

Reference	Design	Disease Focus	Study Aim	Conceptual Definitions	Key Findings - Impact of Disease Q1	Perceptions of Diagnostic Journey Q2
<b>Alcalde et al, 2022</b>  <b>Part 1 only of a 2-part project.</b>  <b>SPAIN</b>	Survey Research  QUANT	Adenomyosis (AD) and Deep Infiltrating Endometriosis (DIE)	To evaluate the overall and sexual quality of life, sexual desire and pain symptoms in women with DIE and women with DIE + AD (and the influence of a flexible extended COC regimen in the long-term in these women).  (Pharmacological intervention aspects not applicable to this evidence review)	Lived experience not defined.  (HR)/QoL not defined.  (HR)QoL – Health Related Quality of Life	DIE + AD group showed higher pain compared to DIE only and control groups. DIE + AD and DIE groups lower HRQoL DIE + AD group showed poorer sexual QoL compared to DIE only and control groups.	NA
<b>Dempsey, 2022</b>  <b>Part 2 only of a 3-part project.</b>  <b>PhD ENGLAND</b>	Participatory Action Research  QUAL	Adenomyosis (AD) and Endometriosis (Endo)  As 1 population	To conduct a needs assessment to inform the development of a complex psychological intervention for people living with endometriosis and/or adenomyosis.  Q: What are the <u>psychological</u> needs and <u>coping strategies</u> of those living with endometriosis and/or adenomyosis?	Lived experience not defined.  Quality of Life (QoL) - The standard of health, comfort and happiness experienced by an individual or group.	Seven needs, thirteen unmet needs (and fifteen coping strategies) identified.  Complex pattern of interconnected physical and psychological needs, adversely impacting on QoL with acknowledgment of the impact of different lived experiences = differing impact on QoL. Dismissive attitudes / not believing / poor understanding causes isolation, fear for future.	Not explicitly explored. - experienced misdiagnosis, being dismissed, and not believed and as a result felt that they often must provide evidence of symptoms and diagnosis.
<b>Omtvedt et al, 2022</b>  <b>NORWAY</b>	Mixed method survey  MIXED	Adenomyosis (AD) and Endometriosis (Endo)  As 1 population	Aim: to find out what patients and relatives consider to be the best possible care in terms of multidisciplinary endometriosis and adenomyosis management and potential development of an	Lived experience not defined.  (HR)/QoL not defined.	Multidisciplinary care was a key issue for the majority, with - a need for a psychologist, a nutritionist, a physiotherapist, and a sex therapist.	NA

			endometriosis centre, to prioritize resources towards the most needed aspects. Assumed Q: What do patients and relatives consider to be the best possible care in terms management of endometriosis and adenomyosis?		The qualitative analysis of free text answers revealed a great need for - updated and easily accessible information - competent health care professionals - respect and being taken seriously/listened to	
<b>Nelsen et al, 2018</b>  <b>USA</b>	Qualitative, cross-sectional, descriptive study	Adenomyosis (AD)	Interviews were conducted to characterize the symptoms and impact of adenomyosis.  Assumed Q: What are the symptoms and impact of adenomyosis?	Lived experience not defined.  (HR)/QoL not defined.	More than 50 different symptoms of adenomyosis were reported; the most common of which were: - heavy menstrual bleeding (87%) - cramps (84%) - blood clots during menstrual bleeding (84%) - bloating (55%) - and low energy/fatigue (52%)  More than 30 <u>impacts</u> of adenomyosis were reported; the most common were: - burdensome self-care hygiene (71%) - fatigue/low energy (71%) - impacts on leisure/social activities (65%) - household/activities of daily living (61%) - travel (61%) - physical activities (61%)	NA
<b>Huang et al, 2021</b>  <b>CHINA</b>	Phenomenological qualitative methodology (Colaizzi's even	Adenomyosis (AD)	Research Q: "What barriers to self-management do patients with adenomyosis have and what requirements do they want?"	Lived experience not defined.  (HR)/QoL not defined.	Four themes were identified: - lack of disease knowledge - challenges and dilemmas of daily life - multidimensional negative emotions - personalised supporting	Not explicitly explored. - most patients did not know about AD before diagnosis, and they were

	steps)				requirements.  Described as challenges and dilemmas of daily life – these are ‘closely related to symptoms and complications’: <ul style="list-style-type: none"><li>- sleep disturbance</li><li>- sexual dissatisfaction</li><li>- disruption in social activities</li><li>- changes of appearance and original roles</li></ul>	unable to recognise the relationship between dysmenorrhea and AD, only 16.7% patients went to a doctor.
Alcalde et al, 2021  SPAIN	Survey Research QUANT	Adenomyosis (AD)	To assess the impact of UA on different aspects of women’s psychological health  HRQoL work productivity estimates its effects in terms of a potential increase in indirect costs	Lived experience not defined.  (HR)/QoL not defined.	With UA compared to those without UA <ul style="list-style-type: none"><li>- significantly lower scores in all domains of the SF-36 questionnaire</li><li>- mean (SD) higher scores in the HADS questionnaire for anxiety and depression.</li><li>- Significant differences (<math>p &lt; 0.001</math>) in percentages of absenteeism, presenteeism, overall work productivity loss, and activity impairment (55.7% vs. 9.9%).</li><li>- The presence of AD was associated with higher yearly estimated indirect costs</li></ul>	NA