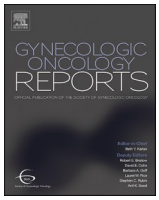
Gynecologic Oncology Reports 54 (2024) 101425

Contents lists available at ScienceDirect

Gynecologic Oncology Reports

journal homepage: www.elsevier.com/locate/gynor



Understanding the patient experience in nonsurgical management of endometrial cancer and complex atypical hyperplasia due to obesity: A qualitative analysis

Aparna Kailasam *, Aminah Jatoi, Evelyn Reynolds, William Cliby, Carrie Langstraat

Mayo Clinic, 200 First Street SW, Rochester, MN 55905, United States

ARTICLE INFO

Keywords:
Conservative management
Hormonal therapy
Endometrial cancer
Nonsurgical management
Obesity
Qualitative

ABSTRACT

Objectives: Patients with class 3 obesity (BMI ≥ 40) and significant medical comorbidities with complex atypical hyperplasia (CAH) and early-stage endometrial cancer (EC) present challenges in standard surgical management. Progestin therapy is an alternative used for patient-centered reasons, including the desire for uterine preservation or because surgery is not a safe option. Our objective was to gain insights into the patient experience when undergoing this treatment approach.

Methods: We identified and recruited patients who received oral or IUD progesterone in the last 5 years for EC or CAH. We conducted semi-structured phone interviews regarding patients' experience with non-surgical management as well as decision-making factors to start progesterone and weight loss. Interviews were audio-recorded and transcriptions were analyzed for common themes.

Results: A total of 20 interviews were performed. We enrolled nine patients with CAH, eight with grade 1 EC, and three with grade 2 EC. The majority of patients (18/20) were managed with IUD. We identified the following 5 common themes support in diagnostic workup and long-term outcomes, autonomy in care, thoroughness in counseling, emotional impact of diagnosis, and perception of obesity as a defining identity.

Conclusion: The themes identified in the present study highlight the challenges and the stigma these patients face. It also demonstrates areas of opportunity in their counseling and care, which will help to build a more effective therapeutic relationship and ultimately lead to greater adherence in care.

1. Introduction

With approximately 61,000 cases treated annually, endometrial cancer (EC) is the most common gynecologic malignancy in the United States (SEER, 2022). With most cases being early stage, the standard of care as determined by the National Comprehensive Cancer Network (NCCN), involves surgical management including staging surgery with a typical cure rate of 95 % (Network and Neoplasms, 2022). Precursors to endometrial cancer (complex atypical hyperplasia [CAH]/endometrial intraepithelial neoplasia [EIN]) are also treated surgically given the risk of development of endometrial cancer (Vetter et al., 2020). Patient risk factors for the development of early-stage, low grade endometrial cancer include obesity, diabetes, hypertension, and nulliparity (Onstad et al., 2016; McDonald and Bender, 2019).

According to the CDC, the prevalence of obesity in the US was 41.9 % of adults from 2017-2020 CDC – National Center for Health Statistics – Homepage, 2023. Calle et al found that patients with class 3 obesity have a relative risk of cancer-related death of 6.25 (3.25–10.4), compared to patients with normal weight. In addition to this increased risk of disease-related death, patients with class 3 obesity (BMI ≥ 40 kg/m^2) and endometrial cancer have higher rates of all-cause mortality, specifically due to cardiovascular disease, diabetes complications, and renal disease (Chia et al., 2007; Flegal et al., 2013). As a result, the National Cancer Institute, National Comprehensive Cancer Network and Society for Gynecologic Oncology have recommended that weight loss to be part of endometrial cancer survivorship plans (Network and Neoplasms, 2022).

Moreover, obesity can be an indication for non-surgical treatment of EC due to concerns regarding the safety of surgery, including an increased need for conversion from minimally invasive to open

* Corresponding author.
E-mail addresses: Kailasam.Aparna@mayo.edu (A. Kailasam), Jatoi.Aminah@mayo.edu (A. Jatoi), Reynolds.Evelyn@mayo.edu (E. Reynolds), Cliby.William@mayo.edu (W. Cliby), Langstraat.Carrie@mayo.edu (C. Langstraat).

https://doi.org/10.1016/j.gore.2024.101425
Received 17 April 2024; Received in revised form 15 May 2024; Accepted 19 May 2024
Available online 27 May 2024

procedures, difficulties with intraoperative airway management, and a higher rate of surgical complication (Bernardini et al., 2012; Blikkendaal et al., 2015; Al Sawah et al., 2018; Siedhoff et al., 2012). The adequacy of staging is also likely compromised in patients with BMI over 40 (Bernardini et al., 2012; Blikkendaal et al., 2015; Al Sawah et al., 2018; Obermair et al., 2016).

An ideal strategy to reduce risk and improve health would be to introduce effective weight loss strategies while attempting nonsurgical management of endometrial disease. Progesterone has been found to be a reasonable alternative treatment option for these patients with response rates of up to 70 % (Pal et al., 2018; Westin et al., 2021). Unfortunately, acceptance of nonsurgical management among patients varies, particularly when a patient is told that the reason is weight-related (Soliman et al., 2008). In addition, a qualitative study conducted in Australia showed that patients had many concerns when undergoing only progesterone therapy, including a lack of understanding of how the treatment works, appropriate counseling for treatment options and trauma related to previous attempts at weight loss (O'Hara et al., 2022). Notably, participants in this study were selected from the feMMe trial, which was a randomized controlled trial in which participants were assigned to progesterone intrauterine device along with observation, weight loss interventions, or metformin (O'Hara et al., 2022; Janda et al., 2021).

Studies have also assessed the efficacy of progesterone therapy with weight loss management. This approach is complex and requires a strong therapeutic patient relationship and patient acceptance. Furthermore, approximately half of patients are unaware that obesity is a risk factor for EC (Pal et al., 2018). If we are to improve overall health, it is critical to understand the patient perspective, develop education tools, and enlist the patient to develop a comprehensive treatment approach. The overall objective of this study was to understand the patient experience with receiving progesterone therapy for EC/CAH/EIN in patients who were not fit for surgery in the United States.

2. Materials and methods

2.1. Patient selection

Following Institutional Review Board approval, we identified participants from the gynecologic oncology clinic at Mayo Clinic, Rochester, MN who were diagnosed with CAH or EC in the last 5 years and were not surgical candidates. Inclusion criteria included diagnosis of CAH or EC in the last 5 years, initial treatment with oral or IUD progesterone therapy, and follow up of at least 12 months. We included both premenopausal and postmenopausal patients in this cohort. Of note, treatment within the last 18 months was initially stated as a criterion. However, given that nonsurgical management of EC/CAH/EIN is somewhat rare, this time period was extended to 5 years. We identified patients via search within the electronic medical record. We aimed to interview patients with a variety of experiences, i.e. those who eventually had surgery vs those who did not, those who were happy with initial conservative management vs those who were not, etc. This was ascertained through the electronic medical record as charts were screened for various experiences prior to recruitment of patients. We then used qualitative methodology to complete semi-structured phone interviews. In consideration of ethical issues, we consider the four areas as outlined by DiCicco-Bloom & Crabtree (DiCicco-Bloom and Crabtree, 2006). Informed consent was obtained verbally prior to completing the phone interview. All participants also signed a HIPAA consent form to allow access to the medical record to obtain demographic information (age, BMI, response to treatment, etc). Our phone script made clear that patient care would not in any way be impacted by participation in the study. In addition, the person conducting the study was never involved in treatment of these patients.

2.2. Interviews

Interviews were conducted over the phone by a single interviewer and were digitally audio-recorded with a hand-held recorder that connected to the phone. A semi-structured format was used with open-ended questions as well as follow up questions based on patient experiences (Supplemental Material). In conjunction, we asked about patients' experience with obesity, attempts at weight loss, and their understanding of how this relates to EC. The interview guide was developed under the guidance of a clinician with extensive experience in conducting qualitative studies. Interviews started with the open-ended request: "When you were first diagnosed with endometrial cancer [or complex atypical hyperplasia], please tell us about your experience." The goal of the question was to focus on the patient's overall experience of receiving progesterone therapy for EC/CAH/EIN. Subsequent questions also explored patients' understanding of their treatment and their treatment options.

IRB approval was obtained for up to 40 patients. However, recruitment stopped once saturation of themes was reached (the point at which no data or idea emerged), which was around 20 patients. All interviews were completed by the same interviewer, AK (a gynecologic oncology fellow). The interviewer had not participated in the clinical care of any of the patients who were interviewed. The medical records of participants were reviewed to obtain demographic information, such as baseline clinical characteristics, diagnosis (EC vs CAH/EIN) as well as response to treatment and time since diagnosis.

2.3. Data analysis

Deidentified transcripts were obtained via transcription from a third-party transcriptionist. Transcripts of interviews were then reviewed by three separate reviewers. All interviews were analyzed with the inductive thematic analysis approach as described by Braun and Clarke (Byrne, 2022). In the inductive approach, we do not assume any preconceived coding. Codes are developed by reading transcripts as key ideas are addressed. AK reviewed all 20 transcripts. Additionally, CLL and EAR, both experienced gynecologic oncologists reviewed transcripts for emerging themes. CLL had prior experience in qualitative research. Participants' as well as clinicians' names were removed from transcriptions and participants were identified by a code number to protect identities. The inductive method uses a 6-step approach by reading and analyzing data without preconceived categories. After familiarization of the transcripts. A coding system was developed based on the qualitative questions and preliminary review of transcripts. The investigators then coded transcripts independently and met to discuss, review and name common key themes. The meeting of reviewers to discuss themes were critical to limit bias which may influence interpretation of the data. All themes were defined together and revisited to ensure all concepts were included.

3. Results

A total of 52 patients were screened and called, with 20 interviews completed. Of these, nine had an initial diagnosis of CAH, eight had a diagnosis of grade 1 EC and three had a diagnosis of grade 2 EC. 18/20 (90 %) patients were initially managed with levonorgestrel IUD and 2/20 (10 %) received oral megestrol acetate therapy. Interviews ranged from 8.5 to 30 min with the median length of interview at 17 min. The median duration of time since the first biopsy was 7 years ranging from 2 to 12 years. Some patients were still undergoing conservative management while 9/20 (45 %) had undergone definitive hysterectomy. Patient demographics and characteristics are included in Table 1. All included patients in this study underwent conservative management of endometrial cancer due to obesity and medical comorbidities. Desire for fertility preservation was not part of the inclusion criteria, but there were varied responses regarding this desire. When asked about resources

Table 1
Interviewee Demographics.

Patient characteristics	n = 20
Age at time of diagnosis, years (median, range)	56 (27, 77)
BMI, kg/m^2 (median, range)	52.0 (35.7, 63.2)
< 40 (%)	2 (10)
41 – 50 (%)	8 (40)
51 – 60 (%)	5 (25)
> 60 (%)	5 (25)
Time since starting treatment, years (median, range)	7 (2, 12)
Insurance Status (%)	
Private	11 (55.0)
State	6 (30.0)
Unknown	3 (15.0)
Initial Diagnosis (%)	
Complex atypical hyperplasia	9 (45.0)
Grade 1 endometrial carcinoma	8 (40.0)
Grade 2 endometrial carcinoma	3 (15.0)
Treatment Received (%)	
Intrauterine progesterone	18 (90.0)
Oral progesterone	2 (10.0)
Weight loss methods used (%)	
Nutrition based counseling/courses	7 (40)
Medical management	2 (13.3)
Bariatric surgery	4 (13.3)
Response to progesterone (%)	
Complete or partial	15 (75)
No response or progression	5 (25)
Final Treatment at the Time of Interview (%)	
Definitive hysterectomy	9 (45)
Conservative management	11 (55)
Time from Progesterone Initiation to Surgery, months (median, range) [n = 9]	11 (1, 101)

and methods used for weight loss, 6/20 (30 %) used nutritional counseling/coaching services, 4/20 (20 %) used medication management, and 4/20 (20 %) underwent bariatric surgery after receiving the diagnosis. 9/20 (45 %) of the participants underwent definitive hysterectomy. Median time on progesterone therapy was 11 months with a range of 1–101 months.

We identified 5 common themes during our study. Table 2 includes subthemes of each of the core themes as well as demonstrative quotes from interviews. All 20 participants indicated satisfaction with their care and the ultimate decision to start with hormonal therapy.

3.1. Theme 1: Support in diagnostic workup and long-term outcomes

The first theme of support in diagnostic workup and long-term outcomes emphasized the role of the emotional and physical comfort/discomfort that affected a patient's perception of the experience. Within this theme, we identified three subthemes: (i) feeling seen and heard as a person, (ii) experience of diagnostic tests, and (iii) understanding of long-term outcomes.

3.1.1. Feeling seen and heard as a person

Multiple interviewees mentioned that being treated respectfully by providers and noting that they were sympathetic made them feel more comfortable in the plan to have conservative management. Every interviewee ultimately expressed gratitude for their experience at the institution and for the ability to speak about the whole experience beyond the diagnosis.

3.1.2. Experience of diagnostic tests/treatment

Several patients commented on the experience of the diagnostic tests as well as treatment. Two participants noted the significant discomfort associated with endometrial biopsies performed every 3–6 months. *"It was extremely. Painful. I bled a lot afterwards. So I was like mega traumatized by that experience" (Participant #18).* In addition, the side effects of progesterone, particularly oral progesterone were undesirable to

Table 2
Core Themes and Subthemes Identified Along with Illustrative Quotes.

Themes and Subthemes	Illustrative Quotes
Support in diagnostic workup and long term outcomes	
Gratitude in being seen and heard as a person	*A little bit more sympathetic, maybe? To my thought process and my plight? (participant 4)*
Experience of diagnostic tests	*I rave about…just how well I was treated and respectfully and, you know, there… there was a conversation instead of being told, you know (participant 9)*
Understanding of long-term outcomes	*That hysteroscopy, the first one was very painful, but the second one that I had that I like when in June or May, which ended up not being necessary…was unreasonably painful (participant 10)*
	A gynecologist here … wanted to do a, an endometrial biopsy. And it was horrifically traumatic for me (participant 18)
	The treatment was very difficult because the progesterone made me very tired. Made me gain weight. A lot of weight. Lethargic. It made me sensitive to heat and… it just… and… and moody (participant 6)
Autonomy in care	
Ability to opt for surgery versus desire to avoid surgery	*I've never had surgery…kinda freaks me out a little bit. So I'm just more comfortable with going this route at the present time (participant 1)*
	I… felt very heavy hearted. Because…I know that they didn't wanna do surgery right away because of my weight (participant 3)
	She recommended I go forward with the hysterectomy and other, you know, surgery. So… I guess I just wanted the shots. And went against medical advice…But it's my body (participant 4)
Desire to preserve fertility	*It's a personal decision I think for a woman… like, getting rid of your lady parts—your uterus and your ovaries—it's… But that's a big deal, um, you know, in terms of you can't have any more kids (participant 6)*
	I guess it was like overwhelming cuz we were trying for… the plan was to try for a kid and then obviously that didn't pan out the way we planned (participant 8)
Timing of care	*I guess that's the state of medical affairs right now. You have to wait your turn. I didn't… didn't know how urgent it was; but it was urgent to me (participant 2)*
	I never expected that it would be prolonged. You know, I just wanted it out (participant 3)
Paternalism	*I remember feeling rather comfortable with Dr. (name) and the conversations that I had with her. Although I will say, you know, she did push the hysterectomy too at first (participant 4)*
	The only thing that I would change is that first gynecologist that I met with because I didn't feel like I had a choice (participant 11)
Thoroughness in counseling	
Time spent by provider in describing options	*You know my appointment was later in the day and then and it was just done and then I was you know went it was just it was overwhelming (participant 10)*
	He was not very compassionate and he didn't explain things very well. (participant 15)
Personal understanding of disease process	*I was, like, estrogen dominant. So, the progesterone somehow balanced things out. And… and would resolve the problem (participant 6)*
	My understanding of why I got the cancer I did or probably the main reason is I had irregular periods…and so, the buildup, basically built up so much that the inside layers were toxic and created the cancer (participant 8)
	As soon as I got that diagnosis, I was more afraid of getting breast cancer than the uterine cancer, so I wanted those cancer cells completely gone (participant 12)
Emotional impact of diagnosis	

(continued on next page)

Table 2 (*continued*)

Themes and Subthemes	Illustrative Quotes
	I wished I'd have had the surgery right away and had it done… as far as stress to my mental health and my physical health was not worth it all (participant 3)
	I'm sure on the grand scheme of cancer, it was probably one of the most minor ones, it still was emotional and overwhelming (participant 10)
	Well, and that kind of scared me and I was terrified to ask for more information about the different options (participant 13)
Perception of obesity as a defining identity	
Communication with providers	*The positiveness of the treatment that I had, you know… she treated me like a person and not like an obese person (participant 14)*
Life long struggle with weight loss	*Any doctor that I first meet with my weight has always come up as something I'm doing wrong, which I understand that, you know, being overweight is…and I was made to feel very ashamed for my weight (participant 11)*
	I definitely have struggled with my weight all my life (participant 9)
	It's a constant life long battle for me (participant 11)
Other approaches to weight loss	*The gastric bypass is not a magical pill, but I'm an active person and that allowed me to be even more active, um which I appreciate (participant 11)*
	We met online… with a doctor and nutritionist and several different kinds of people, and there was… it was a group thing. So, then you would, uh, it was through Zoom so you could see the other people and meet them and kinda hear stories and what was working for people and what wasn't and the struggles that we were all having and… I found that very helpful (participant 3)
	I started taking Ozempic, like, maybe… mmm, about a year and a half ago. And that's when I really noticed I was starting to lose weight more than in the past (participant 6)

patients. *"It was successful, but the treatment was very difficult because the progesterone made me very tired. Made me gain weight. A lot of weight. Lethargic. It made me sensitive to heat and… it just… and… and moody" (Participant #6).*

3.1.3. Understanding of long-term outcomes

Participants indicated mixed views about the indefinite treatment on progesterone therapy. While some patients appreciated the ability to avoid invasive procedures, two participants indicated the stress and intrusiveness of persistent endometrial biopsy. Notably, our institution does not have a standard protocol on frequency of sampling, but providers typically go by the guidelines recommended under fertility preservation in the NCCN by sanpling every 3–6 months. One participant also commented on changes in sexual desire and function on treatment. All these points highlight the importance of counseling about the testing as well as the experience beyond the outcome for the cancer treatment alone.

3.2. Theme 2: Autonomy in care

This theme highlights patients' perceptions on whether they felt they could make decisions regarding surgery and fertility. We also noted how their interaction with providers and the healthcare system played into patients' autonomy in care.

3.2.1. Ability to opt for surgery versus desire to avoid surgery

Participants were split 50/50 on the desire to avoid surgery versus the desire to have surgery. Patients who wished to avoid surgery expressed gratitude for having an alternative option that was less invasive. Conversely, ten of the participants expressed disappointment in the inability to have surgery and feeling that the decision was taken away from them. *"I… felt very heavy hearted. Because…I know that they didn't wanna do surgery right away because of my weight" (Participant #3).*

3.2.2. Desire to preserve fertility

Among the premenopausal patients who were interviewed, four participants indicated a desire to preserve fertility and that they were grateful to have the option of avoiding surgery. Two of these patients had previously been recommended to have surgery and presented for a second opinion. *"My focus was that I want to have children, so if we could beat this and and* [sic] *have children, then that was the route that I wanted to take" (Participant #17).*

3.2.3. Timing of care

Participants expressed frustration on the timeframe from diagnosis to starting treatment and eventually getting surgery. One participant noted that she eventually did undergo surgery, but that she did not know she would be on hormone management until surgical treatment. Another lamented on her perception of providers not feeling the sense of urgency that she felt. *"I guess that's the state of medical affairs right now. You have to wait your turn. I didn't… didn't know how urgent it was; but it was urgent to me" (Participant #2).*

3.2.4. Paternalism

Three participants mentioned that they felt a sense of pressure and paternalism from their providers which influenced their feeling of decision-making. Some patients felt that there was a push towards surgery when they were hoping for a fertility-sparing approach. *"You know…there seems to be like, sort of a, a cavalier or flippant attitude in the gynecological profession toward the removal of women's organs." (Participant #18).* Others indicated a sense of hopelessness in that they were pressured against surgery. *"Well, I wanted to have the surgery right… right away. And they referred me to the uh… internist who would not okay it because of my heart issues" (Participant #2).*

3.3. Theme 3: Thoroughness in counseling

The third theme encompassed patients' experience in the time spent with providers to understand the various options and patients' personal understanding of the disease process. Patients had varied experiences in their perception of the time that providers spent with them. Two patients mentioned that the visits felt rushed and that not enough time was spent on counseling. All 20 patients indicated an understanding of their weight as a reason to avoid surgical management. They all also indicated that they understood that the role of progesterone was to reverse the neoplastic process. None of the patients mentioned the link between obesity and the estrogen excess resulting in carcinogenesis. Of note, in reviewing the consultation notes for these patients, all 20 notes included counseling about the increased risks of surgery in patients with class 3 obesity and above. However, only 3/20 consultation notes included counseling about the correlation between obesity and development of endometrial hyperplasia and carcinoma.

3.4. Theme 4: Emotional impact of diagnosis

Every participant reported shock or fear of the new diagnosis and the unknown with navigating the diagnosis. Participants reported managing the stress and pressure of the diagnosis through a variety of avenues. Two patients described leaning on a higher power to cope with the emotional distress. *"I put my life in God's hands. That he would. Take care of me. And he did" (Participant #16).* Three patients used the word "overwhelming" to describe the experience and felt that this interfered with their ability to ask for more information.

3.5. Theme 5: Perception of obesity as a defining identity

This final theme was present in a significant portion of every interview. Many respondents described being identified as an "obese person," with most of their counseling focusing on this. They also all related some level of a lifelong struggle with losing weight and fluctuating between various weights. When asked about other methods that they had employed in attempting weight loss, respondents stated using medical management, nutritional counseling and classes and bariatric surgery.

4. Discussion

Through qualitative interviews, we explored this patient experience and identified five key themes: support in diagnostic workup and long-term outcomes, autonomy in care, thoroughness in counseling, emotional impact of diagnosis, and perception of obesity as a defining identity. These themes highlight some of the challenges as well as the stigma that this group of patients faces. We aimed to understand how patients felt about undergoing a form of treatment that was not standard of care. The experience was mixed, with approximately half of the patients wishing surgery had been possible sooner and the other half being grateful to avoid surgery. Conservative management as a treatment option of complex atypical hyperplasia and early stage endometrial cancer has increasingly been studied as a viable option (Rodolakis et al., 2023).

Patients undergoing nonsurgical management of endometrial cancer and complex atypical hyperplasia face several stressors in the treatment process. One reason for choosing individual interviews rather than focus groups was to allow participants privacy in discussing this concern. The language chosen for this study was unique in that it explored the patient experience in patients who underwent conservative management for endometrial cancer. Due to the qualitative nature, patients were given the space to discuss many topics. The interviews was open-ended and non-judgmental to hopefully reduce harm.

O'Hara et al previously evaluated the patient experience in the feMMe trial (O'Hara et al., 2022). There were notable differences between their qualitative study and ours. First, the feMMe trial was performed for a combination of fertility preservation as well as surgical morbidity started at BMI 30 kg/m^2, whereas we aimed to limit our study participants to those who received conservative management primarily due to obesity, though we do note that a few of our patients cited a desire to maintain fertility. In addition, all the patients in the feMMe trial had voluntarily joined a clinical trial with the concerted effort for weight loss while on treatment (O'Hara et al., 2022). These differences are demonstrated in the emphasis on the shock of the diagnosis as well as the particular experience with obesity and how they were counseled.

In addition, given that these patients were not enrolled in a trial, there was varying understanding of the length of time for hormonal management as well as the various steps that are involved with monitoring. This highlights the need for a streamlined multidisciplinary (with nutritional services and bariatrics) approach with a clear schedule of steps and resources for these patients. Other studies have previously indicated that participants were unaware of the link between obesity and the increased risk of developing endometrial cancer (Carlson et al., 2012; MacMahon, 1974). Our study similarly showed that while patients understood the link between their weight and surgical management, there was poor understanding about the association between CAH /EC and obesity.

The study demonstrates areas of opportunity to improve counseling and care, particularly in being aware of care for the whole person beyond a disease process. The American Diabetes Association has previously published on the use of a multidisciplinary team-based approach for management of obesity in patients with diabetes (Committee, 2021). They emphasize the combined approach of pharmacotherapy, management by a healthcare professional, diet and exercise programs as well as psychotherapy. These interviews certainly indicate the mental anguish and psychological distress associated with the cancer diagnosis as well as emotional component of weight loss.

There were a number of limitations in this study. The first limitation is that while we attempted to exclude patients who desired fertility, we did have a combination of premenopausal and postmenopausal women. We do recognize that the general applicability of these findings can be affected given the difference in these populations. However, we do feel that the counseling and weight management strategies are universally applicable.

We also acknowledge the risk of bias in this study. The first was the risk of participant bias and recall bias. Interviewees had all undergone treatment 2–7 years ago and may have had biased memories of their experience. Participant bias was possible as all interviewees indicated an overall positive experience. We approached 52 patients for interview, it is possible that the 30 individuals who opted not to participate had an entirely different and potentially less positive experience. Another potential bias is that interviews were conducted in English only and all participants were Non-Hispanic White women. This is reflective of the population at Mayo Clinic. However, it does potentially limit the generalizability of these findings to other populations. Finally, we noted in this study that patients commonly did not understand that obesity is related to carcinogenesis in endometrial cancer (Carlson et al., 2012). As noted in the results, only three of the consultation notes had specific counseling about obesity driving carcinogenesis. We did not have specific questions directed towards this in the interview guide, so we were unable to clearly ascertain whether patients had an awareness of this link. However, there was little mention of this during interviews, which stresses the importance of gynecologic oncologists' role in including this as part of the counseling for these patients.

Overall, this study emphasized the importance of the physician patient relationship, thorough counseling, and patient autonomy. Implementation of a multidisciplinary approach and development of a clinical plan road map may help patients better understand their treatment plan, the disease course, and improve adherence to recommended treatment.

Funding

This project was supported by Grant Number UL1 TR002377 from the National Center for Advancing Translational Sciences (NCATS). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH.

CRediT authorship contribution statement

Aparna Kailasam: Writing – review & editing, Writing – original draft, Visualization, Methodology, Investigation, Data curation, Conceptualization. **Aminah Jatoi:** Writing – review & editing, Validation, Investigation, Data curation, Conceptualization. **Evelyn Reynolds:** Writing – review & editing, Visualization, Formal analysis, Data curation. **William Cliby:** Writing – review & editing, Validation, Supervision. **Carrie Langstraat:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.gore.2024.101425.

References

Al Sawah, E., Salemi, J.L., Hoffman, M., Imudia, A.N., Mikhail, E., 2018. Association between obesity, surgical route, and perioperative outcomes in patients with uterine cancer. Minimally Invasive Surgery 2018, 8.

Bernardini, M.Q., Gien, L.T., Tipping, H., Murphy, J., Rosen, B.P., 2012. Surgical outcome of robotic surgery in morbidly obese patient with endometrial cancer compared to laparotomy. Int. J. Gynecol. Cancer 22 (1), 76–81.

Blikkendaal, M.D., Schepers, E.M., van Zwet, E.W., Twijnstra, A.R.H., Jansen, F.W., 2015. Hysterectomy in very obese and morbidly obese patients: a systematic review with cumulative analysis of comparative studies. Arch. Gynecol. Obstet. 292 (4), 723–738.

Byrne, D., 2022. A worked example of Braun and Clarke's approach to reflexive thematic analysis. Qual. Quant. 56 (3), 1391–1412.

Carlson, M.J., Thiel, K.W., Yang, S., Leslie, K.K., 2012. Catch it before it kills: progesterone, obesity, and the prevention of endometrial cancer. Discov Med. 14 (76), 215–222.

CDC – National Center for Health Statistics – Homepage, 2023.

Chia, V.M., Newcomb, P.A., Trentham-Dietz, A., Hampton, J.M., 2007. Obesity, diabetes, and other factors in relation to survival after endometrial cancer diagnosis. Int. J. Gynecol. Cancer 17 (2), 441–446.

Committee ADAPP, 2021. 8. Obesity and Weight Management for the Prevention and Treatment of Type 2 Diabetes: Standards of Medical Care in Diabetes—2022. Diabetes Care 45(Supplement_1), S113-S124.

DiCicco-Bloom, B., Crabtree, B.F., 2006. The qualitative research interview. Med. Educ. 40 (4), 314–321.

Flegal, K.M., Kit, B.K., Orpana, H., Graubard, B.I., 2013. Association of all-cause mortality with overweight and obesity using standard body mass index categories: a systematic review and meta-analysis. JAMA 309 (1), 71–82.

Janda, M., Robledo, K.P., Gebski, V., Armes, J.E., Alizart, M., Cummings, M., et al., 2021. Complete pathological response following levonorgestrel intrauterine device in clinically stage 1 endometrial adenocarcinoma: Results of a randomized clinical trial. Gynecol. Oncol. 161 (1), 143–151.

MacMahon, B., 1974. Risk factors for endometrial cancer. Gynecol. Oncol. 2 (2), 122–129.

McDonald, M.E., Bender, D.P., 2019. Endometrial cancer: obesity, genetics, and targeted agents. Obstet. Gynecol. Clin. North Am. 46 (1), 89–105.

Network NCC, 2022. Uterine Neoplasms.

Obermair, A., Brennan, D.J., Baxter, E., Armes, J.E., Gebski, V., Janda, M., 2016. Surgical safety and personal costs in morbidly obese, multimorbid patients diagnosed with early-stage endometrial cancer having a hysterectomy. Gynecol. Oncol. Res. Pract. 3, 1.

O'Hara, M., Janda, M., McCarthy, A.L., Nicklin, J., Walker, G., Obermair, A., 2022. Patient experiences of conservative treatment for early stage endometrial cancer and endometrial hyperplasia with atypia using levonorgestrel intrauterine device: A qualitative study. Gynecol. Oncol. Rep. 39, 100914.

Onstad, M.A., Schmandt, R.E., Lu, K.H., 2016. Addressing the role of obesity in endometrial cancer risk, prevention, and treatment. J. Clin. Oncol. 34 (35), 4225–4230.

Pal, N., Broaddus, R.R., Urbauer, D.L., Balakrishnan, N., Milbourne, A., Schmeler, K.M., et al., 2018. Treatment of low-risk endometrial cancer and complex atypical hyperplasia with the levonorgestrel-releasing intrauterine device. Obstet. Gynecol. 131 (1), 109–116.

Rodolakis, A., Scambia, G., Planchamp, F., Acien, M., Di Spiezio, S.A., Farrugia, M., et al., 2023. ESGO/ESHRE/ESGE Guidelines for the fertility-sparing treatment of patients with endometrial carcinoma. Facts Views vis Obgyn. 15 (1).

SEER, 2022. Cancer Stat Facts: Uterine Cancer: SEER.

Siedhoff, M.T., Carey, E.T., Findley, A.D., Riggins, L.E., Garrett, J.M., Steege, J.F., 2012. Effect of extreme obesity on outcomes in laparoscopic hysterectomy. J. Minim. Invasive Gynecol. 19 (6), 701–707.

Soliman, P.T., Bassett Jr., R.L., Wilson, E.B., Boyd-Rogers, S., Schmeler, K.M., Milam, M. R., et al., 2008. Limited public knowledge of obesity and endometrial cancer risk: what women know. Obstet. Gynecol. 112 (4), 835–842.

Vetter, M.H., Smith, B., Benedict, J., Hade, E.M., Bixel, K., Copeland, L.J., et al., 2020. Preoperative predictors of endometrial cancer at time of hysterectomy for endometrial intraepithelial neoplasia or complex atypical hyperplasia. Am. J. Obstet. Gynecol. 222 (1), 60.e1–60.e7.

Westin, S.N., Fellman, B., Sun, C.C., Broaddus, R.R., Woodall, M.L., Pal, N., et al., 2021. Prospective phase II trial of levonorgestrel intrauterine device: nonsurgical approach for complex atypical hyperplasia and early-stage endometrial cancer. Am. J. Obstet. Gynecol. 224 (2), 191.e1–191.e15.