Exploring Endometriosis & Physical Activity Engagement

[Endo-met-ri-osis] A behaviour theory grounded qualitative study

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Introduction

Endometriosis, a condition where tissue similar to the lining of the the uterus, grows in other areas of the body. This can cause non-specific, wide spread, disruptive symptoms such as pain, fatigue, brain fog, disrupted menstrual health (1). This can prevent individuals engaging in physical activity (PA) consistently, a protective health behaviour overall (2). There are gaps in research understanding how to tailor physical activity support for those living with endometriosis to promote future healthy ageing (3,4).

Study Aims

To qualitatively explore and understand what barriers and facilitators currently impact individuals capability, opportunity, and motivation for physical activity (PA) engagement for those living with endometriosis in the UK to contribute to a growing body of research.

Study Design

Semi-structured interviews around experiences of endometriosis, their relationship and behaviour with physical activity. Questions mapped onto the behaviour model COM-B (5) provided a theoretical underpinning to understand attitudes and engagement behaviours.

Participants

A convenience sample of 17 participants between 22 and 47 (M = 33) living with endometriosis diagnosis and / or treated in the UK assigned female at birth. Interviews were conducted in person (n = 2) and Microsoft Teams (n = 15).

Analysis

Transcription supported by Otter.AI, researchers reviewed line by line following thematic analysis procedures (6). Nvivo14 software supported clustering meaningful themes.

Figure 1. Physical Activity Facilitators

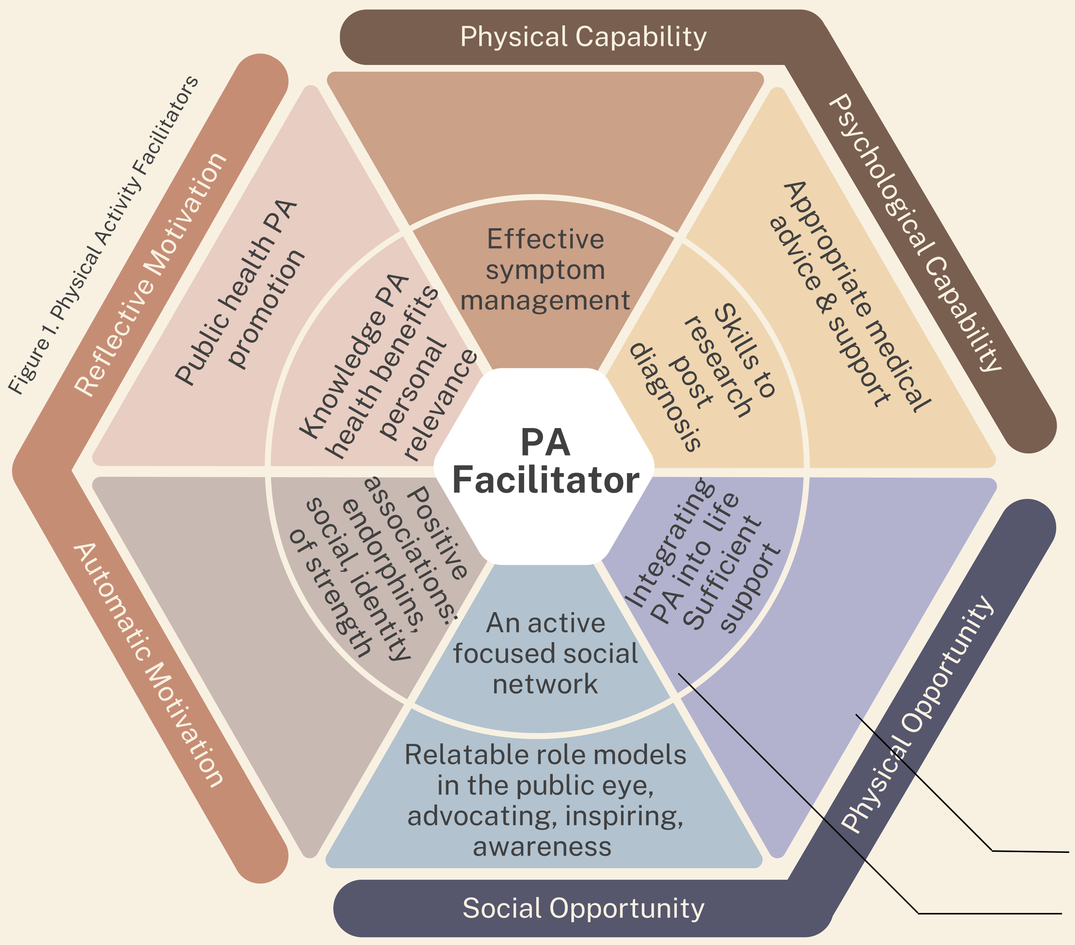
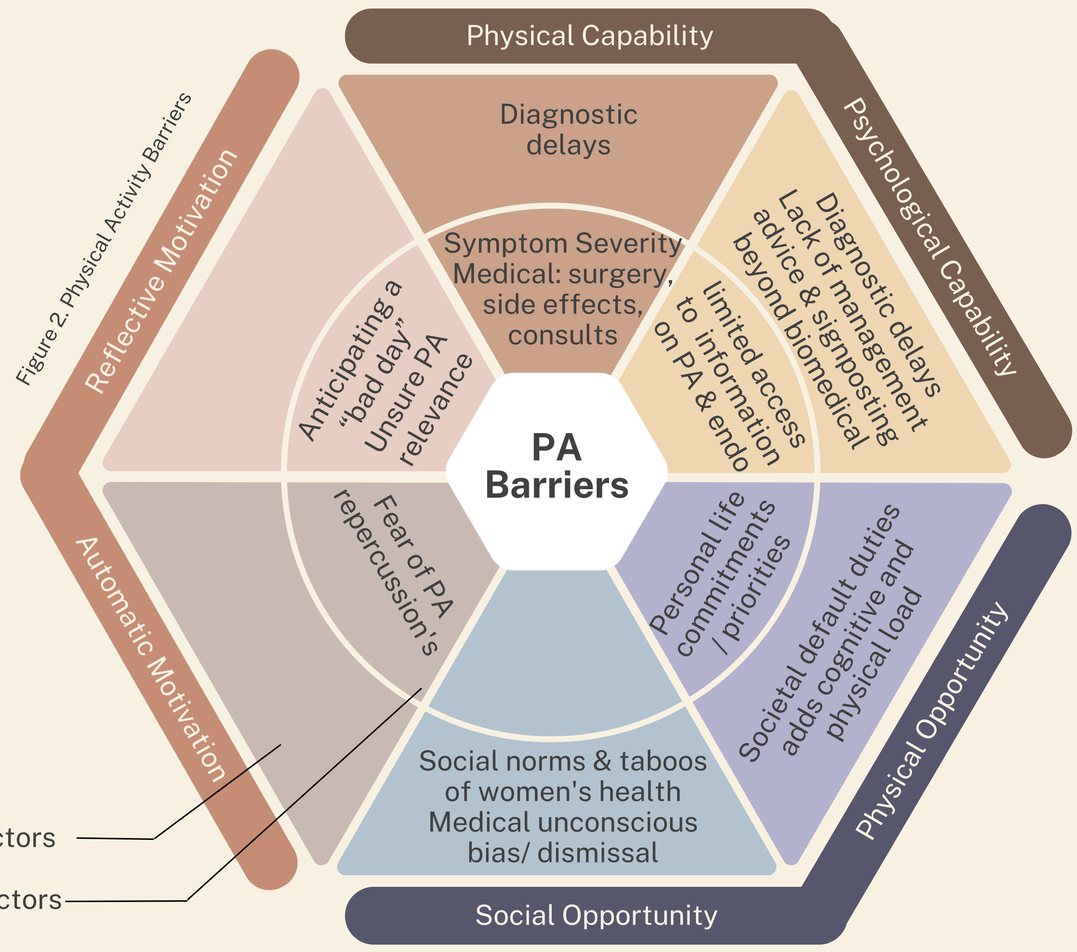


Figure 2. Physical Activity Barriers

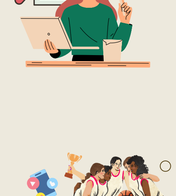


Societal Factors

Individual Factors

Findings

Figures 1 & 2 outline barriers and facilitators for physical activity (PA) engagement for those with endometriosis mapped on the COM-B model, further described below.



- **Systemic Factors Delaying Diagnosis**. A shared experience for many of delayed symptom recognition, awareness and help seeking rooted in societal norms limiting open discussion on women's health topics. Paired with medical dismissal or misdiagnosis results in years of delay. Once diagnosed, varied degrees of support, advice and signposting were offered, leaving many unsure on most appropriate behaviours and actions to self manage their symptoms in-between medical interventions such as surgery and pharmaceuticals.

- **Symptom Management**. Individual physical capabilities were affected by endometriosis symptom severity (pain, fatigue, brain fog). Medical interventions were also disruptive for physical activity routine and engagement: surgeries, medication side effects, multiple appointments and consultations.

- **Symptom Unpredictability & Competing Demands**. Symptom fluctuations impacted PA motivation and fears of risking symptom flare ups from limited available resources. Especially when symptoms challenge day-to-day activates such as work and home duties, PA was de-prioritised over competing demands.

- **Knowledge is Power.** A journey towards understanding symptoms and management post diagnosis. Fundamental to facilitate physical and psychological capabilities to channel efforts appropriately into gaining knowledge and understanding of their endometriosis. Existing knowledge of PA benefits was motivational however endo specific research gaps and individual differences in research experience left many with unanswered questions.

- **Identity Re-framing and Social Influences:** PA opportunity facilitated PA engagement such as sufficient support and accommodations at work or home reduced perceived external pressures. An active-centric network supported motivations to engage in PA, knowledge of PA benefits especially relating to new personal goals and identity as they move towards a "new normal" empowered some, especially when inspired by relatable public role models.

Conclusion

Individual factors of symptom management, adverse side effects and lack of access to information about endometriosis pull individuals' capacity and motivation for physical activity. Access to practical knowledge of endometriosis and PA benefits motivates and enables PA further by environmental support for PA and daily duties.

Wider societal factors delay women's capabilities to come to the point of diagnosis and manage their symptoms due to the lack of open dialogue about women's health within the general population and delays to diagnostic pathways via women's health specialists and medical health professionals. Relevant public role models support awareness, advocacy and empowerment.

Contribution to Knowledge & Future Plans

This research grounded in behaviour theory identifies key priorities and gaps in our understanding of the wider lifestyle impact of endometriosis on an individual and wider system level, not previously explored.

The next steps entail further research exploring day-to-day experiences of living with endometriosis, utilising these findings to build upon and inform intervention designs alongside literature, that tailor and accommodate needs and barriers for those living with endometriosis to support healthy ageing and longevity. There is a need for more endometriosis research overall, furthermore that communicates findings accessibly to those affected, patient and public involvement groups can support these aims, efforts have been made to meet this. Ultimately the research contributes to understanding wider health determinants of the condition post-diagnosis, efforts to improve diagnosis times through women's health education within young populations and diagnostic pathways should also be prioritised.

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