Lived Experiences of Endometriosis Among Trans and Gender Diverse People: Burden, Barriers, and Pathways to Inclusive Care

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Background:

Endometriosis is a chronic inflammatory condition that significantly impacts sexual and reproductive health, wellbeing, and quality of life. Approximately 10% of people who menstruate, including trans and gender diverse (TGD) individuals assigned female at birth, are affected by the disease. Endometriosis investigation, treatment, and awareness is predominantly centered around cisgender women's health, which contributes to delayed diagnoses and additional barriers to healthcare and intervention for TGD patients.

Methods:

Semi-structured online interviews were undertaken with 11 TGD individuals with diagnosed or clinician-suspected endometriosis. Using Braun and Clarke's reflexive thematic analysis, interviews explored how participants experienced endometriosis, navigated healthcare systems, and encountered practices that either supported or compromised gender-affirming care.

Results:

Reflexive thematic analysis generated five themes: (1) the pervasive burden of endometriosis, (2) barriers to timely and appropriate care, (3) cisnormativity and dismissal in healthcare encounters, (4) the hidden labour of navigating care, and (5) towards inclusive and affirming endometriosis care. While participants described barriers commonly reported by cisgender women with endometriosis, such as symptom normalisation/dismissal and delayed investigation, TGD patients experienced additional challenges. These included difficulty finding gender-affirming providers, limited clinician knowledge regarding the intersection of endometriosis management and gender-affirming care (e.g., testosterone therapy), and healthcare environments and treatment options that exacerbated gender dysphoria. These factors contributed to avoidance or delay of care and significant psychological distress.

Conclusion:

TGD people with endometriosis face the dual burden of a poorly recognised health condition and cisnormative healthcare systems that fail to appropriately accommodate gender diversity. Improving endometriosis care for TGD individuals requires improved clinical knowledge, inclusive and affirming healthcare practices and environments, and clinician understanding of how endometriosis management intersects with gender-affirming care. Addressing these gaps may reduce diagnostic delays and healthcare avoidance, minimise distress, and allow for equitable access to endometriosis care for this underserved population.

Disclosure of Interest Statement:

The authors have no conflicts of interest to declare

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