ICS-EUS 2025
ABU DHABI
17 - 20 SEPTEMBER 2025
ADNEC, ABU DHABI, UAE

My body is not mine - the perspective of a woman with endometriosis in the anonymous online survey—qualitative study

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INTRODUCTION

Endometriosis is a chronic inflammatory disease affecting 5–10% of biologically female individuals, often causing pelvic pain, menstrual and sexual discomfort, and bowel or bladder problems [1]. It also impacts mental health, contributing to **anxiety, depression, and poor quality of life**, while symptoms like bloating and scarring can harm body image [2]. Distressing medical experiences, such as invasive exams or harsh treatments, may cause trauma. Because people with endometriosis undergo frequent physical exams and touch, **they face additional physical and psychological risks that can further affect body image** [3].

AIM

The study examined body image perceptions in people with endometriosis to inform treatments that better support mental well-being and patient needs.

MATERIALS AND METHODS

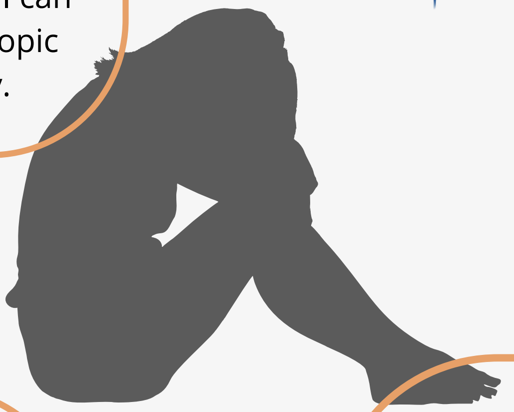
- anonymous survey - social media
- inform consent
- demographic data
- changes in body image, including body ownership, touch aversion, and the impact of physical contact on experiences and relationships
- open question “My body is not mine”
- basic statistics and narrative analysis

RESULTS

PARTICIPANTS (n = 108)
Age: 31.65±6.9 years
BMI: 22.6±4.5 kg/m2
Time since diagnosis: 4.33±6.02 years

Variables	N (%)
Education	
Primary	1 (0.9%)
Secondary	25 (23,1%)
Higher	82 (75,9%)
The change in the perception of the body after the treatment undertaken	
Yes	**93 (87%)**
Positively	30 (27,8%)
Negatively	**63 (58.3%)**
No	15(13.9%)
Do you feel like your body belongs to you less?	
Yes	**67 (62%)**
No	41 (38%)
Do you feel tired of visits and touch?	
Yes	**85 (78.7%)**
No	23 (21.3%)
The touch is less pleasant than before	
Yes	52 (48.1%)
No	**56 (51.9%)**
The touch is more irritating than before	
Yes	53 (49.1%)
No	**55 (50.9%)**
The frequent touch influences the intimacy in relationships	
Yes	28 (25.9%)
No	**80 (74.1%)**
Breaks in regular physiotherapy/visits	
Yes	34 (31.5%)
No	**74 (68.5%)**
Perception of the body influences self-esteem	
Yes	**97 (89.9%)**
No	11 (10.2%)

On one hand, I have no problem with undressing in the office or undergoing an examination, but on the other hand, I can see how it affects me and how the topic later comes up in psychotherapy.



I'm seeking help from many 'specialists', but unfortunately I keep hitting a wall, hearing things like 'But you look fine', 'There's nothing to complain about', 'Please stop making things up.' And yet I feel like, day by day, I'm withdrawing more and more from the world and everyday life.

During the surgery and afterwards, my body didn't feel like my own, and I was extremely exhausted by the unfamiliar touch. Even now, when someone touches me accidentally or without warning, I flinch. But the diagnosis allowed me to get to know and understand my body better. To appreciate it – because even though it's ill and in pain, it still allows me to do so much.

INTERPRETATION OF RESULTS

The diagnosis, disease symptoms, and ongoing treatment, involving frequent physical contact, significantly impact individuals with endometriosis. **While the negative effects of treatment are apparent for some, the psychological burden of medical trauma and the constant medicalization of the body are often overlooked**. Many women may experience **significant changes in body perception, which should be addressed through appropriate forms of therapy.** Additionally, raising awareness among women about the impact of treatment on self-perception is essential to help them prepare for these changes.

CONCLUDING MESSAGE

Endometriosis treatment is often mentally and physically challenging, involving frequent exams and medical interventions that can alter body perception. Greater focus on addressing the care needs associated with these changes is essential, highlighting the importance of patient-centered care that considers all relevant factors.

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3. Van Niekerk, Leesa, E. Steains, and Mandy Matthewson. "Correlates of health-related quality of life: The influence of endometriosis, body image and psychological wellbeing." Journal of psychosomatic research 161 (2022): 110993.