



# The earlier the better: the role of palliative care consultation on aggressive end of life care, hospice utilization, and advance care planning documentation among gynecologic oncology patients

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Received: 27 February 2018 / Accepted: 30 August 2018 / Published online: 12 September 2018  
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## Abstract

**Purpose** To evaluate the role of specialty palliative care consultation (PCC) on end of life care outcomes among terminally ill gynecologic oncology patients.

**Methods** Retrospective chart review of currently deceased gynecologic oncology patients seen at a single, academic institution between October 2006 and October 2016. Clinical characteristics and outcomes were examined using descriptive statistics and logistic regression.

**Results** Two hundred and four patients were eligible. Forty-one percent underwent at least one marker of aggressive care at the end of life. Most (53%) had a PCC prior to death, and of these most were inpatient (89%). Patients with a PCC had higher odds of hospice enrollment before death (OR 2.55,  $p = 0.016$ ) and higher odds of advance care planning documentation before death (OR 6.79,  $p < 0.001$ ). Among patients with an inpatient PCC, 44% underwent a marker of aggressive medical care at the end of life and 82% enrolled in hospice before death. Among patients with an outpatient PCC, 25% underwent a marker of aggressive medical care at the end of life and 92% enrolled in hospice before death. Patients with outpatient PCC were engaged in palliative care longer than patients with inpatient PCC (median 106 days vs. 33 days prior to death).

**Conclusions** PCC increased hospice enrollment and advance care planning documentation. Patients with outpatient PCC had lower rates of aggressive medical care and higher rates of hospice enrollment when compared to inpatient PCC. Location of initial PCC plays an important role in end of life care outcomes.

**Keywords** Gynecologic cancer · Palliative care · Quality of life

## Purpose

Medical care decisions at the end of life are difficult for patients and families to navigate due to the complexity and emotions inherent in the decisions that must be made. Specialty palliative care consultation by a trained palliative care expert helps primary teams facilitate goals of care discussions, symptom management, and medical resource navigation for the terminally ill patient. Early initiation of palliative care results

in patient centered care that is less invasive and more cost effective than standard medical care at the end of life [1]. Due to these benefits, the National Comprehensive Cancer Network (NCCN) and the American Society of Clinical Oncology (ASCO) advise oncologists to have early discussions regarding palliative care services and interventions with advanced cancer patients [2, 3].

Despite the well-intentioned nature of aggressive medical care at the end of life, these interventions have not been found to increase quality of life or survival. Instead, aggressive medical care at the end of life has been shown to have a detrimental impact on patient quality of life without improving survival or palliating symptoms [4–6]. While there is not a standardized definition of aggressive care at the end of life, many investigators use the following criteria recognized by the National Quality Forum: chemotherapy administration within the final 14 days of life, > 1 emergency room visit in the final 30 days of life, > 1 hospital admission in the final 30 days of life, >

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14 days spent admitted to the hospital in the final 30 days of life, ICU admission in the final 30 days of life, death in the hospital, and hospice admission during the final 3 days of life [7].

Unlike aggressive medical care at the end of life, specialty palliative care interventions have been proven to improve quality of life as well as decrease the number of procedures, emergency room visits, admissions to the hospital, and ICU stays [1, 5, 6, 8, 9]. Patients pursuing palliative care in the form of hospice care are more likely to die at home and are less likely to die in the ICU [10]. In addition to providing patients with improved quality of life, palliative care results in decreased hospital costs and reduced burden of medical costs to patients and their families [10]. Palliative care consultation has also been found to increase advance care planning documentation (Do Not Resuscitate orders, Medical Power of Attorney, and Living Will) which is important in establishing a patient's wishes at the end of life. Timely completion of these documents helps ensure that end of life care decisions are made in accordance with the patient's wishes in the event that the patient is no longer able to communicate their desires [11–13].

Palliative care consultation may occur in the outpatient or inpatient setting. Prior research suggests that outpatient palliative care consultations may improve patient outcomes more than inpatient consultation. Patients with outpatient consultation have been noted to have fewer hospitalizations, fewer hospital deaths, and decreased cost of end of life care when compared to patients with inpatient palliative care consultation alone [14, 15].

Gynecologic oncology is a unique specialty in that gynecologic oncologists perform surgical procedures, administer the cytotoxic therapy for their patients, and manage medical admissions for their patients. This allows gynecologic oncologists to provide a continuum of care throughout the duration of a patient's illness. Gynecologic oncologists therefore have a unique opportunity to be the first to participate in end of life discussions with their patients and address end of life care goals with patients. Despite the opportunity for early end of life care discussions with gynecologic oncology patients, recent literature suggests that approximately 40–60% of gynecologic oncology patients undergo at least one type of aggressive medical care at the end of life [16–18]. Given the positive benefits experienced by patients who participate in specialty palliative care at the end of life and the limited information regarding the role that specialty palliative care consultation plays in the end of life care received by gynecologic oncology patients, we desired to further explore these issues. The primary objective of this study was to assess the impact of palliative care consultation on the medical care received at the end of life among terminally ill gynecologic oncology patients at our institution. We hypothesized that palliative care consultation would

decrease the aggressive medical care received at the end of life by patients at our institution.

## Methods

This study was an Institutional Review Board (IRB)-approved, retrospective chart review of all currently deceased gynecologic oncology patients seen at Vanderbilt University Medical Center in Nashville, TN between October 2006 and October 2016. Eligibility criteria included the following: 1.) Women age  $\geq 18$  years, 2.) Women with a biopsy or image proven gynecologic malignancy (i.e., carcinoma of uterus, cervix, ovaries, peritoneum, vulva, and vagina), 3.) Clearly documented date of death within the medical record or within the social security death index, 4.) Death between October 2006–October 2016, and 5.) Received majority of medical care at Vanderbilt University Medical Center in the last 6 months of life.

Exclusion criteria included the following: 1.) Unclear diagnosis of advanced gynecologic malignancy or patients with non-invasive gynecologic disease, 2.) Unable to obtain clear documentation of time, location, or circumstances of death, 3.) Received majority of medical care at an outside institution within the last 6 months of their life, and 4.) Death resulted from an unrelated cause such as trauma, cardiac disease, or pathology unrelated to their malignant disease process.

Demographic information and end of life outcomes were gathered from the electronic medical record for patients eligible for the study. Demographic data collected included age at death, race, partner status, cancer site and stage, and date of cancer diagnosis. End of life outcomes included date of death, location of death, presence of advance care planning document (Do Not Resuscitate, Medical Power of Attorney, and Living Will), date of advance care planning document signature, and aggressive medical care received at the end of life.

The National Quality Forum measures defined above in the introduction were used to define aggressive medical care received at the end of life [7]. The measures included: chemotherapy administration within the final 14 days of life,  $> 1$  emergency room visit in the final 30 days of life,  $> 1$  hospital admission in the final 30 days of life,  $> 14$  days spent admitted to the hospital in the final 30 days of life, ICU admission in the final 30 days of life, death in the hospital, and hospice admission during the final 3 days of life [7].

Our institution's inpatient palliative care service was instituted in October of 2006, thereby defining our study time frame. Our gynecologic oncology service may manage end of life issues such as symptom management and transition to hospice. As a result, not all patients automatically underwent a specialty palliative care consult. Palliative care consultation (either inpatient or outpatient) was left to the discretion of the attending gynecologic oncologist. Patients receiving

inpatient specialty palliative care consultation had the opportunity to follow up as an outpatient for symptom management whether they were in active treatment for their cancer or solely seeking comfort measures. Some patients choosing to pursue hospice care were transferred to Vanderbilt's inpatient palliative care unit (PCU) before transferring to home hospice or an inpatient hospice unit. Some patients remained in the Vanderbilt inpatient PCU until their death. These deaths were recorded as inpatient hospice deaths and not as hospital deaths since the care provided in the PCU is similar to inpatient hospice.

Data regarding location and timing of palliative care consultation was collected. Data regarding the location of initial palliative care consultation included inpatient versus outpatient consultation. The date of palliative care consultation, hospice enrollment (if applicable), institution of advance care planning documents (if applicable), and death were collected.

Clinical characteristics and outcomes were examined using descriptive statistics. Binary logistic regression was used to assess categorical dependent variables with both continuous and categorical predictor variables. IBM SPSS Statistics (v. 24) was utilized for the statistical analysis.

## Results

A total of four-hundred and one patients were identified in the initial screening of Vanderbilt University Medical Center (VUMC) gynecologic oncology patients seen during the study period. Of these, 204 patients (50.8%) met our inclusion criteria as described above. The median age at death was 63 years old. The majority of patients was White, married, had a diagnosis of ovarian or uterine cancer, and presented with stage III or IV disease. See Table 1 for demographics.

### Medical care at the end of life

Eighty-three patients (40.7%) underwent at least one form of aggressive medical care at the end of life. Six patients (2.9%) had chemotherapy in the final 14 days of life. Nineteen patients (9.3%) visited the Emergency Room (ER) more than once. Twenty-six patients (12.7%) had more than one hospital admission. Twenty-one patients (10.3%) spent greater than 14 days admitted during the final 30 days of life. Thirty-one patients (15.2%) were admitted to the ICU in the final 30 days of life. Overall, 43 patients (21.1%) died in the hospital, 46 patients (22.5%) died in inpatient hospice, 100 patients (49.0%) died in home hospice, and 12 patients (5.9%) died at home. Fifteen patients (7.4%) were admitted to hospice less than 3 days prior to death. See Fig. 1.

Logistic regression analysis was employed to predict the probability that a patient received a form of aggressive EOLC at the end of life. The predictor variables used in the model

were age at death, marital status, race, presence of recurrent disease, and palliative care consult prior to death. None of the predictors were significant. There was a trend toward those patients with recurrent cancer being less likely to have aggressive EOLC (OR 0.58,  $p = 0.06$ ).

### Palliative care consultation rates and impact on hospice enrollment, advance care planning documentation, and aggressive medical care at the end of life

One hundred and seven patients (52.5%), had specialty palliative care consultation prior to death. Demographic information regarding patients receiving palliative care consultation is included in Table 1. Of these 107 consultations, 95 (88.8%) were inpatient and 12 (11.2%) were outpatient. Among patients with an inpatient palliative consult, 42 (44%) underwent aggressive medical care at the end of life and 78 (82%) enrolled in hospice before death. Among patients with an outpatient palliative consult, 3 (25%) underwent aggressive medical care at the end of life and 11 (91.7%) enrolled in hospice before death. See Figs. 2, 3, and 4 for comparisons between inpatient and outpatient palliative care consults and for details of type of aggressive care at the end of life received by each type of palliative care consult.

Logistic regression analysis was employed to predict the probability that a patient had created an advance care planning document prior to death. The predictor variables used in the model were age at death, marital status, race, presence of recurrent disease, and palliative care consult prior to death. Using a 0.05 criterion of statistical significance, palliative care consultation prior to death was significant. Patients who underwent palliative care consultation were 6.8 times more likely to have advance care planning documents than those without palliative care consultation (OR 6.79,  $p$  value = < 0.001).

Another logistic regression analysis was employed to predict the probability that a patient would enroll in hospice prior to death. The predictor variables were age at death, marital status, race, presence of recurrent disease, palliative care consult prior to death, and creation of advance care planning document prior to death. Using a 0.05 criterion of statistical significance, age at death and palliative care consult prior to death were significant. Older patients were 1.04 times more likely to enroll in hospice (OR 1.04,  $p$  value = 0.01). Patients who underwent palliative care consultation were 2.55 times more likely to enroll in hospice than those without palliative care consultation (OR 2.55,  $p$  value = 0.016).

### Timing of events

The median time between patients' last ER visit and death was 11 days. The overall median time between admission and

**Table 1** Demographic data

		All patients <i>N</i> (%)	Patients undergoing palliative care consultation <i>N</i> (%)
Age at death (years)	<i>N</i>	204	107
	Mean (SD)	61.6	61.8
	Median	63.0	61
	Min–max	18–94	26–94
Race	White	166 (81.4%)	85 (79.4%)
	African American	31 (15.2%)	19 (17.8%)
	Hispanic	2 (1.0%)	2 (1.9%)
	Asian	3 (1.5%)	1 (0.9%)
	Other	2 (1.0%)	0
Partnered status	Single	27 (13.2%)	15 (14.0%)
	Married	107 (52.5%)	58 (54.2%)
	Divorced	22 (10.8%)	10 (9.3%)
	Widowed	24 (11.8%)	12 (11.2%)
	Unknown/Missing	24 (11.8%)	12 (11.2%)
Cancer site	Ovarian	71 (34.8%)	39 (36.4%)
	Primary peritoneal	14 (6.9%)	6 (5.6%)
	Fallopian	6 (2.9%)	4 (3.7%)
	Uterine	74 (36.3%)	39 (36.4%)
	Cervical	27 (13.2%)	11 (10.3%)
	Vulvar/vaginal	12 (5.9%)	8 (7.5%)
Stage	Not Staged	17 (8.3%)	6 (5.6%)
	Stage I	21 (10.3%)	10 (9.3%)
	Stage II	15 (7.4%)	8 (7.5%)
	Stage III	102 (50.0%)	51 (47.7%)
	Stage IV	49 (24.0%)	32 (29.9%)

death was 12 days. The median time between ICU admission and death was 5 days. For the few patients that did have chemotherapy, the median time between chemotherapy and death was 12 days. The overall median time between hospice enrollment and death was 26 days.

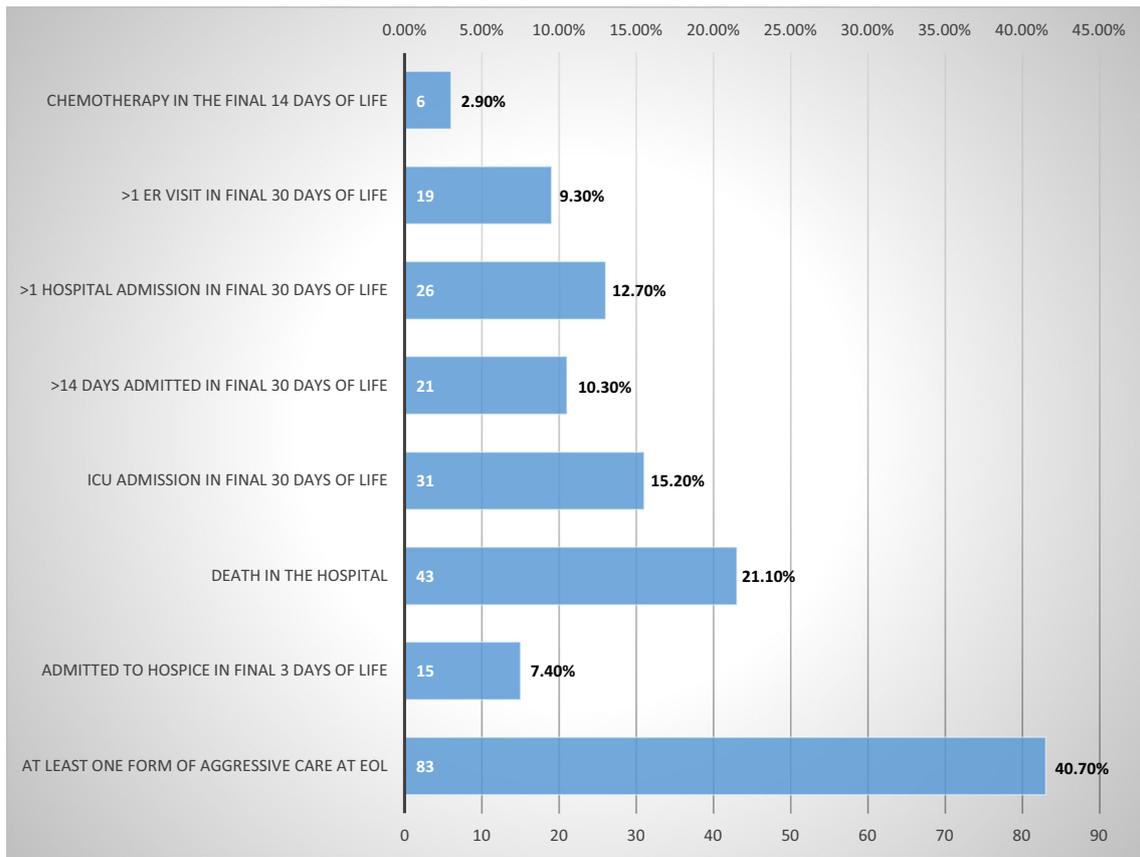
The median time between any type of palliative care consult and death was 35 days. Among patients undergoing a palliative care consult, the median time between hospice enrollment and death was 20 days. Patients with outpatient palliative care consults were engaged in palliative care much longer than patients with inpatient palliative care consults (median 106 days vs. 33 days prior to death respectively).

## Conclusions

Despite the benefits of palliative care at the end of life when compared to aggressive end of life care (EOLC), approximately 41% of our patients experienced aggressive EOLC. Half of our patients received a specialty palliative care consultation before death. Among patients who had specialty palliative care consultation, the vast majority of consults occurred

during an inpatient hospitalization. Patients receiving a palliative care consultation were 2.5 times as likely to be enrolled in hospice and were almost seven times as likely to have advance care planning documents in their medical record prior to death when compared to patients without palliative care consultation. Of those receiving palliative care consultations, patients who had an outpatient palliative care consult experienced lower rates of aggressive medical care and higher rates of hospice enrollment prior to death when compared to those who had inpatient palliative care consults only. These findings highlight the importance of discussing end of life care issues with gynecologic oncology patients and suggest that specialty palliative care consultation may assist patients in pursuing less aggressive EOLC.

Continued improvement in end of life care discussions with terminally ill gynecologic oncology patients is needed. Our research confirms data from other institutions demonstrating that 40–60% of terminally ill gynecologic oncology patients experience aggressive EOLC [16–18]. This data suggests that many patients are undergoing aggressive medical care despite the incurable nature of their illness. It is unclear if this aggressive care is a result of patient desire to pursue all medical

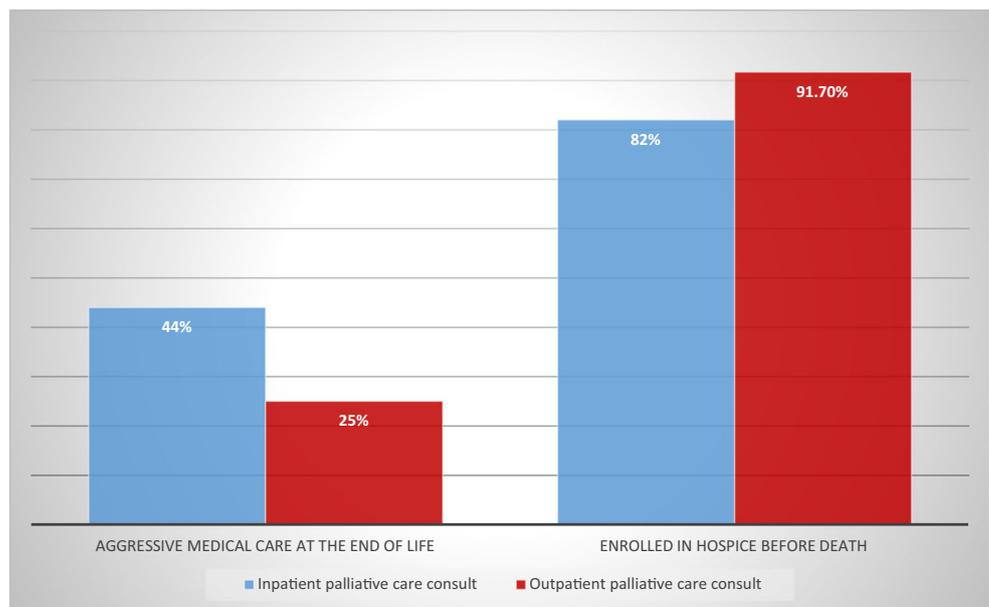


**Fig. 1** All patients undergoing aggressive medical care at the end of life

treatment options, a lack of patient understanding of their disease, or the complex interplay between psychologic and spiritual concerns at the end of life. A patient’s desire to undergo aggressive care should be discussed with them in order to better understand their goals of such care. Palliative care

approaches such as dignity therapy may assist patients with the psychological distress of dying and could perhaps assist in understanding patient motivations to undergo aggressive care at the end of life. Further understanding of this process is imperative as previous research has shown that aggressive

**Fig. 2** End of life outcomes among outpatient vs. inpatient palliative care consultations



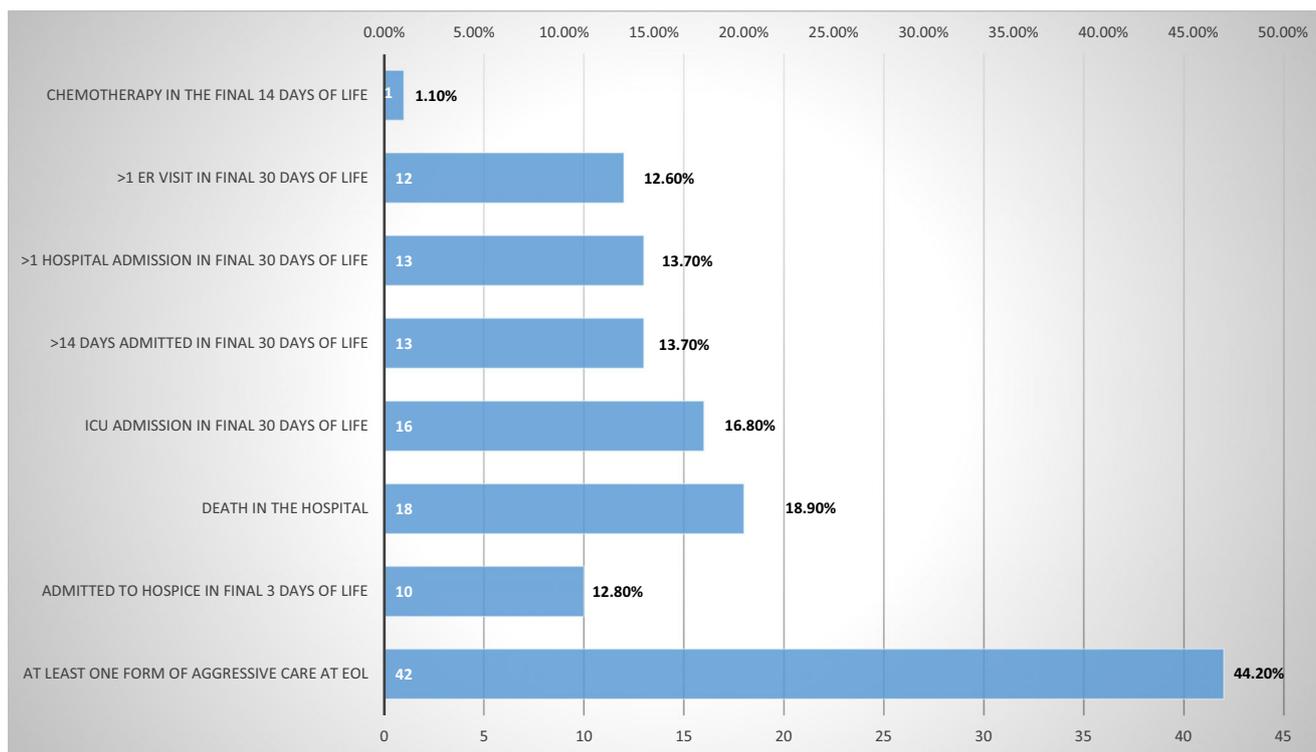


Fig. 3 Patients receiving inpatient palliative care consult undergoing aggressive medical care at the end of life

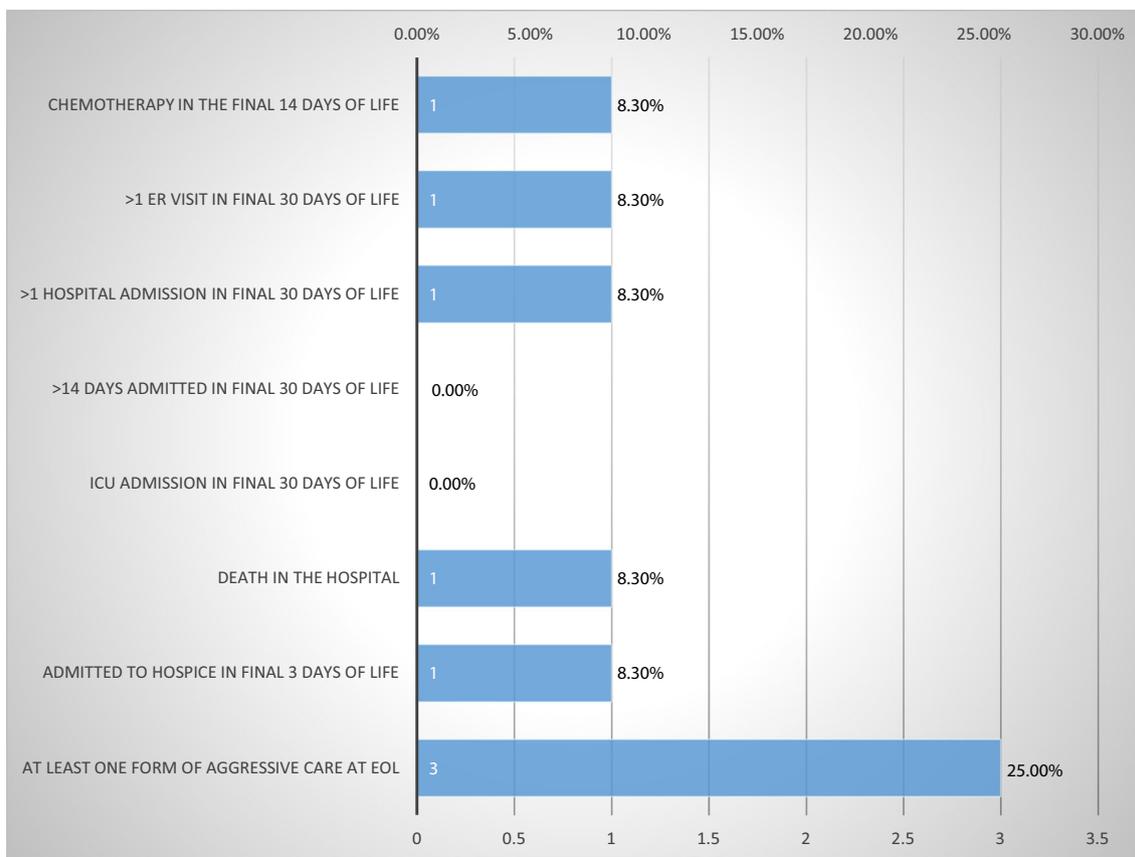


Fig. 4 Patients receiving outpatient palliative care consult undergoing aggressive medical care at the end of life

EOLC does not improve survival or patient outcomes, but rather increases hospital costs and decreases a patient's quality of life without palliating symptoms [1, 5, 6, 10]. Our data suggests that both location and timing of specialty palliative care consult can impact the care received at the end of life.

Outpatient palliative care consultation was associated with whether or not a patient received aggressive EOLC or enrolled in hospice. Among patients with an outpatient palliative care consult, 3 patients (25%) underwent aggressive EOLC and 11 (91.7%) enrolled in hospice prior to death. Comparatively, 42 patients (44%) with inpatient palliative care consults underwent aggressive EOLC and 78 (82%) enrolled in hospice prior to death. This difference is not surprising since patients who receive an inpatient palliative care consult are often very ill at the time of consultation and as a result have often already undergone aggressive EOLC prior to consultation. Although the number of outpatient palliative care consults in our cohort was small, the trend of decreased aggressive EOLC and increased hospice enrollment in patients undergoing outpatient palliative care consult suggests that location of consult may play an important role in the care received at the end of life. This finding supports other studies that have shown outpatient consultations improve patient outcomes by decreasing aggressive EOLC [14]. Additionally, patients in our study who underwent outpatient consultation were engaged in palliative care much longer than patients with inpatient palliative care consults (median 106 days vs. 33 days prior to death respectively). Admittedly, outpatient referral may inherently mean that patients are engaged in palliative care earlier and may confound the importance of outpatient vs. inpatient consultation. Despite this possible confounding, prior research demonstrates that outpatient referral, independent from timing, resulted in fewer hospitalizations, fewer hospital deaths, increased hospitalization, and decreased cost of care [15].

The importance of timing of palliative care consultation is also highlighted in our study. It is clear that palliative care consultation itself decreases aggressive EOLC and many studies have shown that patients benefit more from palliative care when referred earlier [1, 5, 8, 16]. Our study found that the median time between hospice enrollment and death was 20 days in patients with a palliative care consultation. This leaves little time for patients to benefit from symptom management and accomplish tasks such as advance care planning documentation prior to death. A clear consensus of what constitutes “early” referral has not been reached but earlier palliative care referral while patients are pursuing disease directed therapy results in decreased hospital costs, hospital deaths, rates of aggressive EOLC, and improved mental health and quality of life [1, 15, 19, 20]. One can assume that the earlier patients are referred, the more time they have to utilize the benefits of palliative care and hospice. Further investigation regarding optimal timing for

palliative care referral for gynecologic oncology patients should be undertaken.

Engaging patients and their families in dialog about advance care planning may be another way to try to match treatment plans with patient goals. Advance care planning documentation is vital in ensuring that patient's EOLC wishes are documented clearly and followed. Our study demonstrates the positive impact that palliative care consultation has on advance care planning documentation as patients who had a palliative care consultation were almost 7 times more likely to complete advance care planning documentation prior to death when compared to those without a consult (OR 6.79,  $p < 0.001$ ). While increased rates of advance care planning documentation with palliative care consultation have been demonstrated in ICU literature, no studies to date have demonstrated this type of relationship in gynecologic oncology patients [12]. Additionally, palliative care consultation is a way to increase advance care planning documentation in patients who otherwise have increased health care barriers based on race, socioeconomic status, and education [13].

Strengths of our study include having a well-established inpatient and outpatient palliative care team with clear documentation in a shared medical record. This allowed for the accurate compilation of treatment and palliative care data. Our institution is a tertiary care center and therefore has patients with a wide range of diagnoses and prognoses.

Limitations of our study include that it was a retrospective review and included data from a single institution. Additionally, our data was limited by the documentation available in the medical record. For example, there was limited documentation regarding patient and providers' attitudes toward palliative care consultation. Information regarding barriers to early referral was therefore difficult to obtain. Additionally, patients in our population are oftentimes referred for a second opinion from their local provider and therefore inherently may be seeking more aggressive care than has been recommended by another provider, thus, confounding our data and rates of aggressive EOLC. Another factor that may confound our findings is the fact that our patient population at times may require palliative surgery and an inpatient stay for a surgical issue such as a malignant bowel obstruction at the end of life. In those situations, a patient may actually benefit from a surgery and hospital stay at the end of life in order to improve their overall quality of life. This would potentially lead to an increase in hospitalizations at the end of life. In addition, given that the majority of our patients were white and had advanced ovarian or uterine cancer, our data may not be generalizable to other races and populations.

There is significant work to be done to improve end of life care among terminally ill gynecologic oncology patients. Although most patients saw palliative care providers prior to death, our data was similar to other studies in that most of the consults occurred immediately prior to death during an

inpatient hospital stay [14, 15]. This unfortunately leads to decreased utilization of outpatient palliative care resources and in turn does not provide maximum benefit to patients. It appears that the earlier the better when it comes to the benefits of palliative care consultation. One way to maximize the usefulness of palliative care consultation may be early outpatient referral to palliative care. Within our population, outpatient palliative care consultation decreased rates of aggressive EOLC, increased rates of hospice utilization, and increased rates of advance care planning documentation. This early palliative care initiation has the potential to vastly impact patient care at the end of life by encouraging that the patients' EOLC desires are addressed and followed prior to the time immediately surrounding death. Further research should examine optimal timing for palliative care consultation among terminally ill gynecologic oncology patients.

### Compliance with ethical standards

**Conflicts of interest** The authors declare that they have no conflicts of interest related to this manuscript. Dr. Karlekar is on an advisory board for Hospice Compassus.

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