

Endometriosis in South Australia: A Qualitative Study

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Background and Methods

- Endometriosis is under-recognised and inadequately researched: Average time to diagnosis is 6.4 years (O'Hara et al, 2020)
- 50 people with endometriosis were interviewed using a narrative approach and themes were analysed

Results

- Participants were frustrated with the length of time it took to get a diagnosis and believe their quality of life was impacted during the time from symptom onset to diagnosis
- The first feeling that ran through participants' minds after surgical diagnosis was relief and validation
- Main barriers to getting an earlier diagnosis:
 - Lack of education and awareness by the patient, their family and friends, and health professionals
 - Normalisation and dismissal of symptoms, particularly by themselves and female family members
 - Stigma and embarrassment about discussing symptoms
- There was a significant mental health impact from the delayed diagnosis for many participants

Recommendations

- Increased education, research, advocacy and funding through the National Action Plan (2018)
- Early screening tools, digital platforms (EndoZone) and school programs targeting menstrual education