

The BEKind Study – A Longitudinal Study Exploring Self-Compassion, Body Image and Psychological Wellbeing in Women with Endometriosis

Background and Rationale

Endometriosis is a chronic condition which is characterised by highly variable but often debilitating physical symptoms and affects approximately 10% of women of reproductive age (As-Sanie et al., 2019). Common symptoms include pelvic pain, dyspareunia, altered bladder and bowel function, bloating and infertility (Facchin et al., 2017). Comorbidities with conditions such as migraine, irritable bowel syndrome and chronic fatigue are also reported.

In addition to the physical symptoms there are many psychological challenges associated with having endometriosis. Affected women experience greater levels of anxiety and depression compared to the normal population (Simoens et al., 2012) and the condition is associated with having poorer mental health overall (Facchin et al., 2017). Additionally, women rarely remain symptom-free after treatment, which can add to the overall psychological burden associated with the condition because there is a lot of uncertainty surrounding treatment options and progression. Current literature into endometriosis has focused upon surgical or medical treatments and the resolution of pain (Aerts et al., 2018), however more recently, research has emerged which utilises a more biopsychosocial approach. Whilst we understand that endometriosis has a profound impact on the psychological wellbeing of the women affected, there is a paucity of research on broader psychological impacts which means that we cannot fully understand the burden of this condition overall. Similarly, there is a lack of longitudinal data, which means that we are unable to make confident conclusions about the temporal relationship between endometriosis and the psychological symptoms experienced by affected women.

An important area of research which is yet to be explored in endometriosis concerns body image and its relationship to other psychological aspects of wellbeing. Body image is defined as an individual's direct personal perception of their body appearance and function (Stokes & Frederick-Recascino, 2003). Negative body image is common in other conditions that affect women such as breast and gynaecological cancer, and it is associated with psychological factors such as depression, anxiety, poor self-worth and psychological distress. As there are commonalities between these women's health conditions and endometriosis in terms of symptoms and psychological impact, it is hypothesised that body image will be similarly affected in this population. As such, the aim of this research is to measure body image disturbance in women with endometriosis in conjunction with other psychological variables over time to better understand the impact of endometriosis on psychological wellbeing more broadly.

Aims

The primary aim of this study is to conduct an online longitudinal study over six months to determine the extent to which women with endometriosis experience body image disturbance, and delineate other psychological factors associated with changed body image. A secondary aim includes mapping and exploring the trajectories of psychological distress over time.

Methodology

Participants. This study aims to recruit over 300 participants. Women with either a clinical or surgical diagnosis of endometriosis will be recruited through Dr Michael Cooper's private consultation rooms. Clinical staff members will provide eligible individuals with a copy of the study advertisement (either via email or on paper). Three organisations, Endometriosis Australia, EndoActive and the Australian Coalition for Endometriosis will also be involved in the recruitment process. Each organisation will email the study advertisement to their respective online databases inviting participants into the study, and will additionally advertise the study through the organisation's social media platforms such as Instagram and Facebook.

Inclusion criteria are as follows: 1) Previous clinical or surgical diagnosis of endometriosis, 2) Women aged between 18-50 years, 3) Access to the internet 4) Competency of the English language.

Participant Withdrawal. Participants will be advised when enrolling in the study via the Participant-informed Consent Form that they may withdraw from the study at any point without reason.

Procedure. A longitudinal study will be conducted measuring the impact of endometriosis on psychological wellbeing, body image and self-reported self-compassion. Potential participants will be invited into the study via the study advertisement and will independently enrol in the study online.

After completing the consent form, participants will complete the baseline survey which contains demographic questions and study measures. A reminder to complete follow-up surveys will be sent at one, three and six months. The survey will take approximately 30-40 minutes to complete.

Measures.

1. Demographics – age, gender/sex, height, weight, BMI, country of birth, education level, relationship status, employment status, medical and obstetric history, endometriosis symptoms, date of diagnosis and stage.
2. Endometriosis Health Profile Questionnaire (EHP-30) – a 30-item scale which assesses the impact of endometriosis on physical, psychological and social aspects of life using a 5-point Likert scale
3. Self-Compassion Scale (SCS) – a 26-item scale which assesses the extent to which participants treat themselves kindly – six subscales with items rated on a Likert scale from 1 (almost never) to 5 (almost always)
4. Body Image Scale (BIS) – a 10-item scale which measures body image distress as well as cognitions and behaviours pertaining to body image and function.
5. Body Appreciation Scale-2 (BAS-2) – A 13-item scale which is a commonly utilised measure of positive body image
6. Depression and Anxiety Stress Scale (DASS-21) – A validated and commonly used measure for anxiety and depression. Participants are asked to rate the extent to which they agree with statements such as “I find it hard to wind down” on a 4-point Likert scale (0 = Never, 3 = Almost always).
7. Female Sexual Distress Scale-Revised (FSDS-R) – a 12-item questionnaire which measures aspects of sexual distress using a 4-point Likert scale (0=Never, 4 =Always).
8. SF-36 Measure for Psychological Distress – a 36 item questionnaire measuring psychological distress

Expected Outcomes & Impact of Research. It is hypothesized that women with endometriosis will report high levels body image disturbance, anxiety and depression. In order to be able to mitigate these issues and help women cope with the day-to-day challenges of living with endometriosis, the crucial first step is quantifying the level of body image distress and its relationship to other psychological variables. As such, this research will contribute to the literature because the impact of endometriosis on body image has not been fully explored. Additionally, through a longitudinal design, we may be able to delineate predictors of psychological distress over time. This research will form a foundation on which development of interventions that can address body image concerns and improve coping in women with endometriosis.

Data Management Plan

Data ownership and custody. All collected data will be kept in a password-protected file by the research team. The data once collected will be de-identified (by Carla Sullivan-Myers and Prof Sherman) before being shared with any other members of the research team. As this is a longitudinal study, we need to track participant names in order to assess progress over time.

Data collection or generation. Data will be collected via Qualtrics software at each time point and kept in a password-protected file by the research team. The following data will be collected:

- Demographic and medical history information
- Self-reported questionnaires assessing self-compassion body image appreciation or disturbance and various measures to indicate overall psychological wellbeing and quality of life

Data access, use, analysis. Data will be collected via Qualtrics and used only by the research team. Statistical analysis will be conducted using SPSS and M+ and will involve logistic regression analysis and latent growth analysis to determine trajectories of psychological wellbeing over the six month study duration.

Data disclosure, sharing and re-use. Data will not be disclosed to any individuals except those involved in the research team. When complete, analysis of the data will be reported in a research paper and disseminated in academic publications and through conference presentations.

Data storage, retention or disposal. Data will be retained for the minimum period of five years from the most recent publication as required. Data will be stored under password protection on the researcher's computer. The only individuals with access to the research data will be those on the research team.

Describe any risks associated with the data management plan and the strategies for minimising those risks.

This research aims to assess and measure various aspects of psychological wellbeing, self-compassion and body image disturbance in women with endometriosis over a six-month period. Whilst it is highly unlikely that participants will be exposed to any potential risks throughout this study, this research will stimulate participants to think about their bodies and their experience with endometriosis. Whilst this research project isn't in itself psychologically distressing, reflecting upon these issues may cause discomfort for some participants. The risks involved in this research will be mitigated in the following ways. Firstly, the research staff will be available throughout the course of the study, and additional services such as Lifeline will be offered via the patient-informed consent form. Participants will be given the contact details for services such as Lifeline which is a free and confidential service enlisting the help of trained health professionals that may help participants if they require it. All participants will be given the contact details for condition-specific organisations such as Endometriosis Australia and EndoActive. Participants will additionally be advised that they can withdraw from the study at any point. If any participants are experiencing difficulties, they will be referred to the services mentioned above, their General Practitioner, and the Macquarie University Research Ethics Committee where appropriate. If any harm comes to participants, the HREC will be informed within 72 hours of becoming aware of the event.

References:

- Aerts, L., Grangier, L., Streuli, I., Dällenbach, P., Marci, R., Wenger, J.-M., & Pluchino, N. (2018). Psychosocial impact of endometriosis: From co-morbidity to intervention. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 50, 2-10.
doi:<https://doi.org/10.1016/j.bpobgyn.2018.01.008>
- As-Sanie, S., Black, R., Giudice, L. C., Gray Valbrun, T., Gupta, J., Jones, B., . . . Nebel, R. A. (2019). Assessing Research Gaps and Unmet Needs in Endometriosis. *American Journal of Obstetrics and Gynecology*. doi:<https://doi.org/10.1016/j.ajog.2019.02.033>
- Facchin, F., Barbara, G., Dridi, D., Alberico, D., Buggio, L., Somigliana, E., . . . Vercellini, P. (2017). Mental health in women with endometriosis: searching for predictors of psychological distress. *Human Reproduction*, 32(9), 1855-1861.
- Simoens, S., Dunselman, G., Dirksen, C., Hummelshoj, L., Bokor, A., Brandes, I., . . . D'Hooghe, T. (2012). The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Human Reproduction*, 27(5), 1292-1299.
doi:10.1093/humrep/des073
- Stokes, R., & Frederick-Recascino, C. (2003). Women's perceived body image: relations with personal happiness. *Journal Of Women & Aging*, 15(1), 17-29.