

# Struggling to manage a life with pain.

## A qualitative interview study exploring patients' experiences of endometriosis-related chronic pain, including impact on physical activity

Josefin Larsson<sup>a</sup>, Birgit Heckemann<sup>b</sup>, Emma Varkey<sup>c</sup>, Axel Wolf<sup>b</sup>, Sofia Jonsvik<sup>d</sup>, Karin Sundfeldt<sup>e</sup>, Paulin Andréll<sup>a</sup>

<sup>a</sup> Department of Anaesthesiology and Intensive Care Medicine, Institute of Clinical Sciences at Sahlgrenska Academy, University of Gothenburg, Sweden; <sup>b</sup> Institute of Health and Care Sciences Sahlgrenska Academy, University of Gothenburg, Sweden; <sup>c</sup> Department of Health and Rehabilitation/Physiotherapy, Institute of Neuroscience and Physiology, Sahlgrenska Academy, University of Gothenburg, Sweden; <sup>d</sup> Sahlgrenska University Hospital/Östra, Department of Anaesthesiology and Intensive Care Medicine, Gothenburg, Sweden; <sup>e</sup> Department of Obstetrics and Gynecology, Institute of Clinical Sciences at Sahlgrenska Academy, University of Gothenburg, Sweden

### Background

Chronic pain is a debilitating symptom in endometriosis. Many patients experience that healthcare professionals lack knowledge, do not take their problems seriously and a person-centred care approach is lacking. Physical activity is recommended as a complementary treatment strategy for endometriosis. However, knowledge about physical activity and its usefulness as a management strategy in endometriosis is limited, yet essential to develop person-centred care for patients with endometriosis-related chronic pain.

### Aim

To explore patients' experiences of living with endometriosis-related chronic pain, including experiences of healthcare, pain management strategies and impact on physical activity.

### Results

The overall theme, "Managing a life with pain" highlights women's struggle to live a life despite debilitating, endometriosis-related chronic pain. Three categories further illuminate how these women manage to live their lives: "Seeking help" describes the need for extended support and increased understanding from healthcare professionals. "Monitoring and assessing" describes a constant monitoring of pain and energy levels to assess the ability to participate in social or physical activities. "Adapting and taking action" describes the specific adjustments and actions women use to manage the severe pain condition.

*I would like to learn more about the pain. I would like more information about what help that is available for endometriosis. More than just being prescribed painkillers.*

(Seeking help)

*Exercise and movement often trigger pain. I get scared when I have an inkling about worsening pain. Do I really dare to go and exercise?*

(Monitoring & assessing)



*If I'm meeting a friend, I won't do anything until then. Nothing that causes the slightest strain on my body. I take painkillers, I prepare my TENS and my heating pad. I prepare everything there is.*

(Adapting & taking action)

### Method

Fifteen women participating in a large, ongoing randomized controlled trial (NCT05152264), were interviewed during December 2021 – September 2022. The interviews were analysed using qualitative content analysis.

### Conclusion

Endometriosis-related pain causes extensive suffering and patients experience healthcare support as lacking. In order to manage life with pain, a person-centered collaboration between patients and healthcare is needed to develop suitable treatment plans and lifestyle strategies.

### Take home message

Many individuals suffering from endometriosis-related chronic pain feel that healthcare support is lacking. These individuals need a systematic person centred care pathway to manage their everyday pain and to increase physical ability.

