Qualitative and quantitative aspects of sex life in the context of endometriosis: a multicentre case control study

Valerie Bernays, Alexandra Kohl Schwartz, Kirsten Geraedts, Martina Rauchfuss, Monika Maria Wölfler, Felix Haeberlin, Stephanie von Orelli, Markus Eberhard, Bruno Imthurn, Daniel Fink, Patrick Imesch, Brigitte Leeners

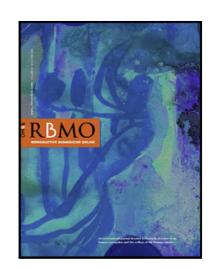
PII: \$1472-6483(19)30795-3

DOI: https://doi.org/10.1016/j.rbmo.2019.10.015

Reference: RBMO 2287

To appear in: Reproductive BioMedicine Online

Received date: 14 July 2019
Revised date: 27 October 2019
Accepted date: 30 October 2019



Please cite this article as: Valerie Bernays, Alexandra Kohl Schwartz, Kirsten Geraedts, Martina Rauchfuss, Monika Maria Wölfler, Felix Haeberlin, Stephanie von Orelli, Markus Eberhard, Bruno Imthurn, Daniel Fink, Patrick Imesch, Brigitte Leeners, Qualitative and quantitative aspects of sex life in the context of endometriosis: a multicentre case control study, *Reproductive BioMedicine Online* (2019), doi: https://doi.org/10.1016/j.rbmo.2019.10.015

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo editing, typesetting, and review of the resulting proof before it is published in its final form. Please note that during this process changes will be made and errors may be discovered which could affect the content. Correspondence or other submissions concerning this article should await its publication online as a corrected proof or following inclusion in an issue of the journal.

© 2019 Published by Elsevier Ltd on behalf of Reproductive Healthcare Ltd.

Highlights

- Women with endometriosis have less often sexual intercourse and petting than control women
- Women with endometriosis desire higher levels of sexual activity then their current level
- As to expect dyspareunia is negatively correlated with sexual activity
- Potentially pain-free sexual options are used to a limited degree and consequently represent a valuable resource to augment sexual activity



Qualitative and quantitative aspects of sex life in the context of endometriosis: a multicentre case control study

Valerie Bernays¹, Alexandra Kohl Schwartz^{1,2}, Kirsten Geraedts¹, Martina Rauchfuss³, Monika Maria Wölfler⁴, Felix Haeberlin⁵, Stephanie von Orelli⁶, Markus Eberhard⁷, Bruno Imthurn¹, Daniel Fink⁸, Patrick Imesch⁸, and Brigitte Leeners¹

- 1) University Hospital Zurich, Department of Reproductive Endocrinology, Switzerland
- 2) University Hospital Berne, Division of Gynecological Endocrinology and Reproductive Medicine, Switzerland
- 3) Charité Berlin, Department of Psychosomatics, Germany
- 4) University Hospital Graz, Department of Obstetrics and Gynecology, Division of Gynecologic Endocrinology and Reproductive Medicine, Austria
- 5) Cantonal Hospital St. Gallen, Department of Gynecology and Obstetrics, Switzerland
- 6) Triemli Hospital Zurich, Department of Gynecology and Obstetrics, Switzerland
- Canton Hospital Schaffhausen, Department of Gynecology and Obstetrics, Switzerland
- 8) University Hospital Zurich, Department of Gynecology, Switzerland

Running title: Sexual activity in endometriosis

Declarations of interest: none

Correspondence address:

Prof. Dr. med. Brigitte Leeners

Department of Reproductive Endocrinology

Frauenklinikstr. 10

CH 8091 Zürich

Tel.: 0041.44.255.50.09

E-Mail: Brigitte.Leeners@usz.ch

Abstract

Research question: What are the specific characteristics of sexual activity in women with

endometriosis compared to women without endometriosis?

Design: Multicentre case control study. Participants were recruited in university hospitals,

district hospitals, and doctor's offices in Germany, Switzerland and Austria. A total of 565

women with endometriosis were pair-matched to 565 control women by age and ethnic

background. Diagnosis of endometriosis was confirmed by histology and disease stage was

classified according to ASRM criteria. Data on sexuality were collected using selected

questions from the Brief Index of Sexual Function and the Sexual History Form.

Results: Altogether, 69.1% of women with endometriosis and 77.8% of control women

engaged in sexual activity during the month prior to the study period (p<0.001). Overall,

42.3% of endometriosis-affected women and 30.5% of the control women desired a higher

frequency of sexual activity (p=0.001). Petting/foreplay and vaginal sexual intercourse were

reported to be practiced less often by women with endometriosis. Frequencies for

masturbation, reciprocal masturbation, oral and anal sex were similar in both groups.

Dyspareunia was negatively correlated with sexual activity (OR 2.42, 95%CI [1.26, 4.63]),

while chronic pain showed no association with sexual activity (OR 1.35, 95%CI [0.93, 1.96]).

Conclusions: Women with endometriosis have lower frequencies of petting/foreplay as well

as of vaginal sexual intercourse than control women; this difference has to be attributed, at

least in part, to dyspareunia. Potentially pain-free sexual options are used to a limited

degree. As endometriosis-affected women desire higher levels of sexual activity, sexual

counselling should be included in medical support.

Key message: Women with endometriosis desire higher frequencies of sexual activity and

use painfree options only to a limited extent. Therefore, sexual counselling should be offered

as a standard component of medical support for endometriosis.

Key words: Endometriosis, dyspareunia, sexuality, sexual activities

Funding: None

Trial registration number: ClinicalTrials.gov, NCT 02511626

Introduction

Sexual health, ie the physical, emotional, mental, and social wellbeing in relation to sexuality (WHO, 2015), is a fundamental aspect of the quality of human life (Arrington et al., 2004). Endometriosis, with its physical symptoms of dyspareunia, chronic pelvic pain, fatigue, and infertility (Kennedy et al., 2005; Ramin-Wright et al., 2018), as well as psychological symptoms such as depression and anxiety (De Graaff et al., 2016; Facchin et al., 2017; Friedl et al., 2015) is known to have a negative impact on sexuality (Barbara et al., 2017; Franck et al., 2018; Leroy et al., 2016; Pluchino et al., 2016; Tripoli et al., 2011). Although, surgical and hormonal treatment of endometriosis can ease endometriosis-related symptoms it does not necessarily allow normal sexual function. Given this background, the prevalence of sexual dysfunction in women with endometriosis varies between 30% and 70%, depending upon the definitions used (Barbara et al., 2017; Donato et al., 2014; Fritzer et al., 2013). To develop adequate counselling adjusted to the specific characteristics of sexuality in the context of endometriosis differentiated knowledge on associations between endometriosis, physical as well as psycho-social endometriosis-related symtpoms and sexuality in couples dealing with endometriosis is mandatory. However, available research has focused on dyspareunia and, sexual needs in the context of endometriosis. Associations between endometriosis and specific sexual activities or strategies to adapt sexuality to limitations imposed by endometriosis, have not yet been systematically investigated (Donato et al., 2014; Evangelista et al., 2014; Fritzer et al., 2013).

Therefore, we (i) evaluated qualitative aspects of sexual activity in women with endometriosis compared to control women (sexual activity during the last month, estimated importance of sexuality, perception of the frequency of sexual contacts, initiation of sexual contact by either the male of the female partner), (ii) compared the quantity of sexual activities (kissing, masturbation, reciprocal masturbation, petting and foreplay, oral sex, vaginal sexual intercourse, anal sex) among women with and without endometriosis, and (iii) investigated the association between endometriosis-related symptoms (dysmenorrhea, dyspareunia, chronic pain, infertility) and possible confounders with sexual activity.

Material and Methods

Study design

This investigation of sexuality is part of a multicentre case control study evaluating quality of life and risk factors of endometriosis (Liebermann et al., 2018; Ramin-Wright et al., 2018; Schwartz et al., 2019; Sperschneider et al., 2019). Data from a set of internationally validated questionnaires supplemented with questions developed by specialists for endometriosis of the University Hospital of Zurich, the Charité Berlin and the central board of endometriosis self-help groups in Germany as well as information extracted from the study participants medical charts was compared between women with surgically confirmed endometriosis and control women without such a diagnosis. The STROBE criteria were used to draft the manuscript (von Elm et al., 2007).

Study participants

Study participants were recruited between December 2010 and June 2016 in thirteen university or district hospitals, as well as associated private practices in Austria, Germany, and Switzerland. Additionally, a small number of participants (n = 66) were recruited from selfhelp groups for endometriosis patients in Germany. These women were older and had a longer time period since the initial diagnosis of endometriosis, but exhibited no differences in educational level when compared to the other study participants. All women signed written informed consent forms for study participation as well as confirming their diagnoses by medical charts.

All study participants had to be sufficiently fluent in German and had to be able to understand and complete the questionnaire. Patients were included if the diagnosis of endometriosis could be confirmed by re-evaluation of histology and operation report according to rASRM criteria (Canis et al., 1997), without any further exclusion criteria. Control women with dysmenorrhea, dyspareunia or any other symptom suspective of endometriosis were only included after surgical exclusion of endometriosis. Control women were pair-matched to the patient cohort by age and ethnic background. Data from 565 women diagnosed with

endometriosis and from 565 control women were available for the present analysis. Post hoc power analysis based on the results of sexual activity was 89.8%.

Evaluation of sexuality and endometriosis-related symptoms

The evaluation of sexuality was based on questions focusing on sexual behaviour selected from the Brief Index of Sexual Functioning Form and the Sexual History Form. The BISF-W is an internationally validated questionnaire designed to measure female sexual function with Cronbach's alpha values of 0.82 and higher (Rosen et al., 2000). The Sexual History Form is a widely used questionnaire to investigate sexual function, dysfunction, and satisfaction, with good internal consistency for the female functioning score. The item-total correlation ranges from 0.18 to 0.85 with the majority of values having a validity between 0.5 and 0.7 (Creti, 1998). The present work focuses on 9 questions, 6 of the BISF-W (BISF-1, BISF-2, BISF-7, BISF-8, BISF-12, BISF-20) and 3 of the Sexual History Form (SHF-8, SHF-9, SHF-30) (see Appendix), chosen to investigate the frequency and type of sexual activities in the context of endometriosis. The Cronbach alpha value for the evaluated questions was 0.63 in the endometriosis and 0.68 in the control group.

Dysmenorrhea, dyspareunia, chronic pain (see Appendix) and infertility were evaluated for their associations with different sexual activities. Pain intensity was assessed with a visual analog scale (VAS, range 0-10 from 0 = no pain to 10 = strongest pain) for dyspareunia and chronic pain. To adjust for confounding factors, previous diseases known to interfere with sexuality (see Table 1a) were included in the analysis. Infertility was defined as not conceiving after one year of regular unprotected intercourse or irregardless of time frame in case of a confirmed etiology (Pfeifer et al., 2013).

Ethical approval

The study was approved by the Swiss ethics commission as well as by the ethic boards of the participating hospitals. The study was conducted in agreement with the guidelines of the World Medical Association Declaration of Helsinki 1964, updated in October 2013.

Statistics

Statistical analyses were performed with IBM SPSS Statistics Version 23.

Descriptive analysis compared demographic characteristics, background, clinical endometriosis-related symptoms, sexual activity among women with and without endometriosis and depicted the clinical history of endometriosis-affected women. Paired ttest was used to compare continuous variables and Pearson's x2 test for qualitative variables. In the endometriosis group, we computed univariate logistic regression with the selected demographic data (age, civil status, partnership duration, parity, happiness with partnership, time since diagnosis of endometriosis, depression) and endometriosis-related symptoms (dysmenorrhea, dyspareunia, chronic pain in general, chronic pelvic pain (pelvis, vagina, anus), infertility) as explanatory and sexual activity as response variable. We detail the odds ratios (OR) with a 95% confidence interval (CI). Positive OR represent a higher probability of no sexual activity. All tests were two tailed. Applying the Bonferroni Holm method to correct for multiple testing zero hypotheses with a p-value below the level of 0.003 was rejected. A *p*-value below 0.05 was still considered to be a tendency.

Results

Table 1a presents demographic characteristics, clinical background, disease symptoms, and characteristics of endometriosis. Demographic data of women with a diagnosis of endometriosis and control women showed no statistically significant differences except for parity. Women with endometriosis had received significantly more often psychiatric treatment than control women, mainly because of depression or anxiety. Table 1b (supplementary files) presents characteristics of endometriosis. Altogether, women with endometriosis (E) suffered significantly more often from dyspareunia compared to women of the control group (C) ("usually to almost always": E 18.8%, C 4.2%; "sometimes": E 33.9%, C 13.8%, p < 0.001).

We observed significant differences regarding qualitative and quantitative (frequencies) aspects of sexuality among women with and without endometriosis. The findings are

reported below and the details are presented in table 2a and 2b. Overall, sexuality was considered as an important factor for the quality of life women in both, 67.2% of the women in the endometriosis group (E) and 69% of the control women (C) (p=0.043). This revealed a marginally significant difference which originates in the subgroups who consider sexuality as either important or very important. Women with endometriosis were significantly less sexually active during the month prior to the study period than women without endometriosis (p<0.001). Also, women with endometriosis perceived the frequency of sexual contacts significantly more often as "too low" when compared to control women (E: 42.3%, C: 30.5%, p<0.001). No significant differences could be demonstrated in the initiation of sexual contacts by the male or the female partner (p=0.291). Our data revealed a significantly lower frequency in the performance of petting/foreplay in the endometriosis than in the control group ("never": E: 31.3%, C 26.6%, p=0.003), and showed a marginally significant lower frequency of vaginal sexual intercourse among the two groups ("never": E: 28.3%, C: 23.3%, p=0.021). The time spent on foreplay (p=0.608), or on vaginal sexual intercourse to the partner's orgasm (p=0.681) was similar between the two groups.

Table 3 presents the results of the univariate logistic regression analysis examining the association among selected demographic data and pain symptoms with sexual activity for women with endometriosis. Being single (OR 11.59, 95% CI [6.64, 20.24]), a partnership duration of more than a year (OR 1.2, 95% CI [1.02, 1.47]), depression (OR 1.93, 95% CI [1.2, 3.11]) and a high frequency of dyspareunia (OR 2.42, 95% CI [1.26, 4.63]) were associated with a higher probability of no sexual activity. Infertility (OR 0.56, 95% CI [0.34, 0.92]) and being unhappy with the partnership (OR 0.19, 95% CI [0.07, 0.49]) were associated with a higher probability of sexual activity. Age, parity, time to diagnosis, chronic pelvic pain and dysmenorrhea showed no association with sexual activity.

Discussion

Whether affected by endometriosis or not, the majority of the study participants estimated sexual activity as an important component of a fulfilling life. Similar findings are reported in the context of other chronic illnesses (Basson, 2010), highlighting the importance of sexuality regardless of the health status. In our study 42.3% of endometriosis-affected women reported the frequency of their sexual activities to be less than desired, which is surprising, as endometriosis is often accompanied by sexual dysfunction including lack of sexual desire (Montanari et al., 2013) and reduced arousal or lubrication (Jia et al., 2013). Women with endometriosis do not report avoiding the initiation of sexual contacts even if possibly accompanied by pain. This may be due to a desire for intimacy, a desire for meeting anticipated expectations of the partner, or a reluctance to allow endometriosis to affect another aspect of their life (Denny and Mann, 2007).

Overall, women with endometriosis were less sexually active than women in the control group. Data regarding frequencies of specific sexual activities, we revealed that women with endometriosis engaged less often in petting/foreplay and vaginal sexual intercourse (Ferrero et al., 2005; Montanari et al., 2013). However, they exhibit no difference in either masturbation or reciprocal masturbation when compared to women without endometriosis. Likewise, frequencies of oral sex were similar among the control and endometriosis group, in accordance with the findings of previous studies (Leichliter et al., 2007). Dyspareunia as a frequent symptom of endometriosis (Ferrero et al., 2005; Montanari et al., 2013; Pluchino et al., 2016) likely explained the reduced frequency of sexual activities, as reported by previous studies (Denny and Mann, 2007; Laumann et al., 1999), but women with endometriosis seem not to compensate by other pain-free sexual options. However, it is worth noting that sexual activity depends not only on dyspareunia but is determined by a complex network of personal, social and situational factors. Psychiatric comorbidities, such as depression and anxiety are more prevalent in women with endometriosis and are known to negatively influence frequency of sexual activity (Laganà et al., 2017). Furthermore, the specific

localisation of endometrial lesions eg. infiltration of the rectovaginal septum, or advanced stages of the disease, can negatively influence sexuality (Cozzolino et al., 2018).

In agreement with previous literature, neither dysmenorrhea nor general or specific pelvic chronic pain showed any association with the frequency of sexual activity (Montanari et al., 2013), although endometriosis-associated pain is a very frequent symptom reported in our and other studies (Allen and Goldberg, 2009; Pluchino *et al.*, 2016; Barbara *et al.*, 2017). As dysmenorrhea occurs within a limited timeframe, penetrative sexual activity can be avoided during this period and often is, because the bleeding may be perceived as unpleasant (Allen and Goldberg, 2009). In contrast, the negative impact of pain apart from menstruation is harder to avoid. As we asked explicitly about dyspareunia and dysmenorrhea, women may additionally have reported only chronic pain unrelated to genital organs; which could explain the lack of an association with sexuality. Otherwise, a higher pain tolerance, a higher rating of the importance of sexual activity, or neglecting pain to meet anticipated/real sexual expectations of the partner may explain this observation. In agreement with other research we found infertility to be positively associated with sexual activity (Whelan, 2007). However, it may also be associated with poor sexual function and avoidance of intercourse (Wischmann, 2010).

To adapt sexual activities to the specific needs resulting from endometriosis-associated dyspareunia, increasing the frequency og pain free sexual activities or using alternative positions in vaginal sexual intercourse (Denny and Mann, 2007) may present valuable options. However, identifying and discussing sexual needs is nowadays still difficult for couples as well as for health care professionals (Donato et al., 2014; Fritzer et al., 2013; Lindau et al., 2011).

Endometriosis-specific medical and surgical therapies may reduce dyspareunia and consequently improve sexual function, however hormonal treatment may interfere with sexual desire (Caruso et al., 2016; Farthmann et al., 2016; Pluchino et al., 2016; Vercellini et

al., 2003; Vitale et al., 2016). Following this discussion, the improvement of sexual activity in women with endometriosis includes established endometriosis-specific surgical and medical treatment (carefully out-wheighting beneficial and undesired effects) as well as counselling on behavioural strategies. We therefore encourage health-care providers to address sexuality and make use of current research. when treating endometriosis. A multidisciplinary approach including gynaecologists, fertility specialists, sexologists and psychotherapists should be offered to provide best possible support (La Rosa et al., 2019). Future studies should address effects of such support on sexuality in couples dealing with endometriosis.

The distinctive quality of this study stems from the high number of women recruited in different clinical settings and the pair-matching of women with and without endometriosis all providing differentiated sexuality-specific and endometriosis-specific information. Potential sources of bias may include participant self-selection, as all women had to have the necessary resources (time, language) and the willingness to talk about intimate aspects of life. The lack of these resources represents the main reason for sample attrition. The return rate in the control group was almost half that of the case group. This may reflect a greater willingness of endometriosis-affected women to contribute to collecting endometriosisspecific data. Otherwise, it may reflect a selection among control women with special attitudes or concerns towards sexuality. All diagnoses of endometriosis were histologically confirmed. As endometriosis may also be asymptomatic, we cannot exclude that some of the control women had endometriosis, which would result in underestimation of our findings. Although we evaluated psychiatric comorbidities, their prevalence especially in the control group was not sufficiently high to provide reliable data on the associations between endometriosis, psychiatric disorders and sexual activity. All women were recruited in comparable countries in terms of access to health care and standard of living, so that results cannot be generalized. Also, we focused on heterosexual couples.

The use of established, validated questionnaires made it possible for respondents to answer personal questions in a private environment. With a Cronbach's alpha of 0.63 and 0.68 the

internal consistency of the selected questions is rather limited. However, we considered the selection of questions from an international validated questionnaire as the best option to gain an insight into the aspects of sexuality in women with endometriosis we wanted to explore. The purpose of this work was to focus on differences in frequencies as well as types of sexual activities and their association with endometriosis related symptoms, e.g. our results do not provide a fully comprehensive analysis of sexuality and sexual disorders.

Conclusion

Motivation and interest in sexual activity are similar in control women and women affected by endometriosis, but women with endometriosis desire higher levels of sexual activity. Women with endometriosis have lower frequencies of petting/foreplay and vaginal sexual intercourse in comparison to the control group what is associated with dyspareunia. Currently, valuable resources to help expand the options for pain-free fulfilling sexual activities are not accessed. Women with endometriosis could benefit from sexual counselling, which should ideally be offered by a multidisciplinary team.

Funding

No external funding was obtained for this study.

Conflict of interest

None.

Acknowledgements

The authors thank Ulrike Held for statistical assistance. We gratefully acknowledge the support of Brigitte Alvera, Theodosia Charpidou, Anna Dietlicher, Franziska Graf, Franka Grischott, Elvira Gross, Nicole Kuenzle, Judith Kurmann, Christina Liebermann, Ilona Lukas, Elena Lupi, Lina Sperschneider, Sarah Schaerer, Karoline Stojanov, as well as the governing

body of the German selfhelp groups for endometriosis in data collection. We thank Esther and Jonas Rosen Bernays as native speakers for their meticulous linguistic revision of the manuscript.

Research data

Due to the sensitive nature of the questions asked in this study, survey respondents were assured raw data would remain confidential and would not be shared.

References

- Allen, K.R., Goldberg, A.E., 2009. Sexual activity during menstruation: A qualitative study. J. Sex Res. 46, 535–545. https://doi.org/10.1080/00224490902878977
- Arrington, R., Cofrancesco, J., Wu, A.W., 2004. Questionnaires to measure sexual quality of life. Qual. Life Res. 13, 1643–1658. https://doi.org/10.1007/s11136-004-7625-z
- Barbara, G., Facchin, F., Buggio, L., Somigliana, E., Berlanda, N., Kustermann, A., Vercellini, P., 2017a. What Is known and unknown about the association between endometriosis and sexual functioning: A systematic review of the literature. Reprod. Sci. 24, 1566–1576. https://doi.org/10.1177/1933719117707054
- Barbara, G., Facchin, F., Meschia, M., Berlanda, N., Frattaruolo, M.P., Vercellinl, P., 2017b.

 When love hurts. A systematic review on the effects of surgical and pharmacological treatments for endometriosis on female sexual functioning. Acta Obstet. Gynecol.

 Scand. 96, 668–687. https://doi.org/10.1111/aogs.13031
- Basson, R., 2010. Sexual function of women with chronic illness and cancer. Women's Heal. 6, 407–429. https://doi.org/10.2217/whe.10.23
- Canis, M., Donnez, J.G., Guzick, D.S., Halme, J.K., Rock, J.A., Schenken, R.S., Vernon, M.W., 1997. Revised American Society for Reproductive Medicine classification of endometriosis: 1996. Fertil. Steril. 67, 817–821. https://doi.org/10.1016/S0015-0282(97)81391-X

- Caruso, S., Iraci, M., Cianci, S., Fava, V., Casella, E., Cianci, A., 2016. Comparative, open-label prospective study on the quality of life and sexual function of women affected by endometriosis-associated pelvic pain on 2 mg dienogest/30 µg ethinyl estradiol continuous or 21/7 regimen oral contraceptive. J. Endocrinol. Invest. 39, 923–931. https://doi.org/10.1007/s40618-016-0460-6
- Cozzolino, M., Magro-Malosso, E.R., Tofani, L., Coccia, M.E., 2018. Evaluation of sexual function in women with deep infiltrating endometriosis. Sex. Reprod. Healthc. 16, 6–9. https://doi.org/10.1016/J.SRHC.2017.12.005
- Creti, L., 1998. Global sexual functioning: A single summary score for Nowinski and LoPiccolo's Sexual History Form (SHF). Handb. Sex. Meas. 261–267.
- De Graaff, A.A., Van Lankveld, J., Smits, L.J., Van Beek, J.J., Dunselman, G.A.J., 2016.

 Dyspareunia and depressive symptoms are associated with impaired sexual functioning in women with endometriosis, whereas sexual functioning in their male partners is not affected. Hum. Reprod. 31, 2577–2586. https://doi.org/10.1093/humrep/dew215
- Denny, E., Mann, C.H., 2007. Endometriosis-associated dyspareunia: the impact on women's lives. J. Fam. Plan. Reprod. Heal. care 33, 189–93. https://doi.org/10.1783/147118907781004831
- Donato, N. Di, Montanari, G., Benfenati, A., Monti, G., Bertoldo, V., Mauloni, M., Seracchioli, R., 2014. Do women with endometriosis have to worry about sex? Eur. J. Obstet.

 Gynecol. Reprod. Biol. 179, 69–74. https://doi.org/10.1016/j.ejogrb.2014.05.022
- Evangelista, A., Dantas, T., Zendron, C., Soares, T., Vaz, G., Oliveira, M.A.P., 2014. Sexual function in patients with deep infiltrating endometriosis. J. Sex. Med. 11, 140–145. https://doi.org/10.1111/jsm.12349
- Facchin, F., Barbara, G., Dridi, D., Alberico, D., Buggio, L., Somigliana, E., Saita, E., Vercellini, P., 2017. Mental health in women with endometriosis: searching for predictors of psychological distress. Hum. Reprod. 32, 1855–1861.
 https://doi.org/10.1093/humrep/dex249
- Farthmann, J., Mengel, M., Henne, B., Grebe, M., Watermann, D., Kaufhold, J., Stehle, M.,

- Fuenfgeld, C., 2016. Improvement of pelvic floor-related quality of life and sexual function after vaginal mesh implantation for cystocele: primary endpoint of a prospective multicentre trial. Arch. Gynecol. Obstet. 294, 115–121. https://doi.org/10.1007/s00404-016-4014-0
- Ferrero, S., Esposito, F., Abbamonte, L.H., Anserini, P., Remorgida, V., Ragni, N., 2005.

 Quality of sex life in women with endometriosis and deep dyspareunia. Fertil. Steril. 83, 573–579. https://doi.org/10.1016/j.fertnstert.2004.07.973
- Franck, C., Poulsen, M.H., Karampas, G., Giraldi, A., Rudnicki, M., 2018. Questionnaire-based evaluation of sexual life after laparoscopic surgery for endometriosis: a systematic review of prospective studies. Acta Obstet. Gynecol. Scand. 97, 1091–1104. https://doi.org/10.1111/aogs.13369
- Friedl, F., Riedl, D., Fessler, S., Wildt, L., Walter, M., Richter, R., Schüßler, G., Böttcher, B., 2015. Impact of endometriosis on quality of life, anxiety, and depression: an Austrian perspective. Arch. Gynecol. Obstet. 292, 1393–1399. https://doi.org/10.1007/s00404-015-3789-8
- Fritzer, N., Haas, D., Oppelt, P., Renner, S., Hornung, D., Wölfler, M., Ulrich, U., Fischerlehner, G., Sillem, M., Hudelist, G., 2013. More than just bad sex: sexual dysfunction and distress in patients with endometriosis. Eur. J. Obstet. Gynecol. Reprod. Biol. 169, 392–396. https://doi.org/10.1016/j.ejogrb.2013.04.001
- Jia, S., Leng, J., Sun, P., Lang, J., 2013. Prevalence and associated factors of female sexual dysfunction in women with endometriosis. Obstet. Gynecol. 121, 601–6. https://doi.org/10.1097/AOG.0b013e3182835777
- Kennedy, S., Bergqvist, A., Chapron, C., D'Hooghe, T., Dunselman, G., Greb, R., Hummelshoj, L., Prentice, A., Saridogan, E., ESHRE Special Interest Group for Endometriosis and Endometrium Guideline Development Group, 2005. ESHRE guideline for the diagnosis and treatment of endometriosis. Hum. Reprod. 20, 2698– 704. https://doi.org/10.1093/humrep/dei135
- La Rosa, V.L., Barra, F., Chiofalo, B., Platania, A., Di Guardo, F., Conway, F., Di Angelo

- Antonio, S., Lin, L.-T., 2019. An overview on the relationship between endometriosis and infertility: the impact on sexuality and psychological well-being. J. Psychosom. Obstet. Gynecol. 1–5. https://doi.org/10.1080/0167482X.2019.1659775
- Laganà, A.S., Rosa, V.L. La, Rapisarda, A.M.C., Valenti, G., Sapia, F., Chiofalo, B., Rossetti, D., Frangež, H.B., Bokal, E.V., Vitale, S.G., 2017. Anxiety and depression in patients with endometriosis: impact and management challenges. Int. J. Womens. Health 9, 323. https://doi.org/10.2147/IJWH.S119729
- Laumann, E.O., Paik, A., Rosen, R.C., 1999. Sexual dysfunction in the United States. JAMA 281, 537. https://doi.org/10.1001/jama.281.6.537
- Leichliter, J.S., Chandra, A., Liddon, N., Fenton, K.A., Aral, S.O., 2007. Prevalence and correlates of heterosexual anal and oral sex in adolescents and adults in the United States. J. Infect. Dis. 196, 1852–1859. https://doi.org/10.1086/522867
- Leroy, A., Azaïs, H., Garabedian, C., Bregegere, S., Rubod, C., Collier, F., 2016.

 Psychologie et sexologie : une approche essentielle, du diagnostic à la prise en charge globale de l'endométriose. Gynécologie Obs. Fertil. 44, 363–367.

 https://doi.org/10.1016/j.gyobfe.2016.03.017
- Liebermann, C., Kohl Schwartz, A.S., Charpidou, T., Geraedts, K., Rauchfuss, M., Wölfler, M., von Orelli, S., Häberlin, F., Eberhard, M., Imesch, P., Imthurn, B., Leeners, B., 2018.

 Maltreatment during childhood: a risk factor for the development of endometriosis?

 Hum. Reprod. 33, 1449–1458. https://doi.org/10.1093/humrep/dey111
- Lindau, S.T., Surawska, H., Paice, J., Baron, S.R., 2011. Communication about sexuality and intimacy in couples affected by lung cancer and their clinical-care providers.

 Psychooncology. 20, 179–85. https://doi.org/10.1002/pon.1787
- Montanari, G., Di Donato, N., Benfenati, A., Giovanardi, G., Zannoni, L., Vicenzi, C., Solfrini,
 S., Mignemi, G., Villa, G., Mabrouk, M., Schioppa, C., Venturoli, S., Seracchioli, R.,
 2013. Women with deep infiltrating endometriosis: Sexual satisfaction, desire, orgasm and pelvic problem interference with sex. J. Sex. Med. 10, 1559–1566.
 https://doi.org/10.1111/jsm.12133

- Pfeifer, S., Goldberg, J., Lobo, R., Thomas, M., Widra, E., Licht, M., Collins, J., Cedars, M., Vernon, M., Davis, O., Gracia, C., Catherino, W., Thornton, K., Rebar, R., La Barbera, A., 2013. Definitions of infertility and recurrent pregnancy loss: a committee opinion. Fertil. Steril. 99, 63. https://doi.org/10.1016/j.fertnstert.2012.09.023
- Pluchino, N., Wenger, J.-M., Petignat, P., Tal, R., Bolmont, M., Taylor, H.S., BianchiDemicheli, F., 2016. Sexual function in endometriosis patients and their partners: effect
 of the disease and consequences of treatment. Hum. Reprod. Update 22, 762–774.
 https://doi.org/10.1093/humupd/dmw031
- Ramin-Wright, A., Schwartz, A.S.K., Geraedts, K., Rauchfuss, M., Wölfler, M.M., Haeberlin, F., von Orelli, S., Eberhard, M., Imthurn, B., Imesch, P., Fink, D., Leeners, B., 2018. Fatigue a symptom in endometriosis. Hum. Reprod. 33, 1459–1465. https://doi.org/10.1093/humrep/dey115
- Rosen, R., Brown, C., Heiman, J., Leiblum, S., Meston, C., Shabsigh, R., Ferguson, D., Goldstein, I., Berman, J., Fourcroy, J., Laan, E., Mitchel, J., Hays, J., Padma-Nathan, H., Phillips, N., 2000. The Female Sexual Function Index (FSFI): A multidimensional self-report instrument for the assessment of female sexual function. J. Sex Marital Ther. 26, 191–208.
- Schwartz, A.S.K., Gross, E., Geraedts, K., Rauchfuss, M., Wölfler, M.M., Häberlin, F., von Orelli, S., Eberhard, M., Imesch, P., Imthurn, B., Leeners, B., 2019. The use of home remedies and complementary health approaches in endometriosis. Reprod. Biomed. Online 38, 260–271. https://doi.org/10.1016/j.rbmo.2018.10.009
- Sperschneider, M.L., Hengartner, M.P., Kohl-Schwartz, A., Geraedts, K., Rauchfuss, M., Woelfler, M.M., Haeberlin, F., von Orelli, S., Eberhard, M., Maurer, F., Imthurn, B., Imesch, P., Leeners, B., 2019. Does endometriosis affect professional life? A matched case-control study in Switzerland, Germany and Austria. BMJ Open 9, e019570. https://doi.org/10.1136/bmjopen-2017-019570
- Tripoli, T.M., Sato, H., Sartori, M.G., de Araujo, F.F., Girão, M.J.B.C., Schor, E., 2011. Evaluation of quality of life and sexual satisfaction in women suffering from chronic

- pelvic pain with or without endometriosis. J. Sex. Med. 8, 497–503. https://doi.org/10.1111/j.1743-6109.2010.01976.x
- Vercellini, P., Aimi, G., Busacca, M., Apolone, G., Uglietti, A., Crosignani, P.G., 2003.

 Laparoscopic uterosacral ligament resection for dysmenorrhea associated with endometriosis: results of a randomized, controlled trial. Fertil. Steril. 80, 310–319. https://doi.org/10.1016/S0015-0282(03)00613-7
- Vitale, S.G., Caruso, S., Rapisarda, A.M.C., Valenti, G., Rossetti, D., Cianci, S., Cianci, A., 2016. Biocompatible porcine dermis graft to treat severe cystocele: impact on quality of life and sexuality. Arch. Gynecol. Obstet. 293, 125–131. https://doi.org/10.1007/s00404-015-3820-0
- von Elm, E., Altman, D.G., Egger, M., Pocock, S.J., Gøtzsche, P.C., Vandenbroucke, J.P., STROBE Initiative, 2007. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. Bull. World Health Organ. 85, 867–72.
- Whelan, E., 2007. 'No one agrees except for those of us who have it': endometriosis patients as an epistemological community. Sociol. Health Illn. 29, 957–982. https://doi.org/10.1111/j.1467-9566.2007.01024.x
- WHO, 2015. Defining sexual health [WWW Document]. WHO Rep. URL http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/ (accessed 12.30.16).
- Wischmann, T.H., 2010. Sexual disorders in infertile couples. J. Sex. Med. 7, 1868–76. https://doi.org/10.1111/j.1743-6109.2010.01717.x



Valérie Bernays is a research fellow within the team of the Department of Reproductive Endocrinology, University hospital Zurich. The present work represents her master thesis and she is currently working on her PhD on vulvodynia.

Table 1a: Demographic characteristics and pain symptoms in women with endometriosis and control women.

	Endometriosis	Control	p value
	women	women	
	n = 565	n = 565	
Age	n = 565	n = 565	0.783
(years ± SD)	38.01 ± 0.3	37.57 ± 0.38	
ВМІ	n = 562	n = 556	0.709
(mean ± SD)	23 ± 0.182	22.9 ± 0.174	
Ethnicity			0.089
Caucasian	89.7% (507/565)	86.5% (487/563)	
Education			0.190
Secondary education	27.3% (142/520)	29.4% (159/541)	
Apprenticeship	32.1% (167/520)	30.3% (164/541)	
Post graduated	37.9% (197/520)	36.4% (197/541)	
Other	2.7% (14/520)	3.9% (21/541)	
Civil state			0.344

Partnership	82.7% (467/565)	80.5% (450/559)	
Single	17.3% (98/565)	19.5% (109/559)	
Ouration of partnership			0.159
< 1 year	5.9% (33/473)	6.8% (36/443)	
1 to 3 years	8.4% (47/473)	11.5% (61/443)	
3 to 7 years	21.5% (120/473)	16.7% (89/443)	
7 to > 15 years	49% (273/473)	48.3% (257/443)	
No partnership	15.2% (84/473)	16.7% (89/443)	
Parity			< 0.001
0	69.2% (361/522)	48.9% (262/536)	
1	17.8% (93/522)	16.2% (87/536)	
2	10.3% (54/522)	25.4% (136/536)	
> 2	2.7% (14/522)	9.5% (65/536)	
Medical history		0	
Malignant tumor	1.1% (6/541)	1.6% (9/548)	0.450
Epilepsy	0.7% (4/541)	0.4% (2/548)	0.404
Stroke	0.9% (5/541)	0.2% (1/548)	0.098
Rheumatological disease	9.1% (49/541)	5.8% (32/548)	0.043
Osteoporosis	3.0% (16/541)	0.7% (4/548)	0.006
HIV/ AIDS	0.6% (3/541)	0.4% (2/548)	0.644
Psychiatric treatment	24.8% (132/533)	12.0% (66/548)	<0.001
because of:			
Eating disorder	2.6% (13/507)	1.5% (7/465)	0.245
Depression	15% (76/507)	5.8% (27/465)	<0.001
Anxiety	7.9% (40/507)	2.2% (10/465)	<0.001
Schizophrenia/psychosis	0.4% (2/507)	0.2% (1/465)	0.614
Obscompuls. disorder	1% (5/507)	0.2% (1/465)	0.125
Addiction	0.8% (4/507)	0.2% (1/465)	0.212
Dysmenorrhea			< 0.001
Never	6.7% (37/550)	29.1% (156/536)	
Not currently	28.9% (159/550)	41.1% (222/536)	
Yes	64.4% (354/550)	29.5% (158/536)	
Dyspareunia			< 0.001

Never/very rarely	34.8% (178/511)	70.7% (367/520)	
Rarely	12.5% (64/511)	11.3% (59/520)	
Sometimes	33.9% (173/511)	13.8% (72/520)	
Usually/almost always	18.8% (96/511)	4.2% (22/520)	
Pain intensity (VAS score)	4.6 ± 0.12	3.3 ± 0.14	< 0.001
Chronic pain (general)			< 0.001
Yes	56.3% (316/561)	13.1% (72/550)	
Pain intensity (VAS score)	4.7 ± 2.44		
Infertility			< 0.001
Yes	64.5% (225/349)	26.2% (86/328)	

Note: Values presented as mean \pm SD or % (n/total).

Table 2a: Qualitative analysis of sexual activites of women with endometrosis and control women

10	Endometriosis	Control	p value
3	women	women	
	n = 565	n = 565	
Current partner			0.344
Yes	82.7% (467/548)	80.5% (450/559)	
Sexul activity during the la	ast month		< 0.001
Yes	69,1% (372/538)	77.8% (416/535)	
Importance of sexuality for	or quality of life		0.041
Very high	14.7% (79/537)	11.6% (62/535)	
High	52.5% (282/537)	57.4% (307/535)	
Low	25% (134/537)	25.8% (138/535)	
Very low	7.8% (42/537)	5.2% (28/535)	

Perception of frequer	ncy of sexual contacts		< 0.001
Adequate	40.1% (203/506)	52.4% (267/509)	
To low	42.3% (214/506)	30.5% (155/509)	
To high	5.1% (26/506)	3.7% (19/509)	
No partner	12.5% (63/506)	13.4% (68/509)	
Initiation of sexual co	ntacts		0.291
Male	38.2% (147/385)	35.6% (144/385)	
Female	8,6% (33/385)	11.9% (48/385)	
Both	53.2% (205/385)	52.5% (212/385)	
DUIT	55.2% (205/385)	52.5% (212/385)	

Table 2b: Quantitative analysis (frequencies) of sexual activity of women with endometriosis and control women

	Endometriosis	Control	p value
	women	women	
	n = 565	n = 565	
Kissing			0.381
once daily	52.2% (271/519)	49.6% (257/518)	
Masturbation			0.939
Yes	69,1% (372/538)	77.8% (416/535)	
Never	51.2% (263/514)	50.1% (257/513)	
Sometimes/month	33.1% (170/514)	31% (159/513)	
Sometimes/week	15.8% (81/514)	18.9% (97/513)	
Reciprocal masturbation			0.700
Never	60.6% (308/508)	57.4% (292/509)	

Sometimes/month	23.4% (119/508)	27.3% (139/509)	
Sometimes/week	16% (81/508)	15.3% (78/509)	
Petting and foreplay			0.003
Never	31.3% (160/513)	26.6% (135/508)	
Sometimes/month	29.7% (152/513)	30.5% (155/508)	
Sometimes/week	39% (201/513)	42.9% (218/508)	
Oral sex			0.544
Never	54.1% (276/511)	49.6% (254/512)	
Sometimes/month	27.3% (139/511)	30.7% (157/512)	
Sometimes/week	18.8% (96/511)	19.7% (101/512)	
Vaginal sexual intercours	se		0.021
Never	28.3% (160/518)	23.3% (120/516)	
Sometimes/month	25.7% (145/518)	29.8% (154/516)	
Sometimes/week	41.1% (213/518)	46.9% (242/516)	
Anal sex		70	0.713
Never	92.5% (470/508)	92.7% (469/506)	
Time spent on foreplay			0.608
<1-10 min	41.8% (200/478)	43.8% (212/484)	
11-20 min	39.7% (190/478)	39% (189/484)	
21-30 min	15.3% (73/478)	13% (63/484)	
>30 min	3.2% (15/478)	4.1% (20/ 484)	
Time spent on sexual int	ercourse till male partı	ner's orgasm	0.681
<1-2 min	7.5% (35/476)	7.7% (36/466)	
3-4 min	16.7% /78/476)	16.1% (75/466)	
5-7 min	22.9% (107/476)	25.8% (120/466)	
8-10 min	19.1% (89/476)	22.7% (106/466)	
11-15 min	19.9% (93/476)	15.5% (72/466)	
>15 min	13.9% (65/476)	12.2% (57/466)	

Note: Values presented as mean \pm SD or % (n/total)

Table 3: Univariate logisite regression analysis of the association among sexual activity during the last month, selected demographic and clinical data as well as pain symptoms for endometriosis-affected women.

	OR	95% CI
Age, n = 565, RC = 18-25 years		
25-35 years	0.7	[0.26, 1.98]
35-45 years	0.75	[0.42, 1.31]
45-60 years	0.86	[0.51, 1.45]
Civil status, n = 565, RC = partnership		
single	11.59	[6.64, 20.24]
Partnership duration, n = 354, RC = < 1 year	<u>C</u>	
> 1 year	1.2	[1.02, 1.47]
Parity, n = 522, RC = 0		
1	0.72	[0.18, 2.79]
2	0.80	[0.19, 3.28]
Happiness with partnership, n = 352, RC = happy		
rather unhappy	0.19	[0.07, 0.49]
unhappy	0.65	[0.21, 2.0]
Time since diagnosis of endometriosis, n = 565, RC = <	< year	
1-3 years	0.92	[0.57,1.49]
3-5 years	0.59	[0.35, 1.01]
>5	0.55	[0.30, 1.02]
Depression, n = 523, RC = no		
yes	1.93	[1.20, 3.11]
Dysmenorrhea, n = 522, RC = never		
not currently	0.96	[0.43, 2.14]
yes	0.92	[0.44, 2.00]
Dyspareunia, n = 503, RC = never		
very rarely/rarely	0.49	[0.24, 0.95]
sometimes	1.34	[0.73, 2.45]
usually/almost always	2.42	[1.26, 4.63]
Chronic pain (general) n = 535, RC = no		
yes	1.35	[0.93, 1.96]
Chronic pelvic pain, n = 274, RC = no		
yes	1.04	[0.25, 4.26

Infertility, n = 338, RC = no

yes 0.56 [0.34, 0.92]

Note: RC = reference category, OR = Odds ratios, CI = Confidence interval

