

Understanding Endometrial Cancer Patient Experience in Australia: A Rapid Review of the Current Evidence

November 2024

Acknowledgements

The Victorian Integrated Cancer Services (VICS) are Victoria's cancer services improvement network. They build relationships between healthcare providers and other cancer care stakeholders to develop, implement and evaluate initiatives that improve the way our member health services provide care and support people affected by cancer.

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Abbreviations

Abbreviation	Definition
ANZGOG	Australia New Zealand Gynaecological Oncology Group
CAM	Complementary and Alternative Medicine
EC	Endometrial Cancer
IVF	In Vitro Fertilisation
OCP	Optimal Care Pathway
NEMICS	North Eastern Melbourne Integrated Cancer Services
TAH	Total Abdominal Hysterectomy
TLH	Total Laparoscopic Hysterectomy
VICS	Victorian Integrated Cancer Services

Executive summary

Background

Endometrial cancer (EC), also known as uterine cancer is the fifth most commonly diagnosed cancer among females and tenth most commonly diagnosed cancer in Australia. The Optimal Care Pathways (OCPs) are a framework to promote high quality and integrated cancer care for all Australians. The OCPs comprise of seven steps which span across the cancer continuum from prevention to end-of-life care. The Victorian Integrated Cancer Services (VICS) Optimal Care Summits program involves assessing cancer care, outcomes and experience in Victoria against these OCPs. In 2024, the VICS Optimal Care Summits team commenced a two-part mixed-methods, strategic consultation approach to identify and agree to priorities for reducing variations and improving EC outcomes and experiences for patients throughout Victoria and understanding the experience of people with EC is a key element. This literature review forms an important component of the first phase of the two-part mixed methods approach. Findings will be used to inform the second, the VICS EC Optimal Care Summit event to be held in November 2024.

Aim

To explore and synthesise existing evidence in relation to the experiences of EC patients across Australia.

Methodology

Articles with the terms specific to patient experiences in the context of EC were searched using two databases: Medline and EMBASE. The search was performed during August 2024. The articles selected were original published Australian research which reported patient experience in adult endometrial cancer populations and published from 2018 onwards. Non-empirical literature such as opinion pieces, descriptions of protocols for clinical trials, abstracts with no available full-text, case reports, conference abstracts, letters to journal editors and editorials were excluded. The primary articles' reference lists were searched to retrieve additional articles.

Results

Of the seven studies that met the inclusion criteria, three were observational studies, three were randomised control trials, and one was an open-label trial. In terms of the OCP steps, one study focused on Step 3: Diagnosis, staging and treatment planning, five studies focused on Step 5: Care after initial treatment and recovery, and one study focused on Step 6: Managing recurrent, residual or recurring metastatic disease. None of the studies provided any information on Step 1: Prevention and early detection, Step 2: Presentation, initial investigations and referral, Step 4: Treatment, Step 7: End-of-life care of the Optimal Care Pathway for EC.

Implication

The research process revealed a significant lack of studies on patient experiences in EC care, particularly for prevention and early detection, presentation, initial investigations and referral, diagnosis, staging and treatment planning with only limited literature available for treatment, care after treatment and recovery and recurrent and metastatic disease management. The Optimal Care Summits program provides an opportunity to support women with EC through advocacy, policy and research, and service improvement.

Introduction

Uterine cancers arise in the uterus where abnormal cells develop and grow. [1] There are two major types, the first type is endometrial cancer (EC) which develops in the lining of the uterus accounts for about 95 per cent of all uterine cancers. [1] The second type of uterine cancers is uterine sarcomas which develop in the muscle of the uterus or within connective tissues which support the endometrium. [1] Symptoms of EC include abnormal vaginal bleeding, unexplained weight loss, difficulty urinating, watery vaginal discharge and abdominal pain. [2]

Uterine cancer is the fifth most commonly diagnosed cancer among females and tenth most commonly diagnosed cancer in Australia. [3] In 2022, it was estimated that more than 3,343 females were diagnosed with uterine cancer and 667 estimated to have died from uterine cancer. [3] This represents a total of three per cent of all female deaths from cancer in 2022. [3]

Uterine cancer incidence is increasing in Australia. [3] The number of new cases of uterine cancer diagnoses increased from 942 in 1982 to 2,974 in 2018. [3] The five-year survival for individuals diagnosed with uterine cancer 83 per cent in 2014-18, increasing from 78 per cent in 1989-93. [3] At the end of 2017, it was estimated the 11,511 people were living who had a uterine cancer diagnosis in the previous five years (2013-17) and an estimated 33,60 people living who had a uterine cancer diagnosis in the previous 36 years (1982-2017). [3]

There are several factors that contribute to the increasing incidence of endometrial cancer in Australia and globally. These include an aging population and an obesity epidemic, which has been identified to be a significant risk factor for endometrial cancer. [4] Socioeconomic factors can also play a role, with higher incidence and mortality rates observed among women from lower socioeconomic backgrounds and Indigenous women. [5]

Endometrial cancer does not currently have an effective population-based screening test for asymptomatic women. [5] Although abnormal uterine bleeding is recognised as an early sign and should trigger immediate investigation. [4] Effective detection relies heavily on the quick recognition of symptoms by women and healthcare professionals. In addition, delays in treatment, particularly for high-risk individuals such as older women or those with obesity, are believed to have a negative impact on survival outcomes. [5]

The Optimal Care Pathways (OCPs) are a framework to promote high quality and integrated cancer care for all Australians. [6] There are seven steps in the OCPs which span across the cancer continuum from prevention and early detection, diagnosis and treatment planning, treatment and care after treatment, managing recurrence and end-of-life care. [6]

Unlike other gynaecological cancers, such as cervical and ovarian cancers, endometrial cancer lacks a dedicated consumer advocacy group in Australia. There is a significant gap in understanding patient experiences with endometrial cancer care in Australia. Understanding patient experiences is crucial to identify gaps and drive meaningful improvements.

The Victorian Integrated Cancer Services (VICS) Optimal Care Summits program is a leading initiative of the VICS and is administered and managed by the North Eastern Melbourne Integrated Cancer Service (NEMICS). The purpose of the program is to identify unwarranted variations in tumour-specific cancer care and cancer outcomes relating to the OCPs and to provide recommendations for the VICS to address at the state, network, and/or health service level. In 2024, the VICS Optimal Care Summits team will begin a

mixed-methods, strategic consultation approach to identify and agree to priorities for reducing variations and improving endometrial outcomes and experiences for patients throughout Victoria and understanding the experience of people with endometrial cancer is a key element.

Aim

To explore and synthesise existing evidence in relation to the experiences of people with EC and their families/carers across Australia. The question below was explored:

- What are the experiences of Australian EC patients in their cancer journey as it pertains to the Endometrial Cancer Optimal Care Pathway?

Methods

Patient experience in medical oncology is a term that refers to different dimensions of the interaction between patients. [7] A search of databases was completed of contemporary literature (2018 onwards), published in English with a focus on EC patient experience in Australia. Databases searched include MEDLINE and Embase, in addition to grey literature sourced via website searches. All articles were reviewed and screened for eligibility and relevance. Websites of relevant organisations such as Australia New Zealand Gynaecological Oncology Group (ANZGOG) and Counterpart were searched to identify any additional studies reported in the grey literature. A basic search using Google Scholar was also undertaken to identify any further articles that may be of relevance. Search terms used are listed in Appendix 1.

Eligibility criteria

Inclusion Criteria

- Population: adults (18 years and older) diagnosed with endometrial/uterine cancer and/ or their carers.
- Types of publication: Publications that report original primary empirical work and published between 2018 – current.
- Types of settings: All types of primary, secondary and tertiary care in Australia providing endometrial/uterine cancer care.
- Types of study design: Conceptual, theoretical, quantitative or qualitative studies of any research design.

Exclusion Criteria

Non-empirical literature such as opinion pieces, descriptions of protocols for clinical trials, abstracts with no available full-text, case reports, conference abstracts, letters to journal editors and editorials were excluded. Literature with only cervical cancer or ovarian cancer noted in discussion or where EC is non-significant throughout the text were also excluded.

Data extraction and synthesis

After the inclusion criteria was applied to titles and abstracts (including executive summaries of grey literature) of full articles that were reviewed, the following data were

extracted: first author, year, study design, objective(s), participants (N), outcomes/results, and key findings.

Findings were analysed using a narrative empirical synthesis in stages based on the review question. Initial descriptions of eligible studies and results were tabulated for EC (Appendix 1) and divided by the seven-step OCP for EC. Patterns in the data were explored to identify any consistent findings in relation to the study questions. Interrogation of the findings explored the influence on different outcome measures, methods, and settings on the resulting data.

Results

Results of the search

After removing duplications, 46 articles were identified that were specific to Australian patients' experience of EC. Due to the paucity of Australian data on the experiences of patients with their treatments received from Australian healthcare providers, all articles had full text review. Based on the inclusion and exclusion criteria, seven articles were included in the literature review.

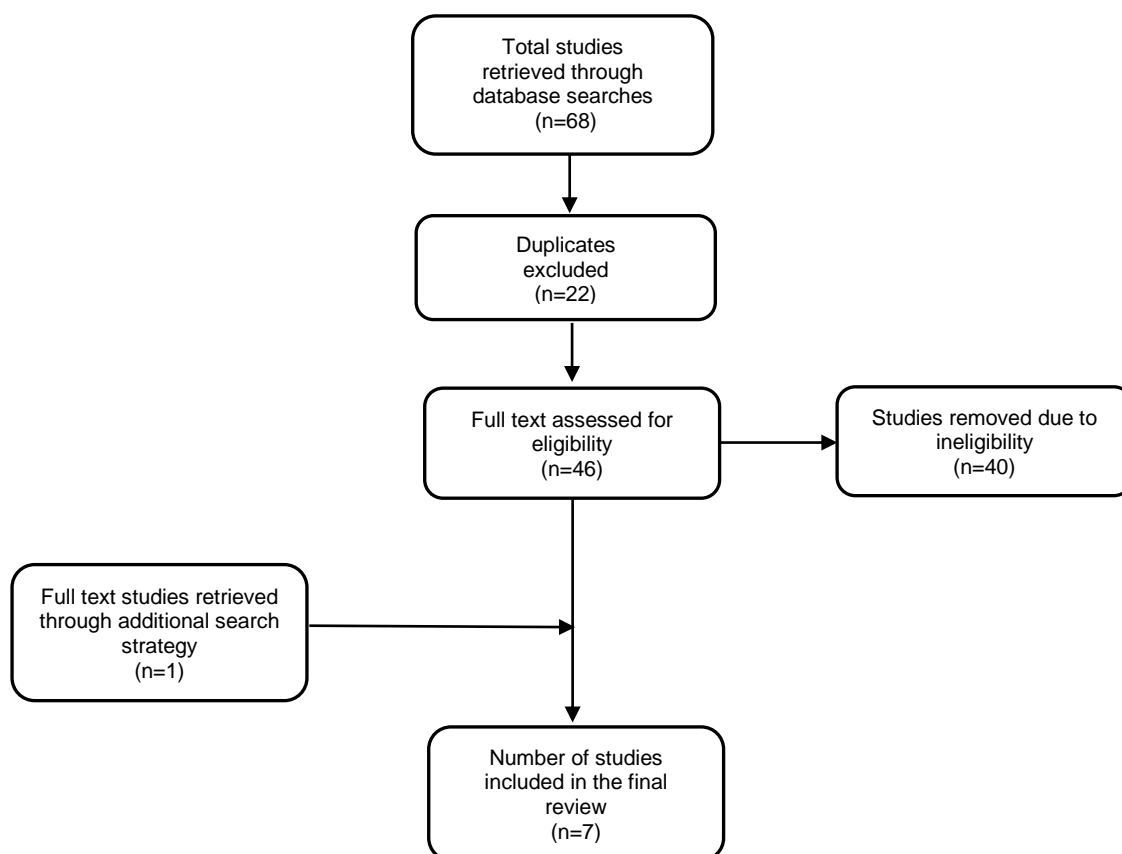


Figure 1. Flow diagram showing the selection process

Of the seven studies that met the inclusion criteria, three were observational studies, three were randomised control trials, and one was an open-label trial. One study focused on Step 3: Diagnosis, staging and treatment planning, five studies focused on Step 5: Care after

initial treatment and recovery, and one study focused on Step 6: Managing recurrent, residual or recurring metastatic disease. None of the studies provided any information on the OCP steps namely: Step 1: Prevention and early detection, Step 2: Presentation, initial investigations and referral, Step 4: Treatment, and Step 7: End-of-life care.

OCP Step 3: Diagnosis, staging and treatment planning

One study evaluated patient perspectives specific to OCP Step 3: Diagnosis, staging and treatment planning. An observational study explored the experiences of 75 reproductive aged women with endometrial cancer regarding diagnosis, decision making, treatment, fertility and some elements of survivorship.

Participants indicated that further improvements could be made in the communication of their diagnosis. They expressed a need for more comprehensive information about treatment options, fertility implications, long-term survivorship, and emotional support throughout the treatment pathway. Additionally, there was also a strong desire for cancer support services. Many of the women involved felt disconnected from the broader EC community or with other women with cancer. The study also highlighted that there is a significant unmet need for enhanced support and information regarding fertility preservation for women with endometrial cancer. [8]

Fertility preservation

Fertility preservation is a transformative field and a rapidly advancing field globally. [9] Some strategies include embryo and oocyte preservation, cryopreservation, and autografting for women. [9] In Australia, embryo or oocyte cryopreservation is the most common method for women seeking to preserve their fertility, with up to 90 per cent of oocytes and embryos successfully surviving the freezing process. [10] While this does not guarantee reproductive success in the future it does empower provide a pathway for future family planning for people diagnosed with endometrial cancer.

Although fertility preservation is frequently presented as an urgent option due to its potential to delay cancer treatment, navigating this pathway can be challenging. [9] This difficulty arises from the well-established fact that both radiotherapy and chemotherapy are highly detrimental to a woman's ovarian reserve and reproductive lifespan, while surgical interventions can lead to permanent infertility. [9] Future fertility and the opportunity to have a family are amongst the most important concerns of people with cancer. [9] Cancer treatment in premenopausal women is associated with lower pregnancy and live birth rates, and these women are also more likely to experience a reduced ovarian reserve compared to those who have not undergone cancer treatment. [9] Despite in vitro fertilisation treatments (IVF) it is also reported that women who do undergo cancer treatment have a lower birth rate. [10] Women who are exposed to chemotherapy or radiotherapy also have a higher prevalence of preterm birth and low birth weight infants. [9]

OCP Step 5: Care after initial treatment and recovery

The results of the literature review identified five studies that focus on OCP Step 5: Care after initial treatment and recovery. [11-15] These studies explored patient experience

outcomes in EC regarding, pelvic floor outcomes, physical activity, allied health telehealth, psychological support and complementary and alternative medicines.

Physical activity after diagnosis

Two studies focused on the consumer perspectives of women with EC and their engagement with physical activity and nutrition.[11, 16] The observational and randomised control trial explored the level of physical activity [16] and nutrition [11] and how these impact quality of life, weight control, dietary intake and changes in behaviour. The studies also discuss barriers and challenges for women to engage in physical activity and nutritional changes.

Taking part in 150 minutes of moderate intensity physical activity per week is a message consistently promoted to cancer survivors by cancer organisation worldwide. [11] In Australia, the recommended weekly minutes of moderate-intensity physical activity is 300 minutes to prevent cancer and unhealthy weight gain. [16] It is estimated that six per cent of EC cases in Australia are due to women doing less than this recommended amount. [16]

The benefits of meeting the physical activity recommendations are associated with reduced morbidity, increased physical function, quality of life during and post-treatment and psychosocial outcomes. [11] Physical activity could lower the risk of EC as it lowers the level of female hormone oestrogen and other hormones such as insulin in the body. [11] Furthermore, engaging in higher levels of physical activity pre- or post- diagnosis of gynaecological cancer is linked to better survival rates. However, despite the quality-of-life benefits, many cancer patients show low levels of physical activity. [11] This level of inactivity is associated with poorer treatment responses, more severe side effects from treatment, and a lower quality of life. It is reported that while 50 per cent of cancer survivors are sufficiently active at diagnosis, only one in three are sufficiently active by 12 months post-diagnosis. [11]

Of those with gynaecological cancer diagnosis, patients with EC had a higher proportion of participants who reported lower levels of exercise. [11] EC patients who participated in the observational study however, reported increased physical activity was associated with quality-of-life improvements such as improved health outcomes, psychosocial outcomes and physical function [11]. Although some individuals did not meet recommended levels of physical activity, any amount of physical activity still contributed to quality-of-life enhancements. [11] This emphasises that from a consumer perspective, even modest physical activity offers benefits. [11] Despite the positive impact that physical activity can have, EC survivors report that specific physical activity and nutrition recommendations were rarely made by oncologists. [12]

A randomised control trial to determine the feasibility, acceptability and safety of a telehealth allied health model for EC patients was conducted. It included the measurement of physical activity and nutritional needs in conjunction with behavioural change and social support of EC patients undergoing adjuvant treatment. [12] EC patients reported a lack of motivation to make physical activity and nutrition changes. [12] In addition to this, they also highlighted that the costs associated with exercise, feeling emotional and external factors like weather were barriers to changing their behaviour. When supported with regular monitoring including diaries and activity trackers, EC patients felt motivated to adhere to their physical activity and nutrition goals and even set new goals for themselves. [12] EC patients also reported enjoying the ability to participate in a remote allied-health program

which reduced the travel burden, was more accessible and less stressful for them. Despite this, some patients struggled with the use of technology in a remote environment. [12] In conjunction with this, EC patients discussed having to manage fluctuating mental health and side effects of their cancer treatments such as fatigue, illness, energy levels, mobility and balance issues, and decreased physical strength. [12] Patients also reported that practical support would be useful for them including recipes, mindfulness and relaxation exercises and information regarding community-based exercise groups. Social elements were recognised by patients as being crucial to improve their motivation and accountability with maintaining physical activity and nutrition regimens. [12]

Pelvic Floor Outcomes

Treatment of EC is primarily surgical and previous studies on urinary function in gynaecological cancer patients have reported a decline in function following cancer treatment. [13] The randomised control trial by Higgs reported that women with early-stage EC undergoing either total abdominal hysterectomy (TAH) or total laparoscopic hysterectomy (TLH) had better pelvic floor functional outcomes compared to those who required more aggressive cancer treatment. [13] They investigated three domains of pelvic distress which includes pelvic organ prolapse, colorectal anal distress and urinary distress.

In both treatment groups, patients reported initial improvement in pelvic floor function six months post-surgery. [13] Patients in the TLH group reported having lower pelvic floor functioning score indicating better well-being particularly in the urinary distress domain but this was not statistically significant. [13]

Patients in both treatment groups reported an initial improvement in functioning scores which slowly declined, however, some beneficial gains were still maintained when compared to their pre-surgical pelvic floor well-being. [13] There was no significant difference between TAH and TLH up to 54 months post-surgery which reassures women undergoing hysterectomy for endometrial cancer for either TAH or TLH that there is no clear benefit in the short term for either treatment options. [13]

Psychological support

Anxiety and depression have been reported to be third prioritised problem after worry and focusing on getting well in patients with EC. [14] Patients are generally more prone to anxiety before surgery rather than depression, however, both anxiety and depression can persist in many women even after the initial treatment for EC. [14]

Secondary data analysis of an international, multicentre prospective randomised control trial reported that around 16.8 per cent (n=121/179) of patients diagnosed with EC were prescribed one or more psychotropic medications during the six-month study period [14] The prevalence of patients prescribed antidepressants was 12.6 percent, while 5.8 per cent were prescribed anxiolytics. [14]

Almost three quarters (71.8%) of EC patients reported that they were already on antidepressant medication before their diagnosis and few new prescriptions were started around the time of surgery or afterward. [14] Most patients with early-stage EC who receive curative treatment reported that they managed their diagnosis well and did not require psychotropic medications. [14]

Perioperatively, more than half of the patients reported a higher usage of anxiolytics. [14] This can reflect the idea that anxiolytics are being used by EC patients for the purpose of overcoming insomnia or neuropathic pain. [14] Most patients continued to use prescribed medication up until the 6-months post-surgery. [14] Anxiolytics were more commonly initiated in the early post-operative phase than antidepressants and about half of the anxiolytic prescriptions were stopped within the first six months post-surgery. [14]

A limited number of EC patients reported visiting a psychiatrist, psychologist or other mental health counsellor during the first six months after surgery. [14] The majority of these patients only attended one or two sessions with a mental health professional. [14]

Despite having a long-term history or a new case of depression and/or anxiety, 21 per cent of these EC patients reported that they did not receive medication which suggests that patients are using alternative care or there may be a lack of knowledge or awareness by their health providers. [14]

Complementary and Alternative Medicines

Women with long-term EC frequently use one or more complementary and alternative medicine (CAM) practices, practitioners or products. [15] Recent literature reports that CAM is not used as a substitute for conventional medicine but rather as an adjunction of it. [15] Despite this, an observational study with 17 women diagnosed with EC, 7-10 years previously suggests that EC patients often turn to CAM to manage comorbidities or to enhance general wellbeing. [15]

Women with EC report that they often seek ways to reduce physical symptoms of cancer treatment such as lymphoedema, stress, weight gain and to improve sleep and relaxation, and aid in general recovery. [15] Additionally, women have stated that they turn to CAM use due to unsatisfactory experience with conventional medicine, lack of personalised care, and to mitigate treatment side effects. [15]

Women often stated that the choice of CAM would be influenced by recommendations through family or friends, personal beliefs or local availability. [15] The preferred CAM provider is typically selected based on their availability and their ability to offer support both clinical and lifestyle-related concerns. [15] Several women reported seeking out CAM practitioners to find relief from symptoms and regain control over their EC symptoms. [15] They often felt a stronger connection with their CAM practitioners in contrast to their dissatisfaction with traditional medical doctors, who they felt did not provide personalised supportive care. [15]

Women reported feeling that CAM practices such as therapies would allow a preventive approach to their health and could complement conventional therapy. [15] Many of the women were often self-motivated to adjust their behaviour for exercise routines, nutritional needs, and stress management strategies to maximise their overall health outcomes. [15] While practices such as yoga and pilates were used, they were often time limited due to cost constraints. Additionally, access to support groups enabled pain and stress alleviation as an alternative to taking medication. [15]

Patients commonly used CAM products such as vitamins to reduce symptoms like lymphoedema and cramps and were often recommended by health professionals and

family members. Women reported that conventional and over the counter medicines were more synthetic as opposed to natural therapies which were perceived to be gentler. [15]

OCP Step 6: Managing recurrent, residual or metastatic disease

Recurrence of EC can depend on several factors including type of cancer, stage and grade at presentation, and the effectiveness of the treatment. [17] Controlling disease and disease related symptoms is often possible but this is dependent on the clinical situation. The results of the rapid literature review identified one open label trial of anastrozole which is a type of hormone therapy aimed at blocking the enzyme aromatase. [17] Aromatase is highly expressed in the endometrial stroma and the local synthesis of estrogens which promotes estrogen induced proliferation of tumour cells. [17] The study investigated the clinical benefit of anastrozole and reported on several quality-of-life domains.

There is evidence that hormonal therapy can be associated with clinical benefit in patients with recurrent/metastatic EC. [16] Patients of the study reported improvements in quality of life including emotional functioning which significantly improved within a couple of months and cognitive functioning and diarrhoea within six months. However, at three months, nausea and vomiting worsened by small but significant amount. [17]

Anastrozole was reported to be associated with clinical benefit at three months in 44 per cent of the patients with metastatic or recurrent EC. [17] By stratifying the data by three-month clinical benefit status, patients reported significant improvements in several quality-of-life domains including emotional functioning, cognitive functioning, fatigue and global health status. [15]. Changes for months one through to three identified improvements in role functioning, social functioning, pain, constipation and financial problems. [17]

Implications

This literature review has limitations including the number of manuscripts. Studies were limited to those published from 2018 onwards and language limited to English only, this may have excluded relevant studies published in other languages. This literature review demonstrates the paucity of research of patient experiences in EC care. While there was some literature on Step 5: Care after initial treatment and recover of the OCP pathway, this did not represent all the key areas. There was no literature relating to treatment summaries, follow-up, communication with the GP and supportive care needs. There was limited literature regarding Step 4: Treatment and Step 6: Managing recurrent, residual or metastatic disease. It is also important to note, that patient experience was not explored at all in relation to Step 1: Prevention and early detection, Step 2: Presentation, initial investigations and referral, Step 3: Diagnosis, staging and treatment planning and Step 7: End-of-life care.

The findings of this review highlight critical gaps in patient experiences and care related to EC in Australia, providing valuable insights for healthcare providers and policymakers. One of the most important implications is the need for improved communication and information dissemination, particularly concerning diagnosis, treatment options, fertility preservation, and survivorship. In addition, the unmet supportive care needs including nutrition, physical activity, psychological and others need to be addressed in people with EC.

The lack of presence of an EC advocacy group further exacerbates the gap of evidence and voices of women with EC in Australia. The availability of a consumer advocacy group may provide an opportunity for a coordinated and strategic approach to consumers sharing the care provided to people with EC and their families.

Conclusion

This review has identified several key areas where improvements are needed to enhance the care and support provided to EC patients in Australia. While the existing literature provides some insights into patient experiences, there are significant gaps. The absence of studies focusing on prevention, early detection, and end-of-life care suggests that these areas require further attention in both research and clinical practice. Healthcare providers, policymakers, and key stakeholders should collaborate to develop strategies that prioritise identifying and addressing patient experiences of people with EC to optimise care provision.

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Appendix One: Summary of the evidence base – EC cancer (n=7)

First Author	Title	Year	Optimal Care Pathway Step (OCP)	Study Design	Objective(s)	Participants (N)	Outcomes	Key Findings
Roman, A	Early Stage, Low Grade Endometrial Adenocarcinoma in Reproductive Aged Women. An Evaluation of Patient Perspectives of Diagnosis, Treatment Decision Making, Management, Fertility and Survivorship: A Qualitative Study	2020	STEP THREE: DIAGNOSIS, STAGING AND TREATMENT PLANNING	Observational Study	To explore the experiences of reproductive aged women with early EC across diagnosis, decision making, treatment, fertility and survivorship.	75	The study highlights unmet needs, particularly around available support and provision of information. These needs should be considered in the future management of these cancer patients	Responses highlight the shock of the diagnosis and improvements which could be made when communicating the EC diagnosis. Common themes also included a strong desire for women to be presented with treatment options, suboptimal information provision around treatment options and implications for fertility and long-term survivorship as well as the significant emotional burden across all aspects of the treatment journey
Higgs, P	Pelvic floor functional outcomes after total abdominal vs total laparoscopic hysterectomy for endometrial cancer	2018	STEP FIVE: CARE AFTER TREATMENT	Randomised Control Trial	To evaluate pelvic floor function in women who have had surgical treatment for early-stage EC as part of the multinational Laparoscopic Approach to Cancer of the Endometrium trial and to compare patients' outcomes who had total abdominal vs total laparoscopic hysterectomy	381	At 6 months post-surgery both groups experienced an improvement in Pelvic Floor Distress Inventory scores compared to presurgical pelvic floor well-being. The magnitude of change from baseline in pelvic floor symptoms did not differ between both treatment groups up to 54 months post-surgery.	Pelvic floor function in EC patients in terms of urinary, bowel, and prolapse symptoms are unlikely to deteriorate following abdominal or laparoscopic hysterectomy and are reassuring for women undergoing hysterectomy for early-stage EC.

Sanjida, S	How many patients enter EC surgery with psychotropic medication prescriptions, and how many receive a new prescription perioperatively?	2019	STEP FIVE: CARE AFTER INITIAL TREATMENT AND RECOVERY	Randomised Control Trial	To determine the prevalence, type, dose, frequency and timing of psychotropic medications prescribed to EC patients. A secondary aim was to study sociodemographic and clinical characteristics associated with receiving a psychotropic medication prescription.	719	The overall prevalence of patients prescribed one or more psychotropic medications was 16.8% comprising of antidepressants and anxiolytics. The majority of patients were already receiving antidepressants before cancer diagnosis, the remaining medications were newly prescribed perioperatively (21.9%, n = 20/91). Patients of younger age (18–50 years), OR who had hypertension history of a previous cancer and ≥2 comorbidities were significantly more likely to receive a prescription of psychotropic medications.	While one in eight EC patients already had psychotropic medications prescribed before surgery for early-stage EC, only few women received a new prescription after surgery. The overall prescription rates were similar to other patients with cancer, but higher than those observed in the general population, likely reflecting the comorbidity burden of patients who develop endometrial cancer. Qualitative data could be used in future research to explore the psychological and quality of life impacts of EC.
Caughey, L	The use of CAM products, practices, and practitioners by long-term endometrial cancer survivors in Australia	2020	STEP FIVE: CARE AFTER INITIAL TREATMENT AND RECOVERY	Observational Study	To understand the use of CAM and factors motivating the use among long-term survivors of EC.	17	All 17 women interviewed used some type of CAM practices, practitioners, or products, specifically 94% concentrated on their diet, 88% focused on their exercise, 59% used a CAM product, 53% visited a CAM practitioner, and 18% used a CAM psychological approach.	Long-term EC survivors commonly use complementary and alternative medicines (CAM) to reduce physical and psychological symptoms and to stop or reduce medications, highlighting a need for lifestyle advice not currently met by traditional healthcare teams.
Fleming, S	Physical activity trajectories following gynecological cancer: results from a prospective, longitudinal cohort study	2020	STEP FIVE: CARE AFTER INITIAL TREATMENT AND RECOVERY	Observational Study	To describe physical activity levels from before and up to 2 years after gynaecological cancer surgery; to explore the relationship between	408	Most women (80%) started with and maintained low levels of physical activity (1–10 metabolic equivalent task hours per week), reported	The low baseline and surveillance levels of physical activity show that most gynaecological cancer survivors have the ability to

					physical activity, patterns and quality of life; and to describe characteristics associated with physical activity trajectories post-gynaecological cancer		no physical activity throughout the follow-up period, or reduced physical activity levels over time. Only 19% of women maintained or doubled physical activity levels, so that by 24 months post-diagnosis they were engaging in sufficient levels of physical activity.	improve their physical activity levels. Women with EC (58% of the sample) were more likely to be overweight or obese and to report low levels of physical activity or none at all. Higher physical activity levels were associated with higher quality of life Integration of physical activity advice and support into standard care could lead to gains in quality of life during gynaecological cancer survivorship.
Edbrooke, L	ENhancing Lifestyle Behaviors in Endometrial CancEr (ENABLE): A Pilot Randomized Controlled Trial	2022	STEP FIVE: CARE AFTER INITIAL TREATMENT AND RECOVERY	Randomised Control Trial	To determine the feasibility, acceptability and safety of a telehealth allied health intervention involving nutrition and physical activity education combined with behaviour change and social support, during adjuvant treatment for endometrial cancer.	44	This pilot trial demonstrated intervention safety and participant acceptability. Levels of feasibility were above pre-specified thresholds with respect to adherence to the intervention and retention at follow-up outcome assessments. Participant experiences and key recommendations will inform modifications to future intervention design for an appropriately powered RCT with multiple recruitment sites.	Telehealth was identified by endometrial cancer patients to be streamlined and easy to navigate. It reduced the travel burden making participation more accessible and they were able to complete questionnaires online, at home, and at their own pace. While there were challenges with utilisation of technology especially with activity monitors. The information from physiotherapists and dietitians were found to be invaluable.
Milleshkin, L	Phase 2 study of anastrozole in recurrent estrogen (ER)/progesterone (PR)	2019	STEP SIX: METASTATIC AND RECURRENT	Open Label Trial	To report the results of the prospective trial in the EC cohort which aimed to investigate the clinical	82	Reductions in the symptoms of pain and fatigue (at 2 months) that can cause women	Patients with EC who had clinical benefit at 3 months reported clinically significant improvements in

	positive endometrial cancer: The PARAGON trial – ANZGOG 0903				benefit rate of the use of anastrozole, in women with hormone receptor positive recurrent or metastatic EC with an additional focus on the impact on quality of life		significant distress were seen.	several QOL domains compared to those with progressive disease; this was evident by 2 months including improvements in: emotional functioning, cognitive functioning, fatigue and global health status.
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Appendix Two: Search Strategy

- exp Endometrial neoplasms
- exp Uterine neoplasms
- Endometrial cancer
- Endometrial cancer patients
- Endometrial cancer survivor
- Endometrial cancer diagnos*
- Endometrial cancer carers
- Surgery.mp
- Hysterectomy.mp
- Lymph node dissection.mp
- Radiation therapy.mp
- Chemotherapy.mp
- Hormonal Therap.mp
- Supportive care,mp
- Symptom management,mp
- Pain management.mp
- Psychosocial support.mp
- Nutritional support.mp
- Palliative care.mp
- Fertility preservation.mp
- Oncofertility.mp
- Advanced care planning.mp
- Hospice care.mp
- Home care services.mp
- Survivorship care.mp
- Survivorship needs.mp
- Survivorship programs.mp
- Patient Experience.mp

- Patient Satisfaction.mp
- Quality of life.mp
- Wellbeing.mp
- Patient reported outcome measures.mp
- Health-related quality of life.mp
- (health* adj3 access*).mp.
- (health* adj3 (disparit* or inequalit* or inequit*)).mp.
- delivery of health care.mp.
- limit to (yr="2018 -Current")

A revised research strategy was also developed in used to find additional resources.

- exp Uterine Neoplasms/
- exp Endometrial Neoplasms/
- (cancer* adj3 endometri*).mp.
- (cancer* adj3 uter*).mp.
- exp Attitude to Health/
- exp emotions/ or psychosocial functioning/
- exp "Surveys and Questionnaires"/
- psychosocial support*.mp.
- (patient* adj3 support*).mp.
- Fertility Preservation/
- supportive care.mp.
- exp "continuity of patient care"/ or palliative care/ or exp time-to-treatment/
- oncofertility.mp.
- exp Terminal Care/
- (patient* adj3 experience*).mp.
- exp Adaptation, Psychological/
- survivorship.mp.
- limit 19 to yr="2018 -Current"
- exp australia/ or new zealand/
- australia*.mp.

