, Clemenshospital, Münster, DEU

Corresponding author: Sebastian D. Schäfer, seb.schaefer@alexianer.de

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Review ended 06/17/2024
Published 08/24/2024

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Rohloff et al. This is an open access article distributed under the terms of the Creative Commons Attribution License CC-BY 4.0., which permits unrestricted use, distribution,

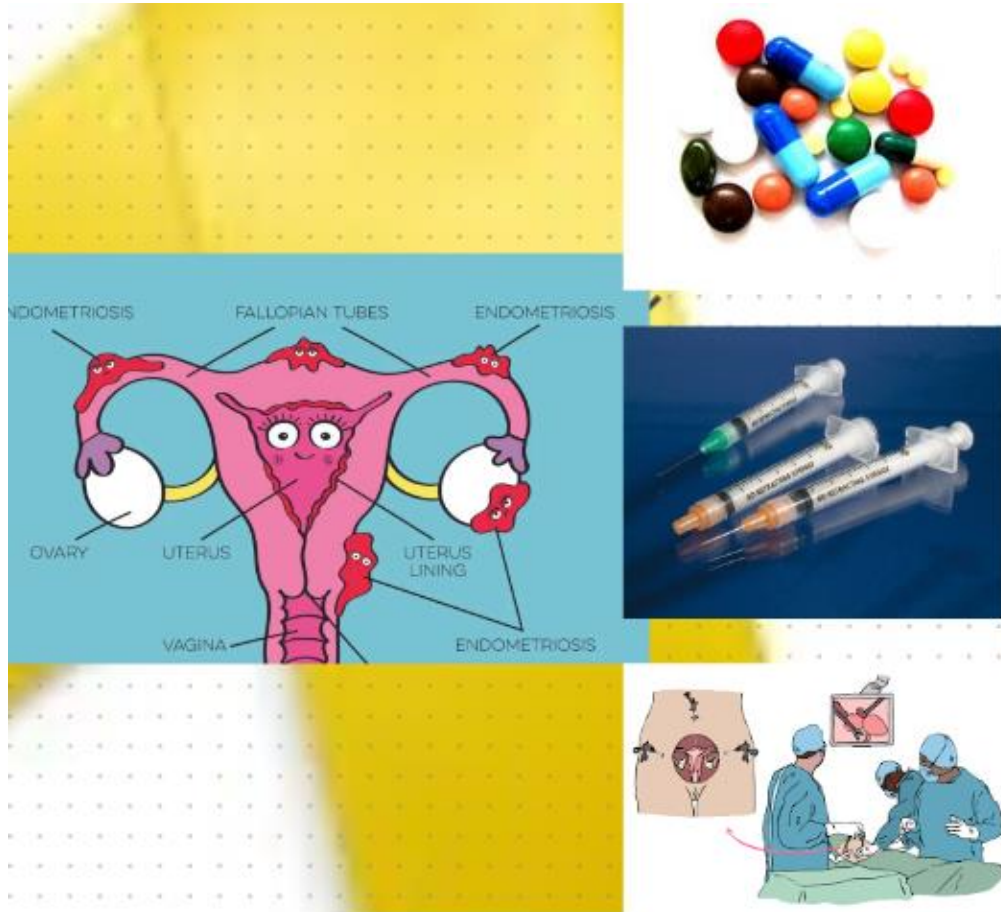
Cave App ipv mensen?

Conclusions

The care situation for endometriosis patients in Germany is insufficient. The present results show that the Endo-App could improve endometriosis care as a holistic treatment support. It was shown that the Endo-App is suitable for improving the quality of life of those affected. The Endo-App can also contribute to improving the visibility of endometriosis in the public sphere, which can have further positive effects on

UN-FUN fact 12: we do not know the real
incidence/ prevalence

UN-FUN fact 13: standard treatment is crap



UN-FUN fact 14: alternative/ additive treatment is ?



Effects of herbal compounds on various aspects of endometriosis treatment: a systematic review

Z. MOMENIMOVAHED¹, H. SALEHINIYA², L. ALLAHQOLI³, A.S. LAGANÀ⁴,
A. MAZIDIMORADI⁵, G. MOAWAD⁶, G. GITAS⁷, I. ALKATOUT⁸

Included Studies

A total of 11 articles published between 2006 and 2023 were included in the study. These studies, with a sample size of 50-208, investigated the effects of herbal compounds for the treatment of endometriosis¹¹⁻²¹. The four studies compared herbal compounds with placebo^{16-18,22} and the rest with other available treatments ([Supplementary Table I](#)).



Conclusions

So far, various approaches have been proposed to reduce the symptoms of endometriosis. The side effects of existing treatments have led researchers to use new, safe, alternative, and effective treatments in this regard. The mechanism of action in some drugs is still debated, but a wide range of preclinical and clinical studies evaluated the effectiveness and safety of medicinal plants in the treatment of endometriosis symptoms and signs. However, there is still a need for well-designed trials to investigate standard interventions and specific and safe doses of herbal medicines so that useful and comprehensive information can be provided to the pharmaceutical industry and health policymakers.

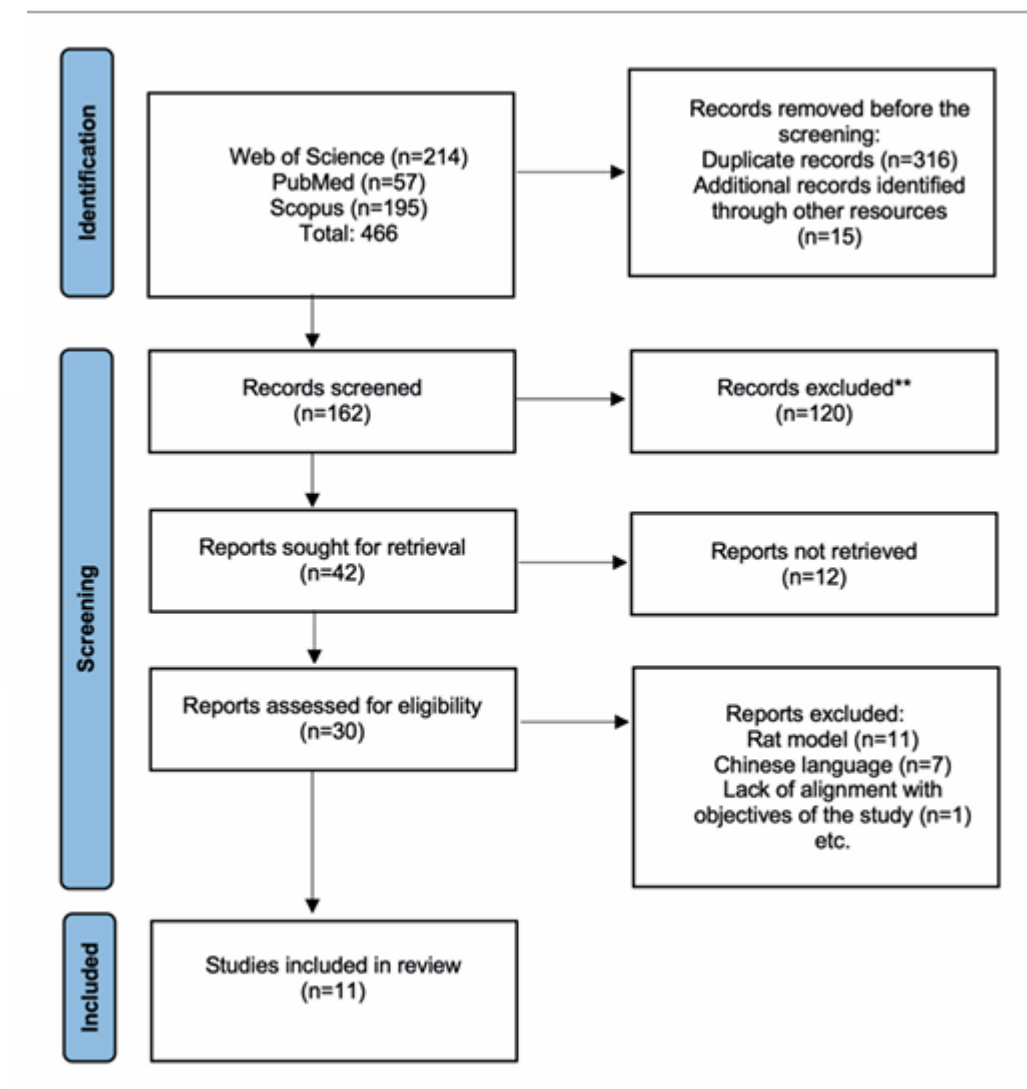


Figure 1. Flowchart of the selected study.



uitkomstmaten



zichtbare letsels

pijnscore

QALY's

begrepen voelen

gezond voelen

pijn lijden

seks en liefde

kunnen werken

PROMS

uitkomstmaten



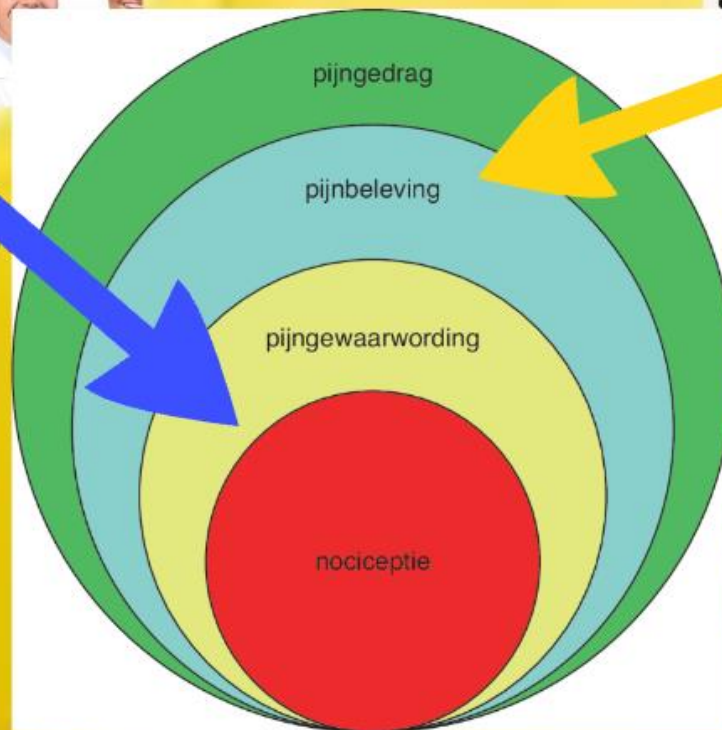
Geef endometriose
een
gezicht
en een
stem



zichtbare le

pijnscore

QALY's



begrepen voelen

gezond voelen

pijn lijden

seks en liefde

kunnen werken

PROMS

Evidence based Be-Wijs

Experience based Be-Leef

Leef Wijs



UN-FUN fact 15: proposed KCE ? Level of evidence?

Assessment of the patient-centredness of care





KCE TRIALS

Budget: 3 Million €

Endometriosis care demands your expertise.
Let's bridge the gaps in knowledge and elevate patient outcomes.

2024 themed call for proposals on endometriosis care

✔ Comparative effectiveness, non-commercial aim, Belgian sponsor or participation to international study



Remember: sociocultural construct etc

Reproductive BioMedicine and Society Online (2022) 14, 20–27



www.sciencedirect.com
www.rbmsociety.com



SYMPOSIUM: RISK, INNOVATION AND IGNORANCE PRODUCTION
ORIGINAL ARTICLE

The missed disease? Endometriosis as an example of 'undone science'

Nicky Hudson

Centre for Reproduction Research, De Montfort University, Leicester, UK



Nicky Hudson is a medical sociologist with particular expertise in social and cultural significance of reproduction, infertility and assisted reproductive technology. Her work also focuses on the sociology of chronic illness. Uniting these themes is an emphasis on questions of individual-biomedicine-society relations. She has received funding for her work from the Economic and Social Research Council, the Wellcome Trust, Foundation for Sociology of Health and Illness, and the National Institute for Health Research. Her research is characterized by a strong commitment to interdisciplinary collaboration, social translation and impact. She leads the Centre for Reproduction Research, an interdisciplinary centre of expertise dedicated to the production of scholarship on the social, cultural and political aspects of human reproduction, based at the Faculty of Health and Life Sciences at De Montfort University (UK).

What is Social REALITY?

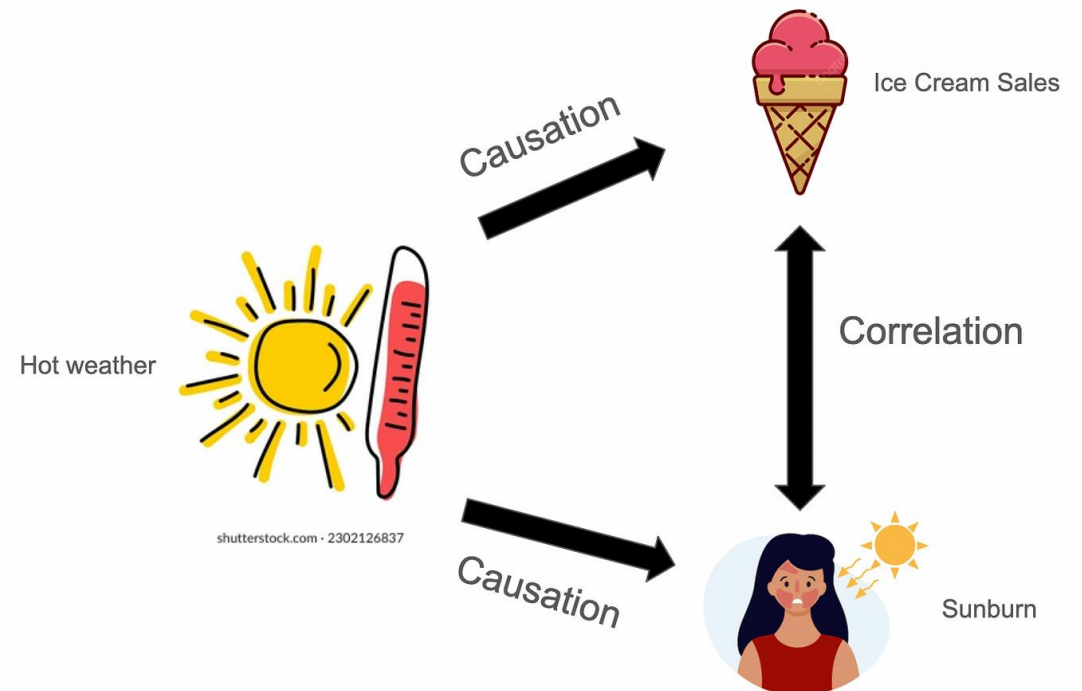
- **Thomas theorem:** "If people define situations as real, they are real in their consequences"
- To understand human inter-actions and relations, sociologists have to understand both **reality**, and **perceived reality**.



W. I. Thomas
1863 - 1947

UN-FUN fact 16: there is no lack of information, but it s a mess

- See fact 3
- E.g risk factors mess up causes, associations and consequences



Genetic and Familial Factors

- **Family History:**
- **Genetic Polymorphisms: Reproductive and Menstrual Factors**
- Menstrual Characteristics:
 - **Menorrhagia:**
 - **Short Menstrual Cycle:**
 - **Early Menarche:**
- Parity and Infertility:
 - **Higher Parity:** inverse association
 - **Infertility:** Infertility is strongly associated with endometriosis. A large cross-sectional study of Swedish female twins found a strong association between infertility and endometriosis [5](#).

Lifestyle and Behavioral Factors

- Smoking and Alcohol Consumption:
 - **Smoking?**
 - **Alcohol?**
- Diet and Physical Activity:
 - **Diet:** meat = risk; vegetables = protective
 - **Physical Activity:** protective

Psychological and Environmental Factors

- **Depression and Stress:**
- **Occupational Factors:** nights shifts, endocrine-disrupting chemicals .

Hormonal and Metabolic Factors

- **Body Mass Index (BMI):** Lower BMI is associated with an increased risk of endometriosis.
- **Hormonal Factors:** Use of oral contraceptives (OC) shows an inverse association with

Summary



Informatie over endometriose

Patiëntenbrochure
gebaseerd op de ESHRE Richtlijn Endometriose

Versie 2022
www.eshre.eu/guidelines

Ontwikkeld ism



Inleiding

Dit boekje is voor jou als:

- U bent gediagnosticeerd met endometriose
- U tekenen of symptomen heeft van endometriose en u denkt dat u endometriose heeft

Good info!

UN-FUN fact 17: those caring for people with endometriosis also need support

- Family
- Professionals :
 - 40–75 percent of Ob-Gyns experience some form of professional burnout (e.g., losing control, conflicting demands on time, or diminishing sense of worth)

Smith RP, Rayburn WF. Burnout in Obstetricians-Gynecologists: Its Prevalence, Identification, Prevention, and Reversal. *Obstet Gynecol Clin North Am.* 2021 Mar;48(1):231-245. doi: 10.1016/j.ogc.2020.11.008.

PMID: 33573788.

<https://www.acog.org/news/news-articles/2019/10/why-ob-gyns-are-burning-out>

UN-FUN fact 18: environmental factor are not proven causes - associations

- Association is no causation
- Se fact 16

UN-FUN fact 19: het gaat over vrouw specifieke zorg

FEITEN & CIJFERS

7 TOT 10 JAAR

◀ Het duurt gemiddeld 7 tot 10 jaar voordat vrouwen de diagnose endometriose krijgen

30 TOT 50%

Schatting: ADHD bij meisjes wordt in 30 tot 50 procent van de gevallen niet herkend

ONTERECHT

Meisjes krijgen vaak onterecht eerst een andere diagnose dan ADHD, zoals een bipolaire stoornis, angststoornis of stemmingsstoornis. ▶

UN-FUN fact 20: there is no cure!

UN-FUN fact 20+: doesn't stop at menopause

Summary

Postmenopausal endometriosis presents with symptoms such as pelvic pain, dyspareunia and bowel or urinary issues, complicating diagnosis due to the absence of menstrual cycles. Management typically involves surgical intervention, cautious use of HRT, and individualized pain management strategies. The risk of recurrence and malignant transformation remains a concern, highlighting the need for further research to inform clinical guidelines.

Key statistics and findings

- **Symptoms:** Persistent pelvic pain, abnormal uterine bleeding.
- **Common Locations:** Pelvis, uterus, ovaries, fallopian tubes, bladder, bowel.
- **Management:** Surgical intervention, cautious HRT use, individualized pain management.

This comprehensive overview underscores the complexity of managing endometriosis in

1 [Postmenopausal endometriosis: a challenging condition beyond menopause.](#)

Menopause (New York, N.Y.), A Vallée et al, 2024

2 [Endometriosis in menopause: a](#)

Endometriosis, M

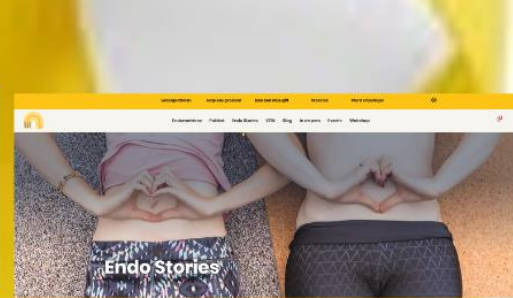
[women with a history of endometriosis: a systematic review.](#)

Human reproduction update, LC Gemmell

RR vs no endo 4,2 (3,5-4,9)

Types of Malignancies: Predominantly epithelial ovarian cancers (endometrioid adenocarcinoma and clear cell carcinoma), other Müllerian-type tumors, and sarcomas.

endoM^Etriosis



7 maart 2023

March 2023

**ENDOMETRIOSIS
ACTION MONTH**



**5 misverstanden
over endometriose**

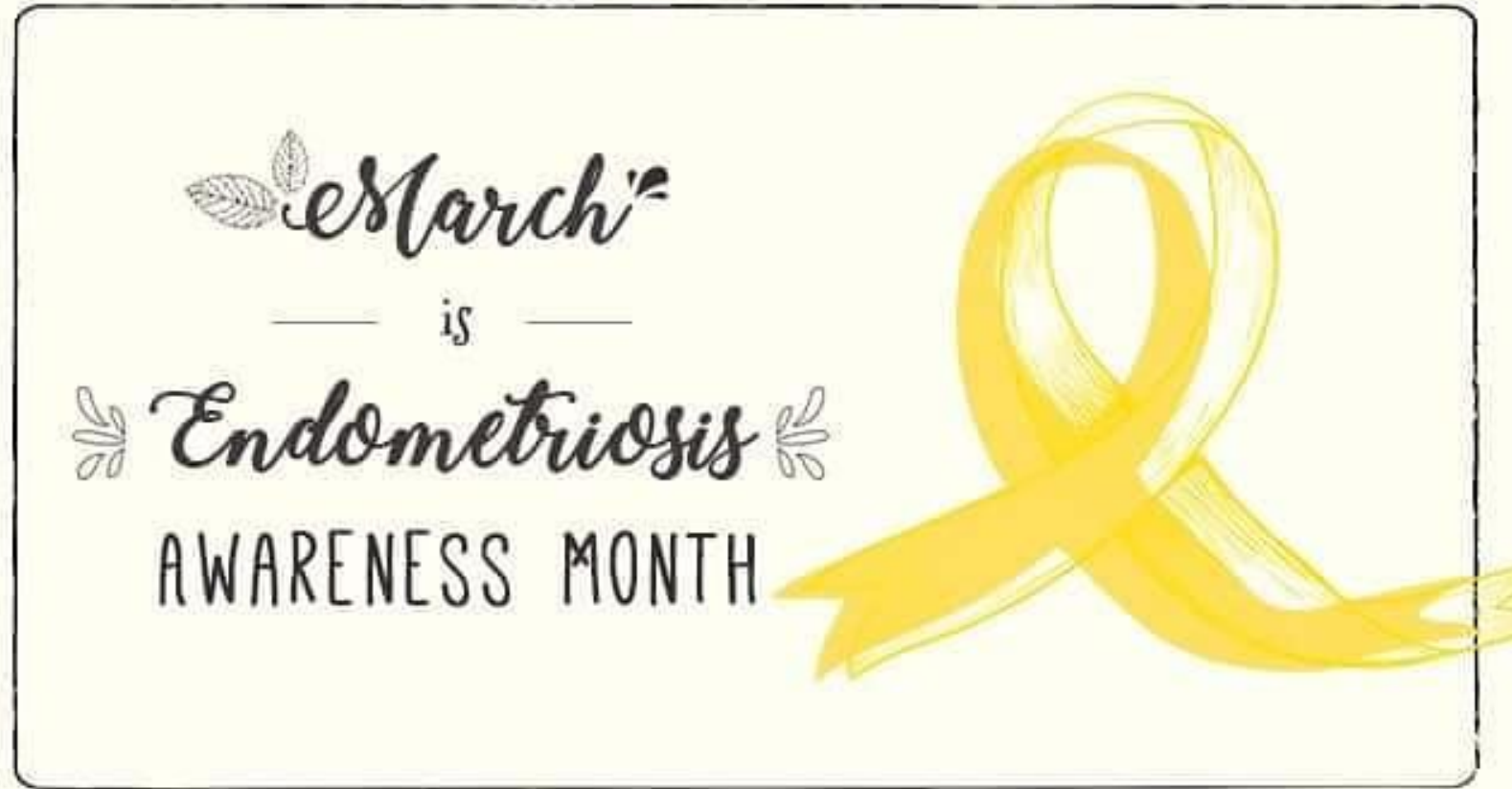


Tien tot twintig procent van de vrouwen lijdt aan endometriose, een aandoening die meestal gepaard gaat met een pijnlijke menstruatie om heel wat andere klachten. Als patiënt kun je gelukkig ook zelf iets doen om je klachten te verminderen, zegt gynaecoloog dr. Christel De Bruyn. Vijf misverstanden over endometriose op de scherp.

Dr. Christel De Bruyn
Gynaecoloog



FUN fact 2,



LET'S TALK ABOUT ENDOMETRIOSE

DR. MED. STEFANIE BURGHAUS • DR. SIGRID MÄRZ



Endometriose-Expertin
Stefanie Burghaus



Symptome verstehen und
mit der richtigen Therapie selbst-
bestimmt Schmerzen lindern.

Stiftung
Warentest
test

