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# Women's Experiences of Living with Adenomyosis: A Scoping Review through the Lens of Levine's Conservation Model

Yayu Handayani Syaidar Putri\*

\*Department of Nursing, Sekolah Tinggi Ilmu Keperawatan PPNI Jawa Barat, Bandung, Indonesia



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## Corresponding author

**Yayu Handayani Syaidar Putri\***  
Sekolah Tinggi Ilmu Keperawatan PPNI  
Jawa Barat  
Muhammad No. 34, Pamoyanan, Cicendo,  
Kota Bandung, Jawa Barat, 40174,  
Indonesia  
Phone : (022) 6121914  
Email: [yayuhandayani22@gmail.com](mailto:yayuhandayani22@gmail.com)

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## Abstract

**Background:** Uterine adenomyosis (UA) is a chronic gynaecological condition characterised by the presence of endometrial tissue within the myometrium, causing dysmenorrhoea, abnormal uterine bleeding, dyspareunia, infertility, and reduced quality of life. Although its physical and psychosocial burden is well recognised, women's lived experiences have not been comprehensively synthesised using a nursing theoretical framework.

**Objective:** To systematically identify, map, and synthesise evidence on women's experiences of living with adenomyosis using Levine's Conservation Model.

**Methods:** A scoping review was conducted following the Joanna Briggs Institute (JBI) methodology and reported according to the PRISMA Extension for Scoping Reviews (PRISMA-ScR). Literature searches were performed in PubMed/MEDLINE, CINAHL Plus, and ScienceDirect, supplemented by grey-literature searching and hand-searching of reference lists. Eligibility criteria were developed using the Population-Concept-Context (PCC) framework. Data were analysed using inductive content analysis and deductively mapped to the four conservation principles of Levine's Conservation Model.

**Results:** Twelve sources met the inclusion criteria, comprising five primary empirical studies, four secondary or contextual sources, and three grey-literature patient narratives. Women with adenomyosis experienced multidimensional challenges across all four conservation domains. These included energy depletion caused by chronic pain and fatigue, structural compromise related to pelvic pain, dyspareunia, and infertility, threats to personal integrity arising from stigma and delayed diagnosis, and disruption of social integrity through impaired relationships, occupational limitations, and financial burden.

**Conclusion:** Adenomyosis profoundly affects women's physical, psychological, and social well-being across all four domains of Levine's Conservation Model. This review provides a theory-informed framework to guide holistic nursing assessment and person-centred care while highlighting the need for further research on diagnostic experiences and nursing-specific interventions.

**Keywords:** Adenomyosis; lived experience; scoping review; Levine's Conservation Model; women's health; nursing; quality of life.

## INTRODUCTION

Uterine adenomyosis (UA) is a common benign gynaecological condition defined by the presence of endometrial glands and stroma within the myometrium, resulting in a diffusely enlarged uterus. The condition manifests with a spectrum of debilitating symptoms including severe dysmenorrhoea, heavy menstrual bleeding (HMB), chronic pelvic pain (CPP), dyspareunia, and impaired fertility (1–4). Although adenomyosis has historically been considered a disease of multiparous women in their fourth and fifth decades, advances in non-invasive diagnostic imaging – particularly transvaginal ultrasound (TVUS) and magnetic resonance imaging (MRI) – have increasingly revealed its presence in younger and nulliparous populations, including adolescents (5,6).

The reported global prevalence of UA varies widely, ranging from as low as 1% to as high as 70%, a variation largely attributable to the diversity of diagnostic criteria applied and the historical reliance on post-hysterectomy histopathological examination as the gold standard (5,7). More recent imaging-based population studies suggest a prevalence of approximately 20% among symptomatic women, with some cohorts reporting substantially higher rates in younger age groups (5). This significant diagnostic challenge is compounded by the condition's frequent co-occurrence with other gynaecological conditions, particularly endometriosis and uterine leiomyoma, which can obscure clinical presentations and contribute to delays in diagnosis. A study drawing on the ComPaRe-Endometriosis cohort found that the average diagnostic delay for adenomyosis was approximately 11 years – longer than the already problematic 10-year average reported for endometriosis (8).

The substantial burden of adenomyosis on women's quality of life (QoL) has been increasingly recognised in recent years. Pain, fatigue, sexual dysfunction, and psychological distress have been documented as frequent consequences of the condition, with ripple effects extending to women's occupational functioning, financial security, relational health, and social participation (9–11). Moreover, women with adenomyosis frequently report experiencing their symptoms as dismissed, normalised, or misattributed by healthcare professionals (HCPs), perpetuating delays in

diagnosis and compounding psychological distress (12). A 2025 commentary in *eBioMedicine* described adenomyosis as an "underacknowledged cause" of pelvic pathology, noting that – despite its substantial burden on wellbeing, no approved therapies exist specifically for adenomyosis, and research in the field lags behind that of comparable gynaecological conditions (13).

Despite this growing recognition of disease burden, the nursing literature on adenomyosis remains sparse. A 2022 systematic review protocol by O'Hara and colleagues noted that due to the variance in clinical presentations of adenomyosis and endometriosis, a patient-centred care approach is essential to address complex healthcare needs, and that the nurse's role in delivering this care remains under-examined (14). To date, no published scoping review has specifically examined women's experiences of adenomyosis through the lens of a nursing theoretical framework – a gap that limits the translation of existing evidence into structured, theory-informed clinical nursing practice.

Levine's Conservation Model (LCM), first described by Myra Estrin Levine in 1967, provides a holistic nursing framework centred on the concept of conservation – the process of maintaining wholeness through the least expenditure of effort (Levine, 1967). The model organises nursing assessment and intervention around four conservation principles: (1) conservation of energy, addressing the balance between energy supply and demand; (2) conservation of structural integrity, concerned with the maintenance of physical body structure and function; (3) conservation of personal integrity, encompassing self-identity, self-esteem, and psychological wellbeing; and (4) conservation of social integrity, addressing the patient's roles within family and community (15,16). This framework has been successfully applied in gynaecological and reproductive health nursing contexts. Studies by Kirca and Ozcan demonstrated in a randomised controlled trial that nursing care based on the LCM significantly reduced fatigue and depression while improving perceived social support and sleep quality in women undergoing infertility treatment. Similarly, a cross-sectional study of women with uterine fibroids guided by the LCM revealed significant intercorrelations between fatigue, sexual dysfunction, anxiety, and

loneliness – domains mapping directly onto the four conservation principles (17).

The present scoping review is motivated by the convergence of these evidence gaps. The foundational scoping review by Taylor (2025), published in *BMJ Open*, identified only six studies meeting eligibility criteria for exploring the lived experience of women with adenomyosis, and recommended more formal evidence synthesis, more primary data collection, and further attention to nursing-relevant dimensions of care (12). No prior review has attempted to analyse these experiences through a nursing theoretical framework. Accordingly, this scoping review aims to systematically identify, map, and synthesise available evidence on women's experiences of living with adenomyosis, analysed through the lens of Levine's Conservation Model, with the goal of informing holistic, theory-driven nursing practice and identifying priority areas for future research.

### Objectives and Review Questions

This review aims to provide a structured synthesis of existing evidence regarding the experiences of women living with adenomyosis, mapped to the four domains of Levine's Conservation Model.

### Primary review question:

"What is known about the experiences of women living with adenomyosis as understood through the lens of Levine's Conservation Model?"

### Sub-questions:

- How does adenomyosis affect women's energy conservation?
- How does adenomyosis affect women's structural integrity?
- How does adenomyosis affect women's personal integrity?

How does adenomyosis affect women's social integrity?

## METHODS

### Study Design and Protocol

This study is a scoping review conducted in accordance with the JBI methodology for scoping reviews as described by Peters et al., (2020), and reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist (19). This design is appropriate given that the primary aim is to map the breadth and nature of existing evidence rather than to synthesise evidence in answer to a specific clinical question, consistent with the established purposes of a scoping review (18,20).

### Eligibility Criteria

Eligibility criteria were developed using the Population–Concept–Context (PCC) framework as recommended by the JBI Manual for Evidence Synthesis (18). Inclusion and exclusion criteria are presented in Table 1.

**Table 1. Eligibility Criteria based on PCC Framework**

| PCC                 | Inclusion Criteria / Kriteria Inklusi                                                                                                                                                                                                  | Exclusion Criteria / Kriteria Eksklusi                                                                                                                                  |
|---------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Population</b>   | Women diagnosed with uterine adenomyosis (self-reported or clinically/imaging/histologically confirmed); studies including mixed samples (adenomyosis + endometriosis) included if adenomyosis data separable or contextually relevant | Non-human subjects; participants without adenomyosis diagnosis                                                                                                          |
| <b>Concept</b>      | Lived experiences of adenomyosis: physical, psychological, social, relational, financial impacts; healthcare interactions; perceptions of diagnosis; self-management; quality of life                                                  | Studies focused solely on medical/surgical/pharmacological interventions without patient experience data; studies focused primarily on another gynaecological condition |
| <b>Context</b>      | All settings (community, clinic, hospital); no geographic, language, or time frame restriction                                                                                                                                         | No context restriction applied                                                                                                                                          |
| <b>Study Design</b> | Qualitative, quantitative, mixed-methods studies; reviews; conference abstracts; reports; grey literature                                                                                                                              | Animal studies; editorials without empirical data                                                                                                                       |

Studies including mixed samples of adenomyosis and endometriosis were considered eligible where adenomyosis data could be contextually separated or where the combined evidence contributed meaningful background to the adenomyosis experience. This approach is consistent with that adopted by Taylor et al. (2025), who noted the historical terminological overlap and shared clinical features of the two conditions in the literature. A pragmatic five-year date limit (January 2020–June 2026) was applied to the electronic searches for feasibility reasons; this is acknowledged in Section 2.3 and in the Limitations.

### Information Sources

The search covered three electronic bibliographic databases—PubMed (MEDLINE), CINAHL Plus, and ScienceDirect—supplemented by structured grey-literature searching using the Google search engine and by hand-searching the reference lists of all included sources. CINAHL Plus was included specifically for its coverage of nursing and allied-health literature, which is central to the nursing-framework orientation of this review. Grey-literature searching used the terms “adenomyosis” AND (“experience” OR “story” OR “lived experience”); the first ten pages of results (approximately 100 records) were screened, and only named, attributable patient narratives or organisational and charity sources with identifiable authorship and date were retained, each appraised for credibility and provenance. Table 2 presents the databases and sources searched, with the rationale for inclusion.

The databases were searched in June 2026 with a pragmatic five-year date limit, covering publications from January 2020 to June 2026. This limit was adopted for feasibility within a postgraduate timeframe and is acknowledged in the Limitations. Full, database-specific search strings (including field tags and MeSH terms) and the dates each database was searched are provided in Appendix A (Supplementary File 1). A manual hand-search of the reference lists of all included sources was also conducted to identify additional eligible sources not captured by the electronic searches.

### Search Strategy

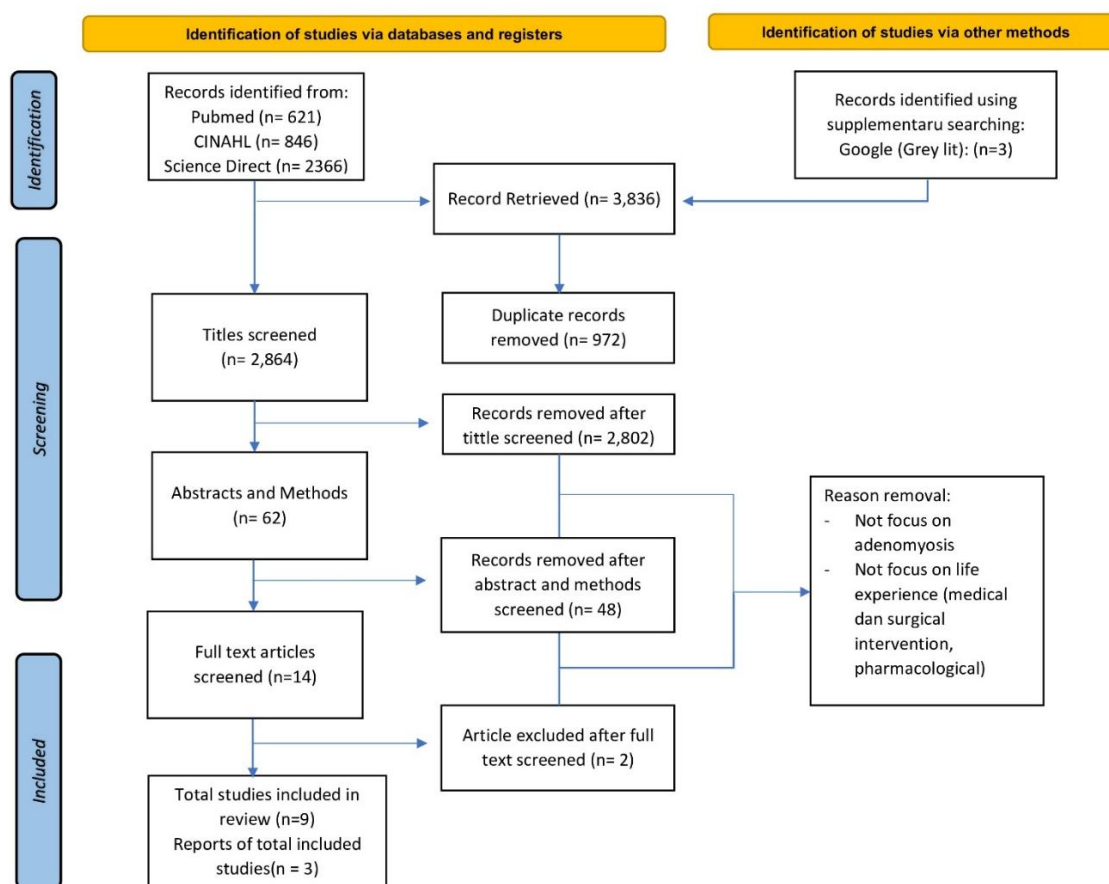
The databases were searched using combinations of keywords with Boolean connectors (AND, OR), truncation (\*), and parentheses. Medical Subject Headings (MeSH) terms were applied where available. The full search strings for each database, with database-specific syntax, field tags, and MeSH terms, together with the date each search was run, are provided in Appendix A (Supplementary File 1). The search strategy was not formally peer-reviewed by a librarian, which is noted as a limitation. An illustrative PubMed string is shown below:

```
(((((Women) OR (Girls)) OR (Girl)) OR (Woman)) AND ((Life Change Events" OR "Life Change" OR "Life Experiences" OR "Life Experience" OR "Life Course" OR "Life Courses" OR "Life Crisis" OR "Life Crises" OR Experience OR Event OR Course OR Crisis OR Life))) OR (Perception)) OR (Quality of Life)) AND ((Adenomyosis) OR (Adenomyoses))
```

### Study Selection

Database searches across PubMed (n=621), CINAHL (n=846), and ScienceDirect (n=2,366), supplemented by grey literature searching via Google (n=3), yielded 3,836 records in total. Following removal of 972 duplicate records, 2,864 titles were screened. After title screening, 2,802 records were excluded, leaving 62 records for abstract and methods screening. A further 48 records were excluded at this stage; primarily due to the absence of adenomyosis as a study focus or an exclusive focus on medical, surgical, or pharmacological interventions without patient experience data. The remaining 14 records proceeded to full-text assessment, of which two were subsequently excluded. All screening (titles, abstracts, and full texts) was performed by a single reviewer, with no independent duplicate verification, which is acknowledged as a limitation. A total of 12 sources were included, comprising nine database sources (five primary empirical studies and four secondary or contextual sources) and three grey-literature sources. The selection process is illustrated in the PRISMA-ScR flow diagram (Figure 1).

## Data Charting



**Figure 1. PRISMA-ScR flow diagram of the study-selection process.**

Data were extracted from included studies using a standardised charting template, developed following the guidance of Peters and Pollock, and adapted to incorporate the four conservation domains of Levine's Conservation Model. The template was pilot-tested on the first two included studies before full application. All data charting was conducted by a single (primary) reviewer; no second reviewer independently verified extraction or the mapping of text segments to Levine's domains. Text segments were first coded inductively and then deductively assigned to the four conservation domains; where a segment plausibly mapped to more than one domain it was recorded under each relevant domain, and material that did not fit any domain was retained and reported rather than discarded, so that the data could challenge as well as populate the framework. Because this was a single-

reviewer review, no inter-rater reconciliation was possible, and confidence in the mapped synthesis is downgraded accordingly. Data extraction was applied to all 12 included sources nine database sources (five primary empirical studies and four secondary or contextual sources) and three grey-literature sources identified via supplementary Google searching. Grey literature sources were charted using a separate extraction template to maintain transparency regarding source type, given their non-peer-reviewed nature, consistent with JBI guidance on the inclusion of diverse evidence types in scoping reviews (Peters et al., 2020). A concise, fully-referenced evidence map is presented in Table 3 (Results); the complete data-extraction charts for all sources are provided as Appendix Table A1 (database sources) and Appendix Table A2 (grey-literature sources).

### Critical Appraisal

Consistent with JBI methodology for scoping reviews, formal critical appraisal of included studies was not conducted. Scoping reviews deliberately seek wide-ranging evidence with considerable methodological heterogeneity; a formal quality assessment is not required for the objective of a scoping review, whose purpose is to map the breadth of available evidence rather than to grade it; the credibility of grey-literature sources was nonetheless appraised (see Section 2.3) (20). This approach is consistent with that adopted by (12) in the foundational scoping review on this topic.

### Synthesis of Results

Results were synthesised by the single reviewer using an inductive approach to basic content analysis, as described in the JBI-endorsed recommendations of (21). Following data extraction, themes related to women's experiences were identified through independent manual reading and analysis of the included sources by the primary reviewer. Themes were then mapped deductively to the four conservation principles of Levine's Conservation Model: energy conservation, structural integrity, personal integrity, and social integrity. Results are presented descriptively and narratively, supported by tabular summaries of the thematic distribution across Levine's domains. Evidence characteristics are presented in tabulated form to answer both the primary and sub-questions of the review.

### Theoretical Framework Application

The application of Levine's Conservation Model as an analytical framework in this review is

justified by its holistic orientation and its demonstrated applicability to women's reproductive health. The model conceptualises the patient as a whole person interacting continuously with the environment, whose integrity must be maintained through nursing intervention across four conservation domains (15,17,22,23). This aligns with the multidimensional nature of adenomyosis burden as documented in the literature, where physical symptoms, psychological sequelae, social disruption, and identity challenges co-exist and interact.

## RESULTS

### Study Selection

Database searches across three electronic databases (PubMed, CINAHL, and ScienceDirect), supplemented by grey literature searching via Google, yielded a total of 3,836 records (PubMed: 621; CINAHL: 846; ScienceDirect: 2,366; grey literature: 3). Following removal of 972 duplicate records, 2,864 titles were screened. Abstract and methods screening was conducted for 62 records, followed by full-text assessment of 14 records, of which two were excluded. A total of 12 studies were included in this scoping review, comprising nine peer-reviewed database studies and three grey literature sources. The full selection process is shown in the PRISMA-ScR flow diagram (Figure 1). A concise, fully-referenced evidence map of the 12 included sources—separating primary empirical studies from secondary/contextual and grey-literature sources—is presented in Table 3.

**Table 3. Concise evidence map of the 12 included sources, classified by evidence type and mapped to Levine's Conservation Model.**

| No                                       | Source (author, year, country) | Source type & design                                             | Sample                          | Key lived-experience findings mapped to Levine's domains                                                                                                   |
|------------------------------------------|--------------------------------|------------------------------------------------------------------|---------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>PRIMARY EMPIRICAL STUDIES (n = 5)</b> |                                |                                                                  |                                 |                                                                                                                                                            |
| 1                                        | Huang et al. (2022) — China    | Qualitative; phenomenological (Colaizzi)                         | 18 women, confirmed adenomyosis | Sleep loss and fatigue (E); dysmenorrhoea and menorrhagia (S); symptom normalisation and dismissal (P); disrupted wife/mother/worker roles (So)            |
| 2                                        | Alcalde et al. (2021) — Spain  | Quantitative; comparative cross-sectional (B-PFSF, FSDS, SQOL-F) | 203 (adenomyosis n = 68)        | Impaired sexual function and higher sexual distress vs controls (S, So); reduced sexual self-worth (P); psychological and work-productivity impact (P, So) |
| 3                                        | Tskhay et al. (2026) — Russia  | Quantitative; prospective cohort                                 | 62 women, Grade III–            | Severe vitality loss and iron-deficiency anaemia (E); high pain/PBAC scores (S); emotional distress                                                        |

|                                                                                |                                              |                                                           |                                                                 |                                                                                                                                   |
|--------------------------------------------------------------------------------|----------------------------------------------|-----------------------------------------------------------|-----------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------|
|                                                                                |                                              | (SF-36, EHP-30)                                           | IV diffuse adenomyosis is 101 (hysterectomy n = 51; UAE n = 50) | improving after treatment (P)                                                                                                     |
| 4                                                                              | Trommelen et al. (2025) — Netherlands        | Quantitative; prospective cohort (QUESTA; SF-12, WHO-QOL) | 348 women with dysmenorrhoea                                    | Physical and mental component scores below population norms (E, P); sexual-activity improvement after treatment (So)              |
| 5                                                                              | Unnisa et al. (2022) — India                 | Quantitative; cross-sectional interventional              |                                                                 | Dysmenorrhoea-related QoL burden and absenteeism (E, S); response to non-pharmacological management                               |
| <b>SECONDARY / CONTEXTUAL SOURCES - reviews, editorial, commentary (n = 4)</b> |                                              |                                                           |                                                                 |                                                                                                                                   |
| 6                                                                              | MacGregor et al. (2023) — Canada             | Narrative review                                          | No primary sample                                               | Contextual: disease burden of dysmenorrhoea; normalisation, absenteeism, higher healthcare costs; hyperalgesic priming (S, P, So) |
| 7                                                                              | Petraglia & Dolmans (2022) — Italy / Belgium | Editorial (Views & Reviews)                               | No primary sample                                               | Contextual: iron deficiency/anaemia as an under-recognised mechanism of fatigue in heavy menstrual bleeding (E)                   |
| 8                                                                              | Vela et al. (2025) — Spain / Latin America   | Expert-consensus review                                   | No primary sample                                               | Contextual: AUB/HMB impact on quality of life and direct/indirect costs (E, So)                                                   |
| 9                                                                              | eBioMedicine (2025) — UK                     | Editorial / commentary                                    | No primary sample                                               | Contextual: synthesises Taylor et al. (2025); calls for a cultural shift against symptom dismissal (P)                            |
| <b>GREY LITERATURE - patient narratives / journalism (n = 3)</b>               |                                              |                                                           |                                                                 |                                                                                                                                   |
| 10                                                                             | Wellbeing of Women (2023) — UK               | Patient narrative (charity website)                       | Single narrative (Beth)                                         | Debilitating fatigue and bed confinement (E); dismissal and long diagnostic delay (P)                                             |
| 11                                                                             | Space For Her (2025) — UK                    | Patient narrative (blog)                                  | Single narrative (Vanessa)                                      | Chronic pain, miscarriage, and isolation (E, S, So); specialist referrals refused after relocation (So)                           |
| 12                                                                             | Otte (2023), The Guardian — UK               | Journalistic patient narrative                            | Three narratives (Karen, Sarah, Emma)                           | Heavy bleeding/clots and misdiagnosis (S); insurance-dependent access to diagnosis (So); peer support and empowerment (P, So)     |

Note. E = conservation of energy; S = structural integrity; P = personal integrity; So = social integrity. Complete data-extraction charts for every source are provided in Appendix Tables A1–A2.

## Synthesis: Women's Experiences Mapped to Levine's Conservation Model

### Conservation of Energy

The conservation of energy principle, which addresses the maintenance of balance between energy supply and demand, was compromised across the included evidence, most directly in the primary empirical studies and, in a contextual sense, in the secondary and grey-literature sources. Chronic fatigue, heavy menstrual bleeding, and anaemia emerged as the most consistently reported threats to energy conservation in women living with adenomyosis.

(24) documented profound energy depletion in 18 Chinese women with adenomyosis, with participants describing an inability to sleep due to continuous pain and heavy bleeding, waking one to two times nightly to change sanitary

products. One participant described pain so severe that she 'hit her head against the wall,' and several reported being unable to work or travel during menstrual periods. Physical barriers; specifically pain, fatigue, and heavy bleeding; were identified as the primary category impeding self-management. These findings were echoed in the grey literature: Beth (25) described being confined to bed for three days during a trip to Hong Kong, while Vanessa characterised the chronic pain as 'wearing down, weakening, isolating' and described being left 'drained and hopeless' following repeated emergency room visits.

The quantitative evidence corroborates the pervasive nature of energy conservation compromise. Tskhay et al., (2026) documented severely impaired SF-36 vitality domain scores at baseline (score: 10) in women with Grade III–

IV diffuse adenomyosis, with scores improving to 29 at 24 months following surgical-medical treatment. Critically, 90% of the 62 women in this cohort presented with iron-deficiency anaemia at baseline, with 55% classified as Grade II–III anaemia despite prior supplementation — a direct consequence of chronic heavy menstrual blood loss. Following treatment, haemoglobin levels normalised in 90% of patients within 12 months, illustrating the magnitude of pre-treatment energy compromise. (27) similarly documented baseline SF-12 Physical Component Summary (PCS) scores of 38.7 in women with symptomatic adenomyosis, significantly below the Dutch normative value of 51.97, confirming a substantial population-level energy and physical functioning deficit.

As contextual (secondary) sources, (28) and (29) provided mechanistic context for these findings, noting that women with heavy menstrual bleeding lose five to six times more iron per menstrual cycle than women with normal flow, resulting in total depletion of iron reserves. Iron deficiency the primary symptom of which is fatigue, occurring even before the onset of anaemia thus represents a critical, yet chronically underdiagnosed, mechanism of energy conservation failure in women with adenomyosis. Both sources highlighted that 46% of women with heavy menstrual bleeding had never consulted a clinician for their symptoms, suggesting that normalisation of menstrual burden perpetuates energy depletion at a population level.

### Conservation of Structural Integrity

The conservation of structural integrity concerns the maintenance of physical body structure and the prevention of physical deterioration. By definition, adenomyosis represents a fundamental threat to structural integrity through pathological myometrial invasion by ectopic endometrial tissue. The structural consequences documented across included studies were multisystemic and severe.

Tskhay et al., (2026) provided the most detailed quantitative characterisation of structural compromise in this review, reporting Pictorial Blood Loss Assessment Chart (PBAC) scores of 130 at baseline in women with Grade III–IV diffuse adenomyosis, reducing to 16 following treatment ( $p<0.05$ ). The EHP-30 pain subscale showed substantial reduction across all

assessment time points, and SF-36 bodily pain domain scores improved from 6 at baseline to 23 at 24 months ( $p<0.05$ ). These figures reflect the profound structural burden of severe adenomyosis on physical functioning and daily capacity.

Alcalde, Martínez-Zamora, Gracia, Ros, Rius, and Carmona (2021) documented the structural impact of adenomyosis on sexual health using validated instruments in a comparative cross-sectional design. Women with adenomyosis demonstrated significantly lower Brief Profile of Female Sexual Function (B-PFSF) scores (indicating impaired sexual function) and higher Female Sexual Distress Scale (FSDS) scores compared to non-adenomyosis controls ( $p<0.0001$  for both). Dyspareunia (Numerical Rating Scale:  $2.36 \pm 3.39$ ) and dyschezia were independently associated with impaired sexual quality of life in regression analyses ( $B = -2.38$  and  $-1.18$ , respectively), highlighting the multisystemic structural reach of adenomyosis beyond the uterus.

(30) highlighted the structural mechanism of untreated dysmenorrhoea, including adenomyosis-related secondary dysmenorrhoea, emphasising that prostaglandin-mediated uterine contractions cause ischaemia and that recurrent dysmenorrhoea leads to 'hyperalgesic priming' of the central nervous system, predisposing women to chronic pelvic pain and cross-organ sensitisation involving the bladder and bowel. The potential for structural compromise to become self-perpetuating underscores the urgency of early structural integrity assessment in nursing practice.

The grey literature provided vivid first-person accounts of structural burden. Karen Dugmore (31) described passing blood clots so large they fell to the floor, requiring five sanitary pads per hour and describing a persistent 'bowling ball feeling' in her abdomen. Sarah (31) reported an enlarged and tilted uterus that was misattributed to irritable bowel syndrome for 30 years; only hysterectomy which confirmed the diagnosis histopathologically resolved her symptoms. Vanessa (32) reported multiple uninvestigated miscarriages alongside severe dysmenorrhoea dating from adolescence.

### Conservation of Personal Integrity

The conservation of personal integrity, encompassing self-identity, self-worth, autonomy, and psychological wellbeing,

emerged across all included sources as the most consistently and profoundly threatened conservation domain in women living with adenomyosis. Two overarching themes dominated: the systematic normalisation and dismissal of symptoms, and the psychological sequelae of living with a chronically unrecognised condition.

Symptom normalisation was documented with striking consistency across qualitative, quantitative, and grey literature sources. (24) reported that most participants had never heard of adenomyosis prior to diagnosis and were unable to recognise the relationship between their symptoms and pathology — with one participant noting that she was unaware her bleeding was abnormal until peers confirmed otherwise. Approximately 16.7% of participants had ever sought medical attention for their symptoms. (30) extended this finding to a population level, noting that 51% of women with significant dysmenorrhoea considered their period 'normal,' and that normalisation of menstrual pain by both patients and clinicians represented a systemic barrier to timely care.

A commentary in *eBioMedicine*, (2025) synthesised the conclusions of (12) in concluding that 'a cultural shift is required' to address the pervasive dismissiveness experienced by women with adenomyosis, noting that women's pain had been 'dismissed and normalised by society' and 'attributed to emotional or psychological factors rather than physical pathology.' This pattern was replicated in granular detail in the grey literature: Sarah (31) experienced 30 years of dismissed symptoms, underwent unnecessary steroid injections, and was told she had irritable bowel syndrome; Beth (25) was dismissed by a physician who concluded that because she did not experience dyspareunia, endometriosis was unlikely; Vanessa (32) was repeatedly reassured that her symptoms were 'perfectly normal for a woman' and described 'pleading for pain to be taken seriously' even after diagnosis.

Psychological consequences were well-documented quantitatively. Tskhay found that EHP-30 emotional distress domain scores were significantly elevated at baseline and improved substantially at 12 and 24 months post-treatment, demonstrating the reversibility of psychological burden when structural causes are addressed. (27) reported baseline SF-12 Mental Component Summary (MCS) scores of 36.7 in

women with symptomatic adenomyosis, compared to a Dutch normative value of 49.8, representing a profound pre-treatment psychological health deficit. Even after treatment, MCS scores remained below the normative population, suggesting that personal integrity damage from adenomyosis persists beyond symptom resolution and may require dedicated psychological support.

Impaired sexual quality of life, reflected in significantly lower SQOL-F scores among women with adenomyosis than among controls ( $p < .0001$ ), constituted a distinct personal-integrity dimension, with sexual self-worth and femininity affected independently of dyspareunia severity (33). Body image disturbance was also prominent: (24) reported participants experiencing adverse treatment effects including weight gain and facial discolouration, adding layers of personal integrity threat beyond those directly caused by the disease.

### Conservation of Social Integrity

The conservation of social integrity addresses the maintenance of individual roles and relationships within the family and broader social community. Adenomyosis was documented across all included sources to impose substantial and wide-ranging threats to social integrity, spanning intimate relationships, occupational functioning, financial wellbeing, and broader community participation.

Sexual health and intimate relationship impairment constituted the most consistently measured social integrity domain in the peer-reviewed literature. A comparative cross-sectional study demonstrated that women with adenomyosis experienced sexual quality of life comparable to women with deep infiltrating endometriosis, and significantly worse than controls across all three validated instruments (B-PFSF, FSDS, SQOL-F;  $p < .0001$ ) (33). Dyspareunia and dyschezia were identified as the primary predictors of impaired sexual quality of life in regression analyses, and the authors noted that the downstream impact on partner relationships had not been formally assessed, representing a gap in the existing evidence. (27) documented significant improvement in WHO-QOL-100 Sexual Activity domain scores following both hysterectomy and UAE, with the former demonstrating significant improvement at every follow-up point and UAE

achieving significance only at 26 and 52 weeks, suggesting differential recovery trajectories for intimate relationship functioning depending on treatment modality.

Occupational impact was a prominent social integrity theme. (30) synthesised evidence demonstrating that 20.1% of women reported school or university absenteeism due to dysmenorrhoea (including adenomyosis-related cases), with 40.9% reporting impaired classroom performance. At the societal level, 1 in 5 women who worked outside the home reported missing work in the preceding month due to menstrual-related disorders, and healthcare costs were 2.2 to 2.9 times higher in dysmenorrhoea cohorts compared to matched controls. (24) provided qualitative depth to these figures, with participants describing being unable to fulfil their professional roles, teachers unable to lecture, employees requiring extended sick leave during probationary periods, and one participant who was forced to change jobs due to symptom severity.

Financial impact was documented in both quantitative reviews and grey literature. (29) highlighted the direct and indirect costs associated with adenomyosis-related HMB and IDA, including medical and surgical treatment costs alongside reduced productivity and absenteeism-related income loss. Sarah (31) noted that access to private medical insurance enabled a faster diagnostic referral, illustrating the healthcare inequity dimension of social integrity burden, whereby financial resources determine speed of diagnosis and access to care. Vanessa (32) described how military family relocation to a new province resulted in all specialist referral requests being refused post-diagnosis, leaving her on a 'solitary path' approaching her fortieth year without specialist support.

Family and social role disruption were extensively described in the grey literature and qualitative evidence. One qualitative study reported that participants described being unable to fulfil roles as wives, mothers, and daughters simultaneously with one participant stating: 'I cannot play the role of a wife, a mother and a daughter; it has affected the quality of family life.' (24). Social participation was curtailed through cancelled travel plans and reluctance to engage in leisure activities beyond menstrual periods, and cultural factors specific to the Chinese context including stigma around

the condition and concerns about uterine removal under the Two-Child Policy added additional social integrity dimensions not present in Western sources. Community connection as a coping strategy was highlighted by Emma Lewis-Kalubowila (31), who noted that peer sharing of experiences was 'so helpful,' and the empowerment derived from finally having 'symptoms with a name' represented a restoration of social integrity through shared identity and recognition.

## DISCUSSION

This scoping review applied Levine's Conservation Model as a nursing theoretical lens to synthesise available evidence on the experiences of women living with adenomyosis. The findings reveal a condition that systematically threatens all four conservation domains identified by Levine, generating a complex, interconnected web of physical, psychological, relational, and social burdens that demand holistic, person-centred nursing care.

The most fundamental contribution of this review is the demonstration that the existing evidence on adenomyosis – though limited in volume, as underscored by (12) who found only six eligible studies in their 2025 scoping review – is nonetheless mappable to a coherent nursing framework. By organising the evidence through Levine's four conservation principles, this review provides what is, to our knowledge, the first synthesis of the adenomyosis lived-experience literature organised through an explicit nursing theoretical framework (Levine's Conservation Model); this claim concerns the framing lens rather than the existence of prior reviews, given the earlier scoping review by Taylor et al. (2025).

The energy conservation domain highlights a largely under-acknowledged but clinically significant dimension of adenomyosis burden. Chronic fatigue, poor sleep, and the physical demands of heavy menstrual bleeding collectively generate a sustained state of energy imbalance that is rarely addressed explicitly in clinical management guidelines, which tend to focus predominantly on pain and bleeding control. Nursing assessment using validated fatigue instruments (such as the Brief Fatigue Inventory or the Multidimensional Fatigue Inventory) and sleep quality tools (such as the Pittsburgh Sleep Quality Index) would provide a structured approach to this dimension of care,

consistent with the evidence that LCM-guided nursing care significantly improved fatigue and sleep quality in women undergoing infertility treatment, a population distinct from adenomyosis, so that transferability, though plausible given shared mechanisms of chronic fatigue and sleep disruption, requires direct evaluation (17).

The structural integrity domain encompasses the most biologically proximate manifestations of adenomyosis, and it is in this domain that medical management has historically been most focused. However, from a nursing perspective, structural integrity challenges extend beyond pain and bleeding management to encompass the nursing assessment of functional limitations, coordination of multidisciplinary pain management teams, and sensitive navigation of reproductive implications. The documented prevalence of dyspareunia and its cascading impact on intimate relationships and self-perception underscore the need for sexual health assessment and counselling as a nursing priority.

The social integrity domain reveals the profound reach of adenomyosis beyond the individual woman's body into the fabric of her relationships, her economic security, and her participation in social life. The occupational and financial impacts documented across studies suggest that adenomyosis should be framed as a public health concern with economic implications, not merely a private gynaecological inconvenience. Nursing responses to social integrity challenges require integrated, multidisciplinary approaches that extend beyond the clinic to encompass social support, occupational health, psychological services, and community resources.

The lived experiences of women with adenomyosis are substantially shaped by persistent gaps in healthcare delivery that disrupt multiple domains of conservation within Levine's framework. (11) found that the most frequently reported unmet needs included clinicians' failure to validate patients' complaints, the absence of long-term therapeutic plans, and inadequate multidisciplinary follow-up, findings that reflect threats to social integrity, wherein a woman's dignity and relational roles are undermined by dismissive clinical encounters. The strong demand for psychological, physiotherapeutic, and sexual health support further confirms that

adenomyosis extends well beyond physical pathology, necessitating a whole-person nursing approach (14). Compounding this, (7) note that adenomyosis remains considerably underdiagnosed due to historical reliance on post-hysterectomy confirmation, often leaving the condition undetected in younger women. Such diagnostic delay threatens energy conservation, as women endure prolonged, unmanaged dysmenorrhea and heavy bleeding that deplete their physiological and psychological reserves, while structural integrity is compromised when myometrial invasion and its reproductive consequences progress without timely intervention. Collectively, these realities reinforce the nurse's role in advocating for early detection and sustained, evidence-informed care across the conservation domains central to Levine's theory.

A key implication of this review is the need for nursing education to explicitly address adenomyosis. The literature consistently documents poor awareness of adenomyosis among HCPs (5,12), which perpetuates diagnostic delays and dismissive healthcare encounters. Incorporating adenomyosis content into nursing curricula, alongside the LCM framework for its assessment and care planning, would contribute to the cultural shift called for by (12).

### Limitations

This scoping review has several limitations. First, consistent with JBI methodology, formal critical appraisal was not conducted, limiting assessment of methodological quality across included studies (12). Second, the application of Levine's Conservation Model as a deductive framework may introduce interpretive bias toward themes aligning with its four domains. Third, a pragmatic five-year date limit (January 2020–June 2026) was applied for feasibility within a postgraduate timeframe; this is a scoping restriction rather than a methodological rationale, so identified evidence gaps may partly reflect the date and database limits rather than a true absence of evidence. Fourth, all screening, extraction, and domain mapping were performed by a single reviewer without independent duplicate verification, which may introduce selection and interpretation bias and reduces confidence in the mapped synthesis. Fifth, only three bibliographic databases plus grey literature were searched and the search was not formally peer-reviewed by a librarian,

further limiting comprehensiveness. Sixth, the limited availability of primary studies specifically focused on adenomyosis, as distinct from combined adenomyosis and endometriosis populations, restricts the specificity of conclusions. Finally, the rapid evolution of this field means that additional evidence may have been published since the search was conducted.

## CONCLUSION

This scoping review is, to our knowledge, the first to synthesise evidence on the lived experiences of women with adenomyosis through the explicit lens of a nursing theoretical framework Levine's Conservation Model rather than the first review of the adenomyosis lived experience overall (cf. Taylor et al., 2025). The findings demonstrate that adenomyosis systematically threatens all four conservation domains, energy, structural integrity, personal integrity, and social integrity, generating a multidimensional burden that demands holistic, theory-driven nursing care. The model offers a clinically actionable framework for organising key nursing priorities: managing chronic fatigue and sleep disruption (energy); pain assessment and multidisciplinary coordination (structural integrity); advocacy, validation, and psychological support (personal integrity); and integrated social, occupational, and financial support (social integrity). Significant evidence gaps remain, most notably the scarcity of research on the diagnostic journey and the limited evidence on nursing roles in adenomyosis care identified within this review, marking these as priorities for future primary research. Developing and testing nursing intervention frameworks grounded in Levine's model represents a logical next step. Ultimately, improving care for women with adenomyosis requires both a cultural shift in how menstrual and gynaecological symptoms are perceived and the development of structured, evidence-based frameworks for holistic nursing practice

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## Author Contributions

YHSP: Conceptualization, Methodology, Literature Search, Study Selection, Data Charting, Data Analysis, Data Synthesis, Writing – Original Draft, Writing – Review & Editing.

The author has read and approved the final version of the manuscript.

## Conflict of Interest

The author declares that there are no conflicts of interest regarding the publication of this manuscript.

## Ethics Approval

Ethical approval was not required for this study because it was a scoping review based exclusively on published literature and publicly available sources, with no involvement of human participants or identifiable personal data.

## Patient and Public Involvement

Patients and members of the public were not directly involved in the design, conduct, reporting, or dissemination of this scoping review.

## Data Availability Statement

All data generated or analyzed during this study are included in this published article and its supplementary materials. Additional information related to the review process is available from the corresponding author upon reasonable request.

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