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# Identifying barriers individuals face in accessing fertility care after a gynecologic cancer diagnosis

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# ABSTRACT

*Objective:* To (1) identify the major barriers premenopausal individuals face in accessing fertility care at the time of gynecologic cancer diagnosis and (2) to assess patient experiences pertaining to fertility. *Methods:* We distributed an online survey about cancer diagnosis and fertility goals to patients ages 18–40 who

had been treated for ovarian, endometrial, or cervical cancer at a single, large academic hospital. Descriptive statistics were used to analyze survey results. Patients who completed the survey were given the option to participate in a follow-up virtual interview. We conducted semi-structured interviews to discuss their fertility goals and barriers to these. Grounded theory was used to qualitatively analyze the interviews.

*Results*: Fifty-five patients completed the survey, and 20 patients participated in the interview. The median age at diagnosis was 32 years old. Seventy-three percent of patients recalled that at the time of their diagnosis they were considering future childbearing, and 32% underwent fertility preservation. Patients reported the emotional response to their diagnosis as a barrier to receiving fertility care, with patients reporting lack of control (80%), shock (55%), and confusion (45%). Patients also identified inadequate counseling (60.0%), lack of time (60.0%), economic constraints (55.0%) and prioritization of cancer treatment (55.0%) as barriers. Nearly all patients had a positive interview experience and expressed desire to help patients in similar situations.

*Conclusion:* Many premenopausal patients diagnosed with gynecologic malignancies are considering future childbearing at the time of diagnosis. Both logistical and emotional barriers prevent them from undergoing fertility preservation before initiating oncologic treatment.

#### 1. Introduction

Premenopausal patients diagnosed with a new gynecologic malignancy have the added burden of potentially losing reproductive options. This occurs from loss of reproductive organs during surgical management of their malignancy, ovarian insufficiency, early menopause, fibrosis, and damage from ionizing radiation. (Taylan and Oktay, 2019; Chan and Wang, 2017) Additionally, many individuals are having children at a later age, increasing the likelihood they will be diagnosed with a gynecologic cancer prior to completion of childbearing. (Taylan and Oktay, 2019) Though options exist to preserve fertility potential, patients often face barriers in accessing these opportunities, particularly those that must be pursued before initiating treatment. Previously identified barriers include feeling overwhelmed at the diagnosis, poor counseling, urgency of treatment initiation, and the cost of fertility treatments. (Taylan and Oktay, 2019).

It is imperative that oncologists and fertility specialists discuss these options with patients prior to treatment initiation, especially with recent improvements in fertility preservation. (Chan and Wang, 2017; Ethics Committee of the American Society for Reproductive Medicine, 2013) Prior studies show that both counseling and fertility-sparing surgery are associated with decreased regret, especially when receiving counseling from a fertility specialist in addition to an oncologist. (Chan et al., 2017; Letourneau et al., 2012).

The American Society of Clinical Oncology (ASCO) created guidelines indicating that clinicians should discuss fertility preservation options as early as possible with patients and answer questions or refer patients to fertility specialists. (Lee et al., 2006) Despite these

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guidelines, barriers still exist. This study uses quantitative and qualitative methods to (1) identify the major barriers premenopausal individuals face in accessing fertility care at the time of diagnosis with a gynecologic cancer diagnosis and (2) to assess patient experiences, particularly around fertility, to learn how to better support such patients in the future.

# 2. Methods

This mixed methods study employed both quantitative and qualitative methods. IRB approval was obtained for both parts of the study.

#### 2.1. Survey

In the quantitative part of the study, a retrospective review was first used to identify potential participants and obtain demographic information. This portion of the study involved an online survey which we distributed to patients ages 18–40 at the time of diagnosis seen for follow up for ovarian cancer, endometrial cancer, or cervical cancer at a single, large academic hospital in New York State (NYS) between 2012 and 2022. We included patients with all cancer stages, as well as tumors of low malignant potential. Patients were excluded if they were actively receiving cancer treatment. Eligible patients received a message through their secure patient portal with a link to the survey. We collected demographic information from the electronic medical record, including patient's self-reported race and ethnicity, for patients who completed the survey. The survey consisted of 21 questions regarding childbearing prior to their diagnosis, plans for future fertility at the time of diagnosis, how they anticipated their cancer diagnosis would affect their plans, the support and counseling they received regarding fertility planning, whether they underwent fertility preservation, and what barriers they encountered. Patients were also asked in the survey whether they would be willing to participate in a follow up interview.

# 2.2. Interview

Those who indicated a willingness to participate in an interview in the online survey were contacted to schedule a virtual interview and we obtained verbal consent at the start of each interview. The semistructured interviews included questions about family planning goals at the time of diagnosis, whether these goals had changed, how they thought treatment would affect their fertility, whether they had pursued fertility preservation, and whether they had experienced barriers to care. The interview script is shown in Fig. 1. We completed a total of 20 virtual interviews ranging from 10 to 40 min which were recorded, deidentified and then transcribed. Four team members independently coded the transcriptions. We used grounded theory to qualitatively analyze the transcriptions until thematic saturation was reached.

# Semi-Structured Video Interview Script:

- Can you tell me about some of your initial thoughts when you first learned of your diagnosis?
- What were your family planning goals prior to your diagnosis?
   o Have they changed?
- How did you think cancer treatment would affect your fertility?
  - Is there anything you wish you knew before starting treatment?
- Did you undergo fertility preservation?
  - o If yes
    - What was your experience like with the process of fertility preservation?
    - What was easy about it?
    - What was difficult about it?
- Can you tell me about your support system throughout your cancer experience?
   If you decided to pursue fertility treatment, where they for or against it?
- Can you tell me about ways your oncologist did or did not support your fertility goals?
  - Were there any assumptions your doctor made about your fertility goals?
- Can you remember any factors that either prevented you or made it more difficult for you to undergo fertility preservation methods before starting treatment?
  - Was it too expensive?
  - Did your insurance cover it?
  - Did your doctor not give you enough information?
  - Did your loved ones or doctor tell you that you should start treatment immediately instead?
- Thank you so much for your time. Is there anything else you would like to add?
- What question did we not ask that we probably should have?
- What emotions did you experience during the process of this interview?

Fig. 1. Script for the semi-structured interviews.

#### 2.3. Statistical analysis

For the survey results, we calculated descriptive statistics, including frequencies and medians. To assess whether specific clinical characteristics were associated with fertility preservation, a combination of Mann U Whitney tests and Kruskal Wallis tests were used. For the interview results, we calculated frequencies of each theme after reaching thematic saturation. Themes were determined from the coded interview transcriptions.

# 3. Results

#### 3.1. Survey results

Surveys were distributed to the 228 patients identified as eligible for the study, and 55 patients completed the survey (24% completion rate). Demographics are listed in Table 1. The median age at the time of cancer diagnosis was 32 years old. Of the 55 patients, 20 were treated for ovarian cancer (36.4%), 12 for endometrial cancer (21.8%), and 23 for cervical cancer (41.8%). One patient identified as Asian (1.8%), 4 Black (7.3%), 48 White (87.3), None of the above (3.6%). Fifty-two patients underwent surgery (94.5%), 13 received radiation (23.6%), and 19 were treated with chemotherapy (34.5%). Twenty-three patients (41.8%) already had at least one child prior to their diagnosis, and 40 (72.7%) were considering future childbearing. Eighteen out of 55 patients (32.7%) underwent fertility preservation. Eleven patients had fertility sparing surgery (20.0%), and 7 patients (12.7%) tried various methods such as oocyte cryopreservation (2), ovarian tissue cryopreservation (2), ovarian tissue transposition (2), or embryo cryopreservation (1). Thirtyseven patients (67.3%) did not undergo any methods of fertility preservation.

Though 38 of the 55 patients (69.1%) knew cancer treatment impacted their fertility, 27 out of 55 (49.1%) respondents did not feel they received adequate counseling at the time of diagnosis (Fig. 2). The most frequent ways patients received information was verbal counseling from their oncologist (60.0%), independent research (56.4%), and through written information or pamphlets (20.0%). One in 5 patients (20.0%) did not recall receiving any counseling. Only 6 patients reported being referred to a fertility specialist (11.3%). In terms of whether their diagnosis impacted their desire to have children, 49.1% of patients reported that their family planning goals were minimally changed or not changed at all, whereas 29.1% of patients reported their goals drastically changed.

#### Table 1

Survey Participant Demographics.

Variable	Number of Patients (%)
Age at diagnosis (years)	Median: 32
	Mean: 32 +/- 5.9
Race	
Asian	1 (1.8)
Black	4 (7.3)
White	48 (87.3)
None of the above	2 (3.6)
Ethnicity	
Not Hispanic	53 (96.4)
Unknown	2 (3.6)
Cancer type	
Ovarian	20 (36.4)
Endometrial	12 (21.8)
Cervical	23 (41.8)
Fertility variables (at time of diagnosis)	
Had partner	40 (72.7)
Did not have partner	15 (27.3)
Had previously been pregnant	29 (52.7)
Had never been pregnant	26 (47.3)
Were considering having children in the future	40 (72.7)
Were not considering having children in future	15 (27.3)



Fig. 2. Patient survey responses (n = 55) regarding how they perceived counseling on how treatment would impact their fertility (1 = little to no counseling, 10 = extensive counseling).

Patients who had children at the time of diagnosis were 72.0% less likely to undergo fertility preservation than patients who did not already have children at the time of diagnosis (p = 0.043, OR = 0.28; 95% CI: 0.067–0.97). Patients who did not undergo fertility preservation were prompted to evaluate the reasons they did not pursue such treatment. The most common barriers included not wanting to delay treatment (49.0%), feeling too emotionally burdened by the diagnosis (18.4%), and lack of adequate counseling from their provider (14.3%). There was no statistically significant difference in those who underwent fertility preservation based on whether they had a partner at the time of diagnosis or not (p = 0.96). Patients between the ages of 25–30 years old at the time of diagnosis were no more likely to undergo fertility preservation than those younger than 25 or older than 30 (p = 0.25). Patients who felt they received adequate counseling were not more likely to undergo fertility preservation (p = 0.78). Additionally, there was no statistically significant difference between the patient's race (p = 0.51) or ethnicity (0.17) and whether they thought they received adequate counseling.

### 3.2. Interview results

Thirty-seven patients indicated they would be willing to participate in an interview, and 20 patients completed the interview. Demographics are listed in Table 2. The median age at the time of cancer diagnosis was 32 years old. One patient was Black (5.0%), 18 (90.0%) were White and the race was "none of the above" for 1 patient (5.0%). Of the patients that completed the interview, 10 (50.0%) had ovarian cancer, 6 (30.0%) had endometrial cancer, and 4 (20.0%) had cervical cancer. Sixteen (80.0%) had a partner at the time of diagnosis, 8 (40.0%) had previously been pregnant prior to diagnosis, and 16 (80.0%) were considering having children in the future at the time of diagnosis.

From the interviews, 80.0% of patients felt they had not yet met their family planning goals at the time of diagnosis. Due to the unexpected nature of this diagnosis at a young age, many patients were noted to have a poor understanding of their own family planning goals and were unsure whether they desired future childbearing. For those who had not met their family planning goals, patients reported that the most common

#### Table 2

Video Interview Participant Demographics.

Variable	Number of Patients (%)
Age at diagnosis (years)	Median: 32
	Mean: 33 +/- 4.5
Race	
Asian	0 (0.0)
Black	1 (5.0)
White	18 (90.0)
None of the above	1 (5.0)
Ethnicity	
Not Hispanic	18 (90.0)
Unknown	2 (10.0)
Cancer type	
Ovarian	10 (50.0)
Endometrial	6 (30.0)
Cervical	4 (20.0)
Fertility variables (at time of diagnosis)	
Had partner	16 (80.0)
Did not have partner	4 (20.0)
Had previously been pregnant	8 (40.0)
Had never been pregnant	12 (60.0)
Were considering having children in the future	16 (80.0)
Were not considering having children in future	4 (20.0)

barriers in seeking fertility care were inadequate counseling from their provider (60.0%), lack of time (60.0%), economic constraints (55.0%), cancer treatment prioritization (55.0%), poor communication (30.0%) from their provider, and lack of support from the medical team (20.0%). These patients faced a significant amount of emotional distress throughout their cancer treatment in combination with potential loss of fertility. Patients reported feeling lack of control (80.0%), shock (55.0%), confusion (45.0%), overwhelm (40.0%), and fear (35.0%). Examples of barriers and emotions experienced from the patient perspective are summarized in Table 3. Multiple patients noted frustration with the lack of support groups specifically for premenopausal individuals undergoing treatment for gynecologic malignancies, and numerous patients expressed a desire to help patients in similar situations. Nearly all patients had a positive interview experience and were appreciative of the opportunity to reflect upon their experiences. Many commented on the lack of these important conversations during their treatment, one patient remarking she felt "[a] little more at peace" after the interview.

#### 4. Discussion

Our objectives were to identify barriers premenopausal patients with gynecologic malignancies face in pursuing fertility preservation and to assess their perspectives on the experience. Approximately half of the patients in our study reported feeling they did not receive adequate counseling regarding the impact of their diagnosis and treatment on their future fertility. Ultimately about one third of patients underwent some type of fertility preservation, the majority of which was fertility-sparing surgery. Previous studies have reported a wide range (30–90%) in the percentage of patients receiving fertility counseling. (Gonçalves et al., 2022) Our study's rate (10.9%) of patients being referred to a fertility specialist is lower than previously reported rates (13–39%). (Goncalves et al., 2022).

Gynecologic oncologists report higher rates of counseling and consideration of fertility than the rates patients report receiving. A study of gynecologic oncologists reported that 68% always considered a patient's fertility before initiating treatment, with 16% always and 44% often referring patients to a reproductive endocrinologist. (Shah et al., 2017) Another study of gynecologic and medical oncologists showed gynecologic oncologists were more likely to routinely consider a patient's fertility (93% vs 60%) and were more likely to provide alternative regimens to preserve fertility (61% vs 37%) than other oncologists. (Forman et al., 2010) Receiving adequate counseling has been shown to

#### Table 3

Examples of Barriers and Emotions Experienced by Patients in Interviews.

Barrier	Quotation from Patient	Emotional Experience	Quotation from Patient
Inadequate counseling	"I felt really disappointed and frustrated that I wasn't given all of the information that could have been far more helpful"	Lack of control	"It was one of those things where I didn't get the option to preserve so it was either do this or it will progress and get worse"
Lack of time	"It's not a lot of time to do that and consider what it would mean to, you know, save an egg. Or why you would want to do it. Or whether that would be a think you were glad you did later. I really didn't get to think about all of that"	Shock	"It's been one of the most jarring and startling and ungrounding things that's ever happened to me"
Economic	"Like I don't have money for that. Insurance does not cover that I think so I couldn't do any of that"	Confusion	"My initial thought was I didn't know what was going to happen, if we'd ever be able to have kids"
Cancer treatment prioritization	"Dr. X said no because all of the hormones would cause the cancer to increase" "and he made some good points like if you're not here to take care of a kid, you've got to think of yourself first"	Overwhelm	"Everything kind of escalated kind of quickly, and you know" "then it was just kind of like worst scenario just happened and then I got swept into the oncology gynecology office and met with Dr. XX and it was just a lot in my life at the time"
Poor provider communication	"I felt inadequately prepared for like decisions I could have made anticipating more treatment."	Fear	unie "First and foremost on our mind was definitely you know, very scared that we'd never be able to have kids"
Lack of support from medical team	"I don't wanna say flippant, but it was very clinical like there was not a hey this is a devastating diagnosis, you know, how can we work you through this."		

decrease long-term regret in these patients. (Chan et al., 2017; Deshpande et al., 2015) The realities of clinical practice make it difficult for oncologists to have these extensive conversations. However, it is important that providers arrange for additional appointments with social workers, therapists, and fertility specialists to give patients space for emotional processing. Throughout the interviews, patients emphasized their desire to discuss their fertility options and emotions regarding potential infertility with physicians, social workers, counselors, or other patients in similar situations. Many patients noted the lack of support groups specifically for premenopausal patients with these diagnoses and felt that these would be helpful given the unique challenges they face. The data suggest that giving patients adequate information and opportunities for reflective conversations will help increase confidence in their treatment decisions and provide therapeutic benefit.

The main barriers to fertility preservation noted on the survey were urgency of treatment, emotional burden of the cancer diagnosis, and lack of adequate counseling. From the interviews, the most common barriers were inadequate counseling, lack of time, cost, cancer treatment prioritization, poor communication from their provider, and perceived lack of support from the medical team. Some of these barriers are difficult for clinicians to address, such as lack of time and high cost of fertility care. Barriers that could be more easily addressed include inadequate counseling, poor provider communication, and lack of support from the medical team. A prior review including female patients with gynecologic and non-gynecologic cancers identified similar themes that hindered patients in the fertility preservation decision process. These included information provision, fear of perceived risks including delay in cancer treatment, lack of referral from oncology team, emotional overwhelm and how to prioritize treatments, personal situations, and financial concerns. (Jones et al., 2017) The consistency of these themes provides a foundation for areas to improve this process for patients.

An important theme that emerged from the interviews was the intense emotional response patients had to their diagnosis and the impact this had on their ability to consider and proceed with fertility treatment. Over half the patients interviewed noted shock at their diagnosis, and 80.0% felt a lack of control. Many felt this carried over to their fertility options. Patients reported feeling they did not have options or the opportunity to make decisions for themselves about future fertility, even if the options were discussed, given the need to start treatment quickly. Providers must be keenly aware that patients struggle with the competing demands of fertility preservation and cancer treatment and that most have not yet met their family building goals at the time of diagnosis. Helping patients better understand the timeline will allow them to weigh their options in the context of their own disease. Observational studies on oncologic outcomes for patients who elect to delay treatment to pursue fertility treatment would help to direct counseling and decision making for future patients.

Our study's limitations include the retrospective nature of the study design. Subjects were surveyed and interviewed after completing oncology treatment and thus were at risk of recall bias. Subjects also selfselected to participate in the study. There was a 24% response rate to the survey, which may be due to the nature of recruiting patients through our secure patient portal. Patients may not regularly check their portal, especially given that these patients are no longer receiving active treatment. Additionally, the study was conducted at a single academic institution, resulting in a relatively small sample size. This may limit generalizability of our findings, and future direction can involve a multiinstitutional study.

Due to the small sample size and single geographic area, there was particularly limited diversity in our subjects' racial demographics. However, it is well-documented in the literature that fertility care is primarily accessed by White individuals. Black, Hispanic, and Asian patients are less likely to pursue fertility care, which highlights an additional barrier in access to fertility preservation services for minority patient populations. (Huddleston et al., 2010) In a study looking at the duration of attempting conception before seeking treatment, Black and Asian individuals waited a median of 28 months, Hispanic individuals waited a median of 38 months, while White individuals waited a median of 23 months. (Galic et al., 2021) Another study found that compared with White individuals, Black and Hispanic individuals had been attempting to conceive for 20 months longer prior to being seen at an infertility clinic, found it more difficult to find a doctor they felt comfortable with, to get an appointment, get time off from work approved, and to pay for the fertility treatment (p < 0.0001). (Missmer et al., 2011).

It is important to note that our study was conducted in an academic center located in New York State (NYS). As of 01/2020, NYS mandated insurance coverage of standard fertility preservation services when a medical treatment may directly or indirectly cause iatrogenic infertility. (Medicine ASoR, 2023) This mandate was implemented during our study's time period. In the future, it would be interesting to study whether our patients were more likely to receive information about or undergo fertility preservation post-mandate. Unfortunately, the NYS

mandate did not include public insurance coverage of fertility preservation, including Medicaid. (Services NYSDoF, 2023) It would also be interesting to study the difference in private versus public insurance coverage post-mandate and whether this influenced patients' decisions to pursue fertility preservation.

With improving survival for patients with gynecologic malignancies and delayed reproductive age, we can anticipate more patients in this situation. It is important to focus on balancing effective cancer treatment, quality of life, and survivorship. Continuing to address barriers to fertility treatments is critical to ensuring patients receive optimal care and maintain a high quality of life after treatment.

## CRediT authorship contribution statement

Julia Schlossman: Conceptualization, Writing – review & editing. Michelle Vu: Conceptualization, Writing – review & editing. Alexandra Samborski: Writing – review & editing. Karolina Breit: Writing – review & editing. Kelly Thevenet-Morrison: Writing – review & editing. MaryAnn Wilbur: Conceptualization, Writing – review & editing, Supervision.

# **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.

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