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Women's experiences of living with adenomyosis and perceptions of the diagnostic journey: a scoping review

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ABSTRACT

Objectives Uterine adenomyosis is a common gynaecological disease that can be debilitating. It is poorly understood and may be overlooked in clinical settings. A research gap exists as there are currently no published scoping reviews on perceptions and experiences early in the illness course. As part of a professional doctorate thesis, the aim of this review is to systematically retrieve and describe available literature, exploring the impact of living with adenomyosis and perceptions of the diagnostic journey.

Design A scoping review is conducted using JBI methodology.

Data sources Medline, CINAHL Plus, Web of Science, Google Scholar, Cochrane library, JBI and PROSPERO databases, EThOS online and Google. Searches were made from database inception to July 2023.

Eligibility criteria The characteristics of the evidence sourced were deliberately broad. Studies exploring the experiences and perceptions of women diagnosed with adenomyosis were considered.

Data extraction and synthesis Titles and abstracts were initially screened. Subsequently, eligibility was clarified through methods section inspection, and the remaining studies were read in depth. A manual hand-search of references of selected studies was conducted. Prespecified data were extracted, charted and categorised into themes.

Results Six eligible studies were found, with themes describing impact and burdens, as well as several categories of unsupported needs. No studies specifically focused on perceptions of the diagnostic journey, but some eligible studies made minor reference to this and are included.

Conclusions This review highlights the profound impact of adenomyosis and is the first to explore the lived experiences and the diagnostic journey. Understanding the burdens of disease in terms of perceptions and lived experience in combination with the experiences of diagnostic interactions is vital to improving diagnostic pathways. Education with improved multidisciplinary collaboration and further qualitative and case study research will be crucial to achieve this goal.

Registration A priori protocol was registered (https://doi.org/10.17605/OSF.IO/2UDYN) and published (https://doi.org/10.1136/bmjopen-2023-075316).

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ JBI methodology has been adopted, supporting review systematicity and transparency.
- ⇒ A protocol was published prior to conducting this scoping review.
- ⇒ Critical appraisal of sources was not conducted.
- ⇒ Definitional variations across sources may impede evidence discovery.
- ⇒ Non-English language evidence may remain undiscovered.

INTRODUCTION

Throughout this review the terms woman and women will be used. This is defined as persons assigned female at birth but includes anyone living with uterine adenomyosis (UA), regardless of gender identity.

Rationale

UA is a common gynaecological disease and occurs when the lining of the uterus (endometrium) grows into the muscular wall of the uterus (myometrium). It can manifest inconsistently, and this can hinder diagnosis. Symptoms can be debilitating and include pelvic pain, heavy vaginal bleeding, infertility and poor pregnancy outcomes, and as a poorly understood condition, it may be overlooked in diagnostic settings.[1–3] Commonly, UA coexists with other gynaecological conditions such as endometriosis and uterine fibroids, and diagnostic criteria are still a matter of debate among medical professionals.[4] Despite imaging advances,[5 6] diagnosis poses significant challenges, and the gold standard is still posthysterectomy histopathology, with variable consistency as there are at least nine different histopathological diagnostic frameworks being used.[7] Indeed, diagnosis may take years to be realised,[8–10] influenced by divergent symptoms, inconsistent levels of awareness among healthcare professionals (HCPs) and variable reliability and interpretation of the diagnostic interventions used. Subsequent prevalence estimates vary widely (from as low as 8.8% to as high as 61.5%), being predominately biased towards postsurgical populations.[7] Interestingly, in Italy and using ultrasound imaging, Zannoni *et al* more recently report a UA burden as high as 46% in their sample of 14- to 24-year-olds presenting with chronic pelvic pain.[11] Furthermore, Loughlin *et al*'s[12] extensive retrospective interrogation of US electronic medical records highlights the complexities of such estimations, exposing high numbers of symptomatic women aged 18–55 years with potentially undiagnosed UA, suggesting previous prevalence estimates based on histology are greatly underestimating population disease burden.

This work is motivated by the principle that having a better understanding of the presentation and perceptions of UA, the impact and burden the condition has and the lived experience of women's diagnostic journeys is key to improving the healthcare experience of those living with UA. The importance of qualitative systematic reviews in this field of reproductive health should not be underestimated. A comprehensive understanding of what is known, cocreated with the lived experiences of women, is at the very heart of appreciating knowledge gaps,[13 14] thus allowing HCPs to improve diagnosis and strengthen healthcare provision pathways. A scoping review (ScR) is commonly used when a field of study is emerging or there is not enough homogeneity to enable fair comparisons within available evidence with differing methodological approaches.[15] A preliminary planning search found no systematic reviews and a dearth of peer-reviewed studies. Importantly, no prior ScR was identified. This highlighted the need to conduct a broad search to map existing knowledge. Consequently, an ScR approach is warranted for this literature review, and the JBI methodology is followed.[16–18]

Objectives

This review aims to provide insight into the current understanding of UA, the characteristics of existing evidence, the approach and methods employed, main conceptual definitions and key findings. The primary review questions were developed using the Population–Concept–Context (PCC) framework as recommended by Peters *et al* and the *JBI Manual for Evidence Synthesis*,[16] linked directly to achieving the primary review aim to explore two concepts within current literature (Q1 and Q2).

> Q1: What research exists that explores the lived experience of the impact of UA?
>
> Q2: What research exists that explores perceptions of the diagnostic journey in UA?

These questions are kept broad to capture all relevant evidence available. Subquestions delve deeper into PCC attributes and help understand the background of the evidence available. Each subquestion relates to both Q1 and Q2.

- What are the characteristics of the samples studied?
- What approaches have researchers used (to investigate the lived experience of disease impact/to evaluate perceptions of the diagnostic journey)?
- What measurement methods have been used?
- How have concepts been defined (lived experience/diagnostic journey)?
- What factors were investigated or identified (in relation to the lived experience of disease impact/perceptions of the diagnostic journey)?

METHODS

Protocol

This work adheres to the JBI methodology for ScRs and is reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews Checklist.[16 19–21] To support trustworthiness and applicability of findings, a protocol was registered a priori (Open Science Framework) and published.[22 23]

Eligibility criteria

Inclusion criteria were developed in line with the PCC framework. To capture all available evidence, no time frame/date filtering was used for the searches. While non-English language papers would not have been immediately excluded, none were found due to the English language search terms used.

Population

This review considered all documents researching human adults diagnosed with UA.

Concept

This review considered descriptive and or interpretive evidence that draw on the direct experiences of persons diagnosed with UA including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

Context

The context included all settings, not limited by geography, language or time frame (no time frame filtering during searches, and the search time frame will be determined by the earliest documents available in the database being interrogated).

To aid the selection process, a list of clear exclusion criteria was systematically applied (table 1), enabling

Table 1 Exclusion criteria

1	Exclude if subjects are non-human
2	Exclude if there is no focus on adenomyosis, with a significant coexisting diagnosis of another gynaecological pelvic disease
3	Exclude if the focus is solely on medical, surgical or pharmacological interventions
4	Exclude if lived experience, symptom impact, quality of life or diagnosis is not included as an outcome (as defined in the introduction)
5	Exclude if the participants are the same as in a previous related study, unless there is a separate qualitative analysis

most of the evidence found to be excluded at an initial review of the title and abstract. Regarding point 2 of the exclusion criteria, the historically close association, assumed commonalities and shared use of definitional terminology in previous adenomyosis and endometriosis research were apparent in preliminary searches. Indeed, both were historically seen as the same disease.[24] Subsequently, evidence that includes both adenomyosis and endometriosis within the same study population was included to capture background and contextual information relevant to this review. This was more fully outlined in the review protocol.

Information sources

The searches were run between April 2023 and July 2023. Full search strategies, including the dates searches were run, are tabulated in online supplemental file 1. Electronic databases (Medline, CINAHL Plus and Web of Science) were systematically searched, as well as Google Scholar. Cochrane library databases, the JBI database, the PROSPERO database of systematic reviews and EThOS (British Library theses database) were searched. Finally, an advanced search was conducted on Google. Due to the time constraints of a doctoral thesis by a single researcher, the searches were not formally rerun at the conclusion of the ScR.

Search

The databases were searched with no time frame limits, from database inception to July 2023. Keywords with Boolean connectors, truncation and parenthesis were adopted. Due to the number of sources being explored, Medical Subject Headings were not used as these are not available in all sources and cannot be applied systematically to ensure quality of conduct and reporting.[25]

References for studies identified were collated in an Excel spreadsheet: table 2 provides an example of one search.

References were managed by uploading to the RefWorks web-based bibliography and database manager, where duplicates were deleted, and abstracts were easily retrieved and stored.

Selection of sources of evidence

Qualitative, quantitative and mixed-methods studies were considered where perceptions, first-hand experiences or quality of life (QoL) were included as an outcome. Primary evidence and secondary reviews were considered.

The screening process was conducted in phases. As this work was being conducted as part of a professional doctorate thesis, the primary author predominantly conducted these phases, with input as required from the coauthor supervisors. Titles and abstracts were initially screened by the primary author (MAT). When further clarification of eligibility was required, the methods sections were also reviewed in a second screening phase. Full texts of candidate studies were then read to finalise inclusion. Finally, a manual search of the reference lists was conducted, and a coauthor (MMcB) provided second opinion agreement on the eligibility of those studies making it to the final stage of selection.

Data charting process

Following the guidance as described by Peters *et al*,[16] an extraction template successfully provided a consistently systematic approach to data extraction with a focus on the PCC framework. Data from the final included studies were extracted as described by the original author(s) (this process was completed by the primary author MT only). Other than the addition of recording study limitations, no revisions were made to the template during the charting process (see online supplemental file 2).

Data items

Evidence characteristics are tabulated to provide information that answers the primary and secondary review questions. Results are presented descriptively.

Lived experience was defined as the umbrella term that includes the 'impact' or 'burden' of living with UA, in terms of not only dealing with the direct physical symptoms, but it also encompasses burdens of disease such as social, emotional and financial burdens. Experience also included any reporting of women's perceptions.

Critical appraisal

ScRs are deliberately seeking to find a wide-ranging amount of evidence often with considerable methodological heterogeneity. It is recognised that this makes a formal quality assessment counterproductive,[26 27] and a formal quality appraisal was not conducted.

Synthesis of results

Results were synthesised using an inductive approach to basic content analysis as described in the JBI-endorsed recommendations of Pollock *et al*.[18] After extraction, the data analysis

Table 2 Reference management Excel spreadsheet example

Run	Date	Database	Keywords search	Restriction	Results	Tag name file in RefWorks
1	13 July 2023	PubMed (Medline, life science journals and online books)	Search: (((adenomyosis(Title/Abstract)OR "adenomyosis uteri"(Title/Abstract)) AND (diagnos*(Title/Abstract))) AND (journ*(Title/Abstract)OR pathway*(Title/Abstract)OR perception*(Title/Abstract))) AND (experienc* OR life OR living)	Human	3	13 July 2023 Run1 Q2 PubMed

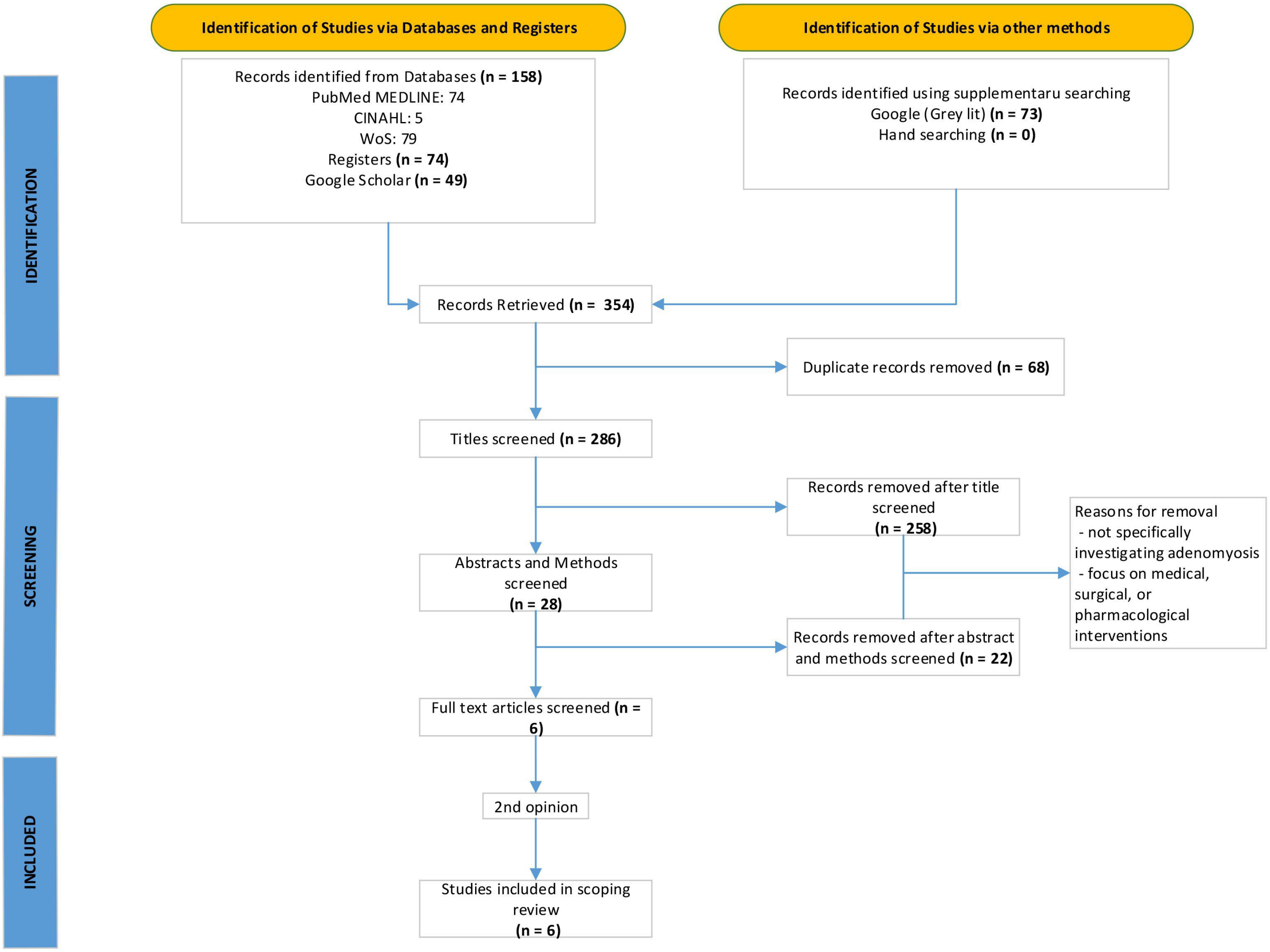


Figure 1 Review question 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram.

management software NVIVO was used to organise and categorise themes related to lived experience.

Experiential data (impacts of disease) were identified, as described by the evidence's cited author(s). From this data, categories were developed by the researcher and are presented using graphic illustrations, supported by narrative discussion.

Patient and public involvement

Although not directly involved in the development of this review, patient and public involvement engagement with Endometriosis UK reflected a positive and supportive response to the project that this ScR supports.

RESULTS

Selection of sources of evidence

The screening process and exclusion reasons are detailed in figures 1 and 2, PRISMA flow diagrams.[19] Most records could be excluded based on the title and/or abstract, under two exclusion criteria; no focus on UA within sample and/or were investigating medical, surgical or pharmacological interventions. Only six studies were found that fulfilled the eligibility criteria and progressed to full-text screening. These were all for Q1 as surprisingly none were found for Q2.

Characteristics of sources of evidence

The characteristics of the eligible evidence are tabulated (see online supplemental file 3) and include study setting, methods employed, aim and study focus, sampling detail and study limitations.

Two report research studies undertaken in Spain,[28 29] one in England,[30] one from Norway,[31] one from the USA[32] and one from China.[33] Two are from the same Spanish research group published in close succession,[28 29] but both are included as there is variance of study aim, participant numbers and analysis. Interestingly, there is an indication of emerging contemporary research activity in this field as despite no time frame criterion set during searches, five of the six studies included were published between 2021 and 2022, with one from 2018.

Two research study contributions measuring the usefulness of interventions provided evidence that met this review's criteria and hence included.[29 30] No study was found that explores the experience of diagnosis specifically.

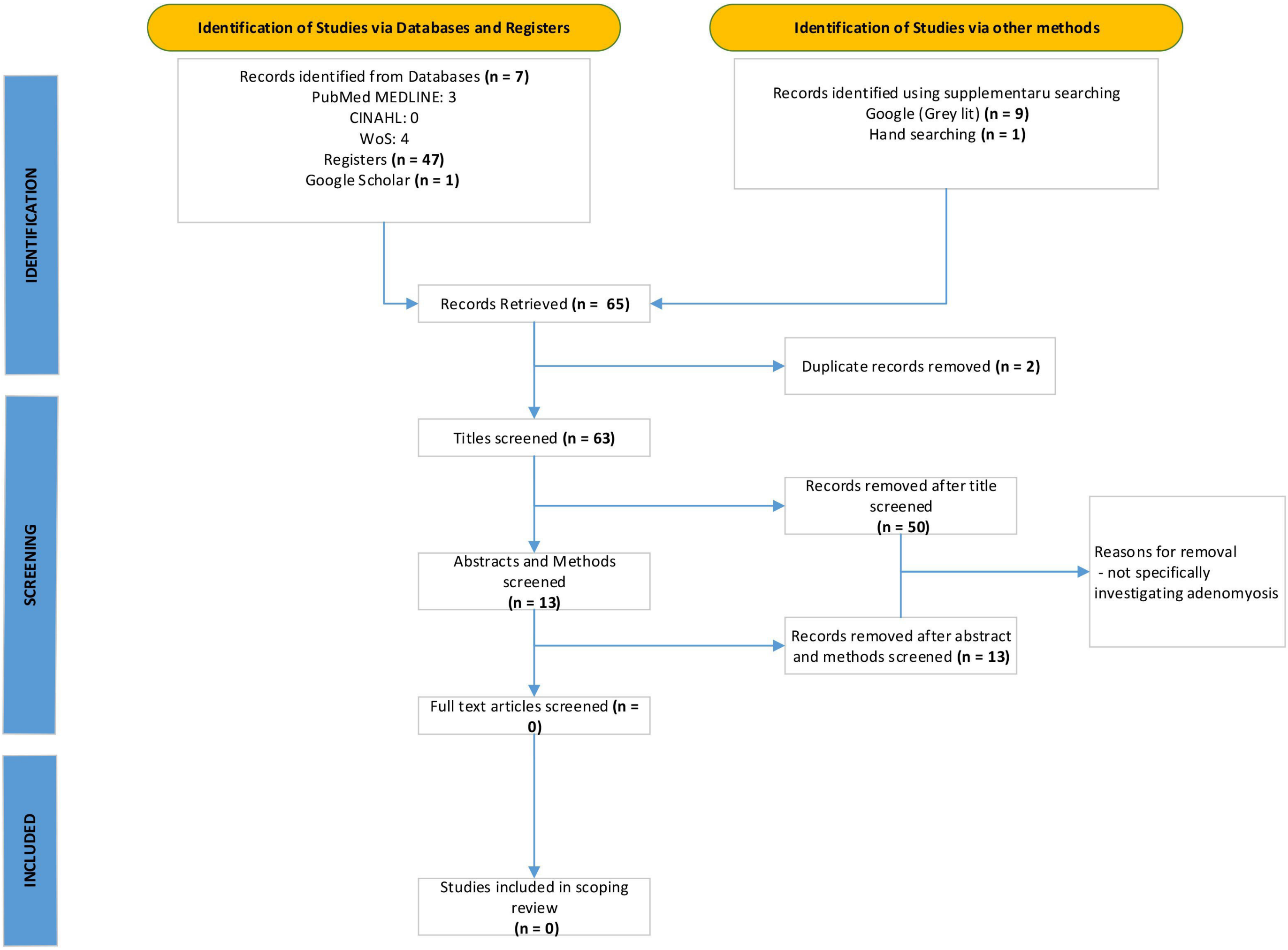


Figure 2 Review question 2 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram.

Three studies use samples that include both UA and endometriosis:

- Alcalde *et al*[29] aimed to improve the understanding of sexual QoL, comparing three groups: a control group, those with deep infiltrating endometriosis (DIE) and women with DIE and UA.
- Only one part of Dempsey's[30] extensive three-part PhD work was used for this review. Their research into the psychological needs and coping strategies of women living with endometriosis and/or UA (to inform the development of a psychological intervention) extensively describes the impact on women's QoL. However, relevance to this review is limited due to their small sample, significantly biased towards endometriosis with no analysis differentiation.
- Omtvedt *et al*[24] explored unsupported needs in terms of healthcare provision needs using a large but undifferentiated population sample of women with endometriosis and/or UA. As it is impossible to identify the impact on women specifically with UA versus those with endometriosis, relevance to this review is limited.

The three remaining studies are focused specifically on women with UA:

- Nelsen *et al*[25] aimed to improve treatment options by understanding women's experiences of UA.
- Huang *et al*[26] explored self-help and better support interventions.
- Alcalde *et al*[21] focused on the effect on mental health and the occupational impacts.

Confirmation of a UA diagnosis was objectively sought by medical imaging in three studies,[28 29 33] while two demanded only a participant self-declared (formal) diagnosis,[23 24] with the remaining one using both methods in their sample.[32]

Most of the studies used purposive and convenience recruitment strategies from hospitals and clinics.[28 29 33] Dempsey[30] and Omtvedt *et al*[24] advertised via social media and support group platforms, while Nelsen *et al*[32] used a combination of both methods.

Most studies listed small sample size as a limitation.[28–30 33] Huang *et al*[26] list a small sample but justify this as 'data saturation was achieved.' Alcalde *et al*[22] justify their small sample as being comparable to previous research in the field. Alcalde *et al*'s[21] statistically analysed quantitative research failed to meet their statistically estimated target of a 1:2 ratio but was also comparable to other similar research studies. Dempsey[23] acknowledged the smallest sample of six in their participatory research study, with a single mixed sample of endometriosis or UA participants, and no separate analysis. Similarly, although a much larger sample number was achieved in their mixed-methods research, Omtvedt *et al*[24] investigated both conditions within the same sample with no separate analysis.

Alcalde *et al*[22] list selection bias as they recruited from a single clinic. Although not explicitly stated, all included studies used varying degrees of convenience sampling to achieve their purposive sampling strategies. Understandably, the need to purposely recruit people will result in conveniently available populations being targeted.

Within the evidence found, the heterogeneity of approach and methods used is noteworthy, highlighting the benefits of conducting an ScR. Two used a quantitative approach with validated questionnaires and statistical analysis,[28 29] two used a qualitative interview approach employing thematic or content analysis techniques,[32 33] one used a qualitative workshop and coresearcher approach with photovoice techniques and thematic analysis[30] and one used a mixed-methods questionnaire approach of closed and open responses.[31]

Results of individual sources of evidence

A summary of the extracted data with the significant relevant findings that answer the review questions is tabulated (see online supplemental file 4).

The main findings relate to the lived experience of disease impact, across all studies for review Q1 and are summarised under the collective term 'impact of disease.' No studies were found specific to review Q2, and there was limited mention of women's perceptions. Subsequently, although not an explicit focus for the six Q1 included studies, they were retrospectively reviewed for any Q2 elements relating to the experience of diagnosis, and these data have been included.

The key findings of three of the six papers are focused on disease impact.[28 29 32] Dempsey[30] and Omtvedt *et al*,[31] while listing some impacts, predominantly detail the (unsupported) needs as described by those with the condition, such as the need for empathy, the need to be believed, the need for knowledgeable support and understanding. One author's output lists both categories of findings.[33]

Figure 3 provides a visual overview of the category themes found, specific to each of the six evidence sources. Figure 4 illustrates the combined refined categories from the findings across all six studies, demonstrating disease 'impact' categories (physical impact, psychological and mental health impact, relationship impact, occupational impact and financial impact) and includes the related listed subcategories. The listed subcategory findings taken from each study are listed by order of most prioritised mention.

Figure 5 illustrates the combined findings across all six studies, demonstrating the unsupported 'needs' categories (knowledge needs, respect and dignity needs). When developing categories, it became apparent that a new third unsupported 'needs' category was required. This has been called 'care needs' and includes the need for empathy and support, care continuity and the need for better forward planning. Knowledge needs relate to society in general but especially relate to poor HCP knowledge. Also, participants themselves report the need to know more about the condition they live with. The

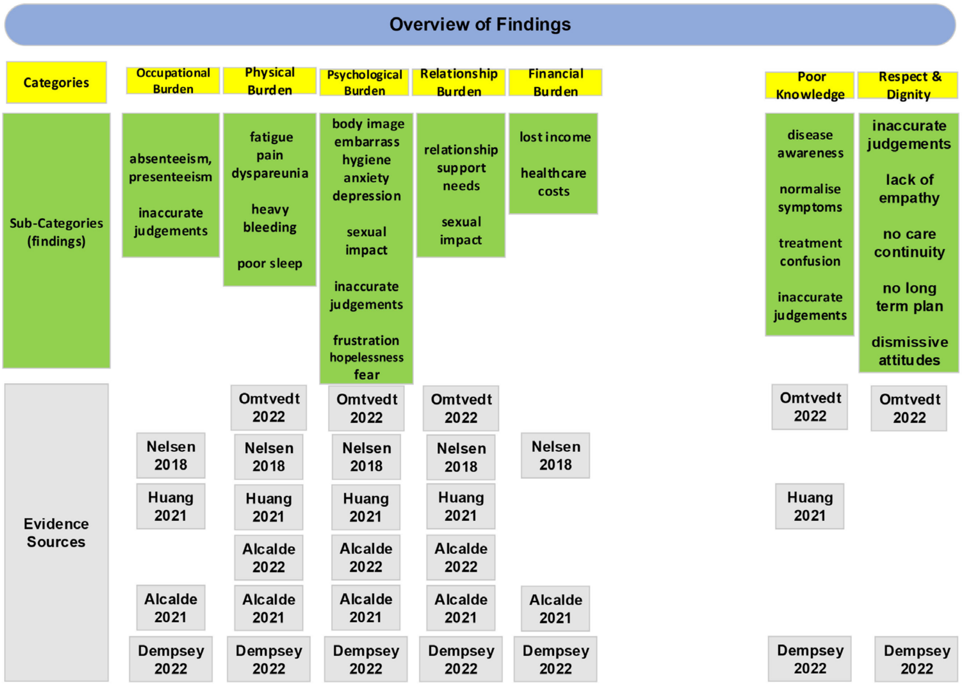
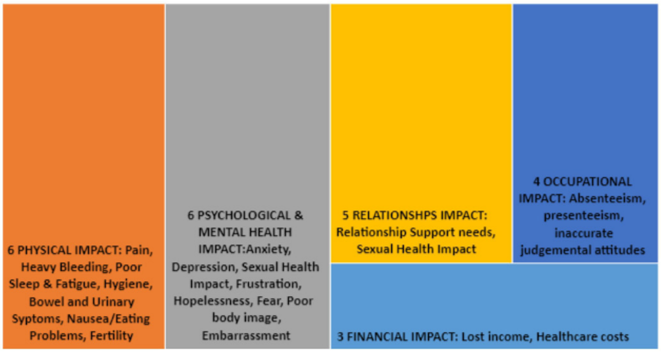


Figure 3 Overview mapping of findings.



Stated figures relate to number of articles listing the category.

Figure 4 Disease impact tree map of categories and subcategories. Stated figures relate to number of articlse listing the category.

category of respect and dignity encompasses a recurring theme and relates to the generally poor, unempathetic and inaccurate judgements and attitudes encountered in all aspects of daily living with UA.

Synthesis of results

The charted results are synthesised to provide a summary of how the collective findings of this review relate to the review questions.

Figure 6 offers a visual synthesis of the extracted data aiming to highlight the significant burdens of living with UA. Nelsen *et al*[32] provide the most extensive outline of physical symptoms, listing 50 symptoms specific to UA. Pain, heavy vaginal bleeding patterns, fatigue and poor sleep patterns have a psychological impact in terms of body image, embarrassing hygiene issues, social, relationship and sexual health challenges. Subsequently, this spirals into frustration, hopelessness, fear, anxiety and depression.[28 30 31] Alcalde *et al*'s[28] research has a specific aim to assess the occupational impact, but three further studies also list occupational impact as a burden of the disease.[23 25 26] Financial impact in terms of lost income, as well as spiralling personal healthcare-related costs, is listed in three of the six studies.[28 30 32] Interestingly, Huang *et al*[26] identify how the additional impact of collective societal ideals, culture and beliefs can influence an individual's lived experience. Although this specific aspect of culture was not categorised for this review, it does offer a unique perspective in this regard.

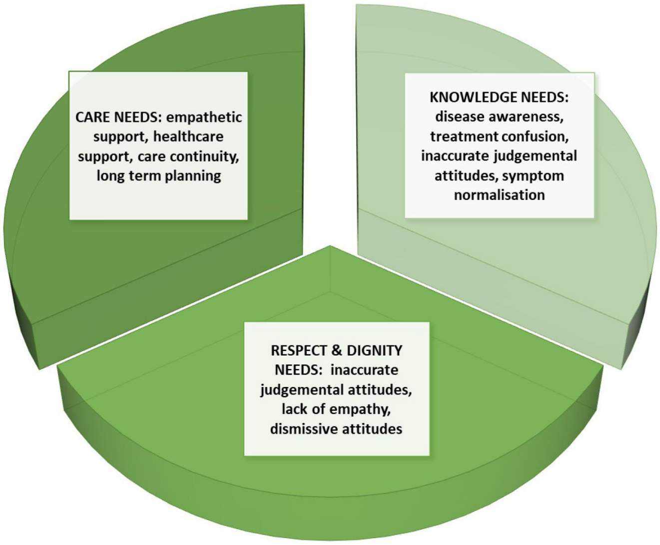


Figure 5 Needs chart of categories and subcategories.

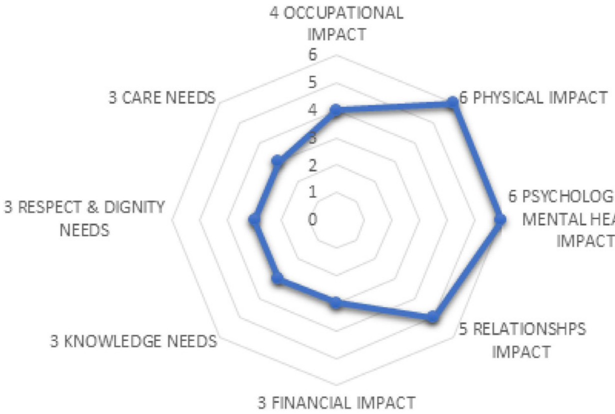


Figure 6 Category spread over the six articles.

Knowledge needs within society (poor understanding) are reflected not only in HCPs' poor knowledge but are also listed as an issue for individual participants, for example, normalisation of own symptoms and not seeking healthcare advice.[26] Furthermore, a recurring theme within both Omtvedt *et al's*[24] and Dempsey's[23] research highlights that participants experience poor respect and a lack of dignity, such as inaccurate judgements, lack of empathy, no care continuity or long-term care planning, as well as dismissive attitudes across all aspects of living with this condition. Participants associate such attitudes as a reason for poor responsiveness from HCPs during their experienced healthcare interactions.

As no studies were found specific to review question 2 (Q2: What research exists that explores perceptions of the diagnostic journey in UA?), included studies were retrospectively examined for elements relating to diagnosis, and although limited, diagnostic barriers are highlighted in two studies. Dempsey's coresearchers stated they had experienced 'misdiagnosis', dismissive attitudes and not being believed.[23] Huang *et al*[26] also highlight the diagnostic delays due to poor knowledge levels among those with the condition, as well as among their families; lack of understanding leading to normalisation of menstrual symptoms and lower advice seeking.

DISCUSSION

As reflected in this review, women may suffer in silence with their symptoms being dismissed or normalised. This further exacerbates their health issues, prolongs suffering, delays diagnosis and prevents treatment interventions, leading to worsened health outcomes and reduced QoL. Moreover, the lack of attention and research on women's health issues hinders medical advancements and the development of effective treatments specifically tailored to women's needs. Additionally, occupational anxiety and stress are reported through poor performance and absence from the workplace. In this regard, financial losses are described in terms of lost wages, as well as increased healthcare costs for those in private healthcare systems.

The three most common inter-related themes that are described across all sources are physical, psychological and relationship burdens (see figure 6). The physical burdens highlight heavy bleeding, fatigue and pain symptoms most commonly. Pain during sexual intercourse is especially problematic with resulting relationship and psychological burdens. It is acknowledged that women's pain or discomfort can be dismissed, with their symptoms being attributed to emotional or psychological factors rather than physical ailments.[34 35] This view is deeply rooted in gender stereotypes and inequalities that portray women as more emotional and less credible when it comes to their health concerns. The consequences of not taking women's health problems seriously are far reaching, with prolonged physical and mental ill-health, reduced health outcomes and poor QoL.[10]

Other themes relating to knowledge needs and poor healthcare responsiveness are highlighted, with inaccurate judgements by HCPs as well as wider society in general. This review highlights the lack of respect and dignity, which are a common source of women's psychological distress and perceived by participants to hinder diagnosis and treatment. Indeed, stigmatisation surrounding women's health perpetuates the ongoing lack of research in this field and contributes to the diminished seriousness of menstrual health problems[36 37] and continues that lack of awareness and understanding of common menstrual conditions. Further heightening diagnostic delays is the general poor knowledge of this disease within society. With the lack of discussion, dismissive attitudes and the ongoing stigma associated with menstruation and period-related health, research and promoting understanding are compromised.[36–42] To improve knowledge and understanding of UA, a cultural shift is required across societies, thus encouraging a more advice-seeking population and raising awareness within healthcare communities.[43 44] Only then will we begin to reduce the care inequities that women experience and tackle the deteriorating ill health of those with UA. While it would be inaccurate and unfair to suggest that all HCPs do not believe women, there have been instances where women's health concerns are dismissed or not taken seriously, leading to a patient perception that such concerns are not believed.[45]

This review demonstrates the impact and burdens of UA, as well as the unsupported needs of women. Understanding these factors is critical to understanding diagnostic requirements and support care improvements. Indeed, a poor appreciation of impacts and burdens (manifestations of disease) combined with poor levels of knowledge, understanding and attitudes (responsiveness) has been linked to poor diagnostic pathways and perpetuating diagnostic errors. The National Academies of Sciences, Engineering and Medicine (NASEM) Committee of Diagnostic Error in Healthcare[46 p 355–357] is an extensive US report that not only recognises the need for improved education and training to achieve diagnostic efficiency but also concludes that successful, responsive diagnostic pathways are built on teamworking across HCP communities, *in collaboration with* patients and their families. This provides clarity to appreciate the inter-related nature of disease impact with the diagnostic pathway, and the two aspects are critical to improving our understanding of the lived experience of UA and the various perceptions of patients and practitioners that accompany any journey to achieving an eventual diagnosis. Furthermore, NASEM warns that 'diagnostic errors may cause harm to patients by preventing or delaying appropriate treatment, providing unnecessary or harmful treatment or resulting in psychological or financial repercussions'.

It is encouraging to see the recent addition of easily accessible UA information, on UK National Health Service websites.[47 48] However, the findings of this review underscore the need for collaboration and improved knowledge of all involved, as an integrated process. Critically, this must include individuals with lived experience, as well as the expertise of the HCP communities. This is supported by NASEM whose report highlights the improving but still ongoing need to prioritise the patient perspective as a vital, but often missing, factor in diagnostic performance.[49]

This review reflects the need for a more comprehensive approach and honest discourse about women's health to address the unique challenges faced by women. The perceived unhelpful attitudes around respect and dignity not only highlight poor responsiveness at healthcare interactions but also suggest a much deeper cultural issue. Further qualitative research of women's experiences as well as HCP perceptions is required to further understand current challenges to diagnosis and how the cultural barriers around menstrual health can be broken down.

Limitations

This ScR presents the evidence that exists outlining what it means to live with UA. While offering several advantages, it is important to acknowledge limitations. As is commonly the case, most ScRs do not assess the quality or rigour of the included individual studies, and this is true for this review. Consequently, there is no detailed analysis of the methodological strengths and weaknesses of the included studies, and additionally, the heterogeneity of the included evidence limits readers ability to draw definitive conclusions.

A limitation was anticipated a priori, in that lived experience, HRQoL and/or QoL may be poorly defined in sources found. This was found to be the case, and lived experience was seldom mentioned with HRQoL and/or QoL mentioned but rarely defined. Subsequently, the authors have defined lived experience as an umbrella term that includes the condition's impacts and burdens, and this may introduce ambiguity to conclusions made.

Due to the specific historical associating and subsequent ambiguous differentiating terminology used, evidence that included both adenomyosis and endometriosis within the same samples was included, as otherwise the review may exclude significant background and contextual information that is considered important to this review. This inability to confidently examine UA evidence specifically is a limitation of this review.

Furthermore, it must be highlighted that two of the six studies did not differentiate between participants with UA and endometriosis,[23 24] with Dempsey[23] further acknowledging only one participant with UA in their sample. Despite formally fulfilling the inclusion criteria of this review, this limits the credibility of this evidence, specific to this review.

Despite these limitations, given the dearth of available evidence in this field of study, this ScR has been a valuable tool for mapping the literature, filling the research gap for such a review, and has provided a valuable overview of what is currently understood.

Conclusion

This ScR highlights the significant impact that UA has on women's physical and mental health. Ongoing research is crucial to achieve improved diagnosis and management. Increasing awareness among HCPs (primary, secondary and imaging), as well as women and society in general, will be pivotal for early identification and appropriate onward referral. Furthermore, this review emphasises that improved knowledge of the impact and burdens of disease, when taken in combination with experienced healthcare interactions, is vital to improve diagnostic and care pathways. Logical next steps include more primary data as well as a more formal evidence synthesis of current and emerging qualitative studies.

Funding

This ScR did not receive any grant from funding agencies and was conducted as part of a (professional) doctorate thesis with the University of Dundee. Two of the included evidence sources state no funding,[28 29] one declares their research was conducted as part of a fully funded PhD studentship,[23] one was funded by GlaxoSmithKline (GSK), with GSK contributing to the design of the study and the acquisition, analysis and interpretation of the data,[25] one study[31] declares some of the research team received student and postdoctoral funding from national health organisations and one provides no funding declaration.[26]

Updated searches

For ongoing awareness of current literature, the Web of Science alert process was initiated. Also, the primary author repeated the searches of Medline on 23 October 2024 (limited to the time frame 1 April 2023 to 31 October 2024). This resulted in one further recent 2024 paper.[50] This Chinese study aims to establish an assessment scale for tracking symptoms in patients. Through interviews with women diagnosed with UA, they have established a wide variety of symptoms for their electronic tracker WeChat application, adding to the knowledge base of physical symptoms experienced and offering interesting ongoing evidence collection for the future.

Contributors This review has been developed as part of a professional doctorate thesis. MAT is the postgraduate student researcher and corresponding author. TJC, MMcB and FEM are university supervisors for this thesis. MAT, TJC, FEM and MMcB have been involved with the study's conception and design. MAT drafted the manuscript. MAT, TJC, MMcB and FEM have been involved in revisions. All authors have critically revised the manuscript for important intellectual content. All authors have read and approved the final manuscript. MAT is responsible for the overall content as guarantor and accepts full responsibility for the finished work and/or the conduct of the study, had access to the data and controlled the decision to publish.

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Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

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