End-of-Life Care Planning in Patients with Recurrent Gynecologic Cancers

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Objectives: Most women with terminal gynecologic cancers do not have do-not-resuscitate (DNR) orders upon hospital admission and many do not receive effective palliative care. Our objective was to assess quality care indicators involving end-of-life care among gynecologic oncology patients treated at our institution.
Methods: An IRB-approved, retrospective review was performed on all patients with recurrent gynecologic cancers who died between January 2009 and October 2012. Data included: rates of DNR, advance care plans, and health care power of attorneys; Hospice/Palliative Care Medicine (HPCM) involvement; intervals to death from diagnoses and DNR status; and end-of-life care. Chi-squared, Mann-Whitney and discriminate analyses were utilized.
Results: Complete data were available for 130 of 345 (37.7%) patients with cervical, uterine, ovarian, or vaginal/vulvar cancer. Eighty-three (63.8%) patients were DNR at their last hospitalization, 84 (64.6%) had HPCM involvement, and 18 (13.8%) had an advance care plan. Patients were significantly more likely to have DNR status when HPCM was involved, with a diagnosis of ovarian cancer, and as the duration of time between diagnosis and death increased ($p = 0.0001$).
Conclusions: DNR status is associated with an ovarian cancer diagnosis, HPCM involvement, and increasing time from diagnosis to death. Earlier intervention from providers or HPCM could allow for greater patient autonomy and fewer interventions at end-of-life.

Key Words: End-of-life care; Gynecologic oncology

Introduction

In the MAHEC OB/GYN Residency Program, our residents care for women with recurrent and terminal gynecologic cancers under the direction and supervision of the faculty at HOPE: Women's Cancer Center. As such, we have an obligation to provide appropriate, acceptable, patient-centered, end-of-life care for these patients. Behaviors consistent with "reduction of harm" in end-of-life care include: referring and advocating for palliative care, ensuring proper code status documentation [e.g., full vs. do not resuscitate (DNR)], ensuring that advance care plans or directives are in medical records and honored, facilitating a smooth transition into palliative care (e.g., stopping invasive testing and futile medical treatments), ensuring effective pain management,[1] and respectfully clarifying goals of care.[1-2]

Patients and oncologists do not always agree on an end-of-life care plan nor do they always agree on the goals of the care (i.e., curative vs. palliative).[1-4] Most oncology patients do not have advance care plans or directives; only 7% reported discussing advance care plans with their oncologists.[5] Most women (55%) with terminal gynecologic cancers do not have code orders upon hospital admission.[6] Many women with terminal diseases do not receive effective pain management[1] or palliative care.[1-6]

This project sought to assess specific quality care indicators with patients diagnosed with recurrent gynecologic cancers including rates of: DNR and advance directive documentation; aggressive end-of-life care post DNR order; involvement with hospice/palliative care teams; and end of life care.

Methods

An IRB-approved, retrospective chart review was performed on all patients with recurrent gynecologic cancers and terminal diagnoses who died in January 2009 through October 2012. The list of patients who died in the appropriate time frame was generated electronically from the outpatient electronic health record (EHR). We manually extracted research data points from both the outpatient and hospital EHR. Data points extracted included: patient's age; ICD9 diagnosis code; stage of cancer at diagnosis; medical interventions; characteristics of the last hospitalization – indication for admission, diagnosis, length of stay, and discharge location; date of death; place of death; documented advance care plans in the hospital EHR; DNR status at death (DNR vs. full code); the level of provider who ordered the DNR (resident, oncologist, or hospice/palliative care medicine (HPCM) physician); the person requesting the DNR [patient or healthcare power of attorney (POA)]; documented medical interventions (types and rates) after the DNR order; and HPCM involvement.

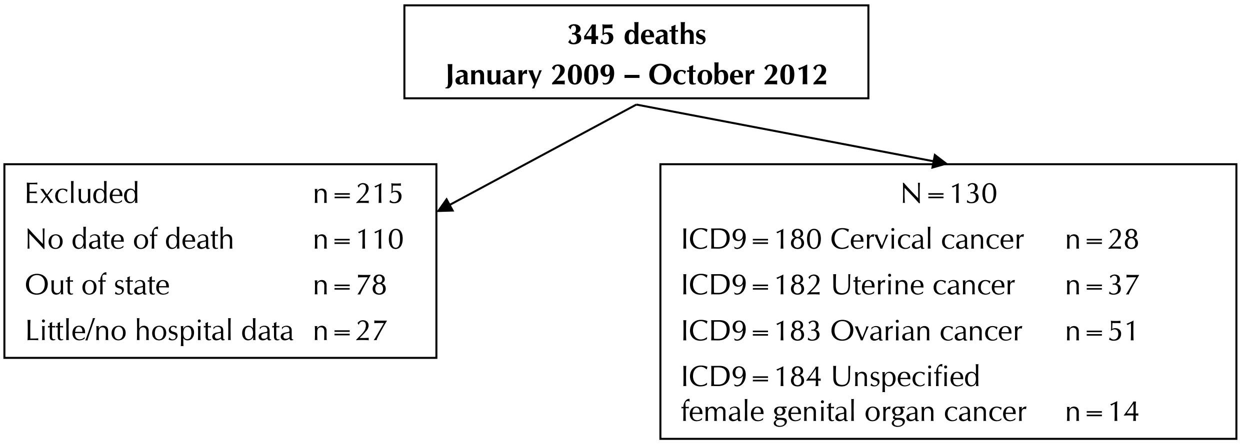
If no mention of DNR or full code was documented, we defaulted to full code. Recurrent disease status was defined by documented relapse. We categorized the indication for hospitalization as either medical care, surgical care or supportive care; we defined supportive care based on intent to transition to hospice upon admission, compared to medical care requiring medical management and surgical care requiring surgical intervention. We used documented dates of initial and terminal diagnosis, DNR status, and Hospice/Palliative Care Medicine (HPCM) involvement to calculate the intervals to death from the event and determine the type and number of medical interventions after the DNR status was decided. Number of interventions was calculated by summing the number of surgeries, radiological tests, and whether the patient had chemotherapy, radiation therapy, medical consults, ICU admissions, and resuscitation (Yes = 1, No = 0).

We use a discriminate analysis to examine predictors of DNR at time of death – specifically HPCM involvement, site of disease, documented advance care directive, number of interventions, and duration of time between diagnosis and death. Differences in significant predictors were compared between patients with versus without DNR using Chi Square for categorical variables and Mann-Whitney U test for continuous variables; a comparison of duration from DNR to death for women with post-DNR medical interventions versus those with none was calculated using the Mann-Whitney U test. All analyses were two-tailed with $p < 0.05$ as statistical significance.

Results

Complete data were available for 130 of 345 (37.7%) patients. Charts were excluded primarily due to the patient's residency outside of the state of North Carolina and/or a lack of the exact date of death, thus limiting the availability of data and the ability to calculate the intervals to death, respectively (see Figure 1).

Figure 1. Flow Diagram of Included and Excluded Charts



Characteristics of Patients’ Course of Illness and Treatment

Median age at diagnosis was 63.8 (20 – 95.5) years. Disease sites included cervix [28 (21.5%)], uterine [37 (28.5%)], ovarian [51(39.2%)], and vaginal/vulvar [14 (10.8%)]. The majority of initial diagnoses were either in stage III [75 (50%)] or IV [33 (25.4%)]. Relative to death, diagnoses occurred at a median of 1.65 (0.05-32) years.

The majority of patients had undergone radiologic studies [115 (88.5%); Median = 3 (0 – 78)] and surgery [114 (80%); Median = 1 (0 – 9)]. Likewise, a majority had undergone chemotherapy [72 (55.4%)] or chemotherapy and radiation treatment [35 (26.9%)]; 3 patients (2.3%) had undergone radiation treatment only.

Thirty patients (23.1%) had received a medical consult. Seven (5.4%) had been in the intensive care unit (ICU), but only 1 patient had undergone resuscitative efforts.

Indication for the final hospitalization was primarily for medical care [70 (53.8%)] or surgical care [19 (14.6%)]; 41 (31.5%) were admitted for supportive care. The median length of stay was 4 days (1 – 41). Nineteen (14.6%) patients died during this hospitalization; 58 (44.6%) were discharged home, 7 (5.4%) to a skilled nursing facility, and 46 (35.4%) to a hospice organization (facility, inpatient or home).

Median age at death was 65.5 (33 – 99.5) years. Place of death was available for 114 (87.7%) patients. Twenty-two women (19.3%) died in the hospital and 46 (40.3%) died in a hospice facility; 40 (35.1%) died at home, and 6 (5.3%) died in a skilled nursing facility.

Documentation of Code Status and Advance Directives

Eighty-three of the 130 patients had a DNR order at their final hospitalization (see Figure 2). DNR status was declared by 57 (68.7%) patients and 26 (31.3%) by the healthcare powers of attorney. The provider ordering the DNR was most often oncology faculty rather than residents or HPCM physicians (60.2%, 27.7%, and 12.0%, respectively). Only 18 (13.8%) patients had an advance care plan (see Figure 3).

Figure 2. Percentage of Patients By Code Status

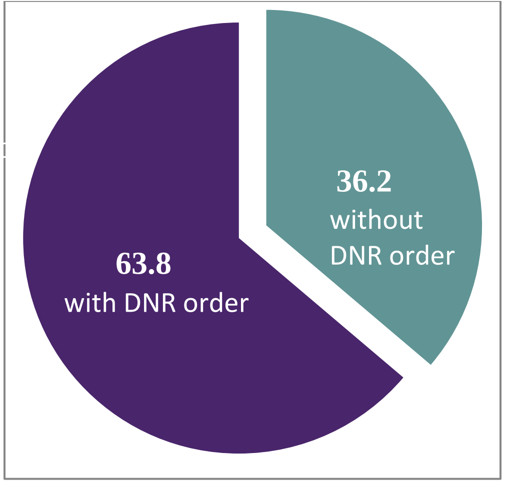
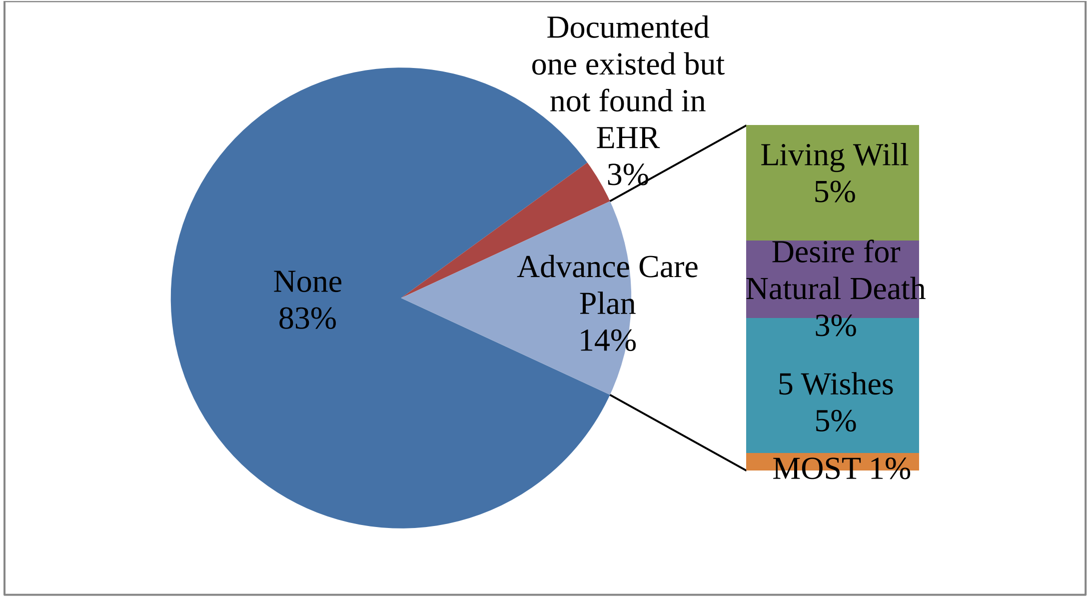


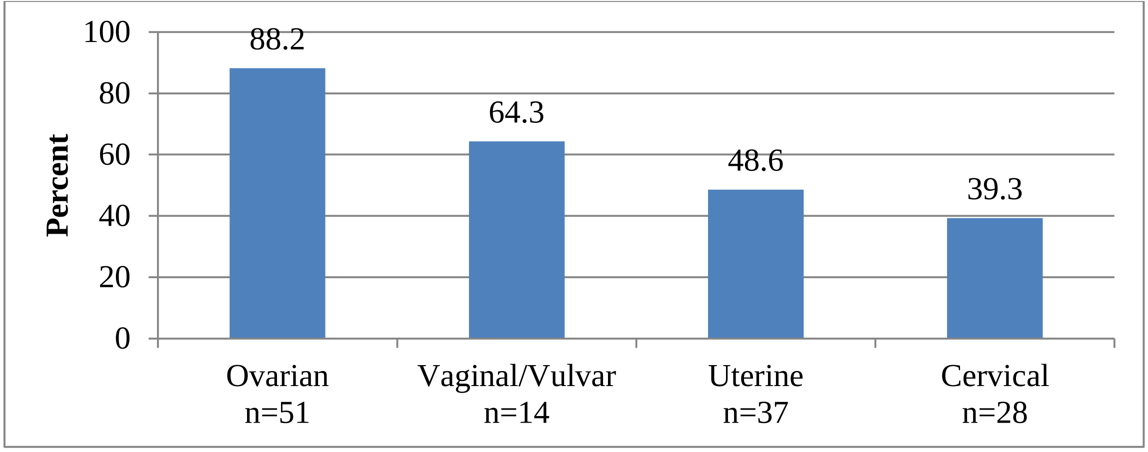
Figure 3. Rate and Type of Advance Care Plans



Predictors of DNR Status

Significant predictors of the documented DNR order during the final hospitalization included HPCM involvement, site of cancer and number of interventions (Eigenvalue = 0.606; p=0.0001). When HPCM was involved, 83.3% were DNR as compared to 28.3% without involvement (p=0.0001). Patients were also significantly more likely to have DNR status with diagnosis of ovarian cancer (p=0.0001; see Figure 4) and as the number of medical interventions increased (p=0.0001). Women with DNR had a median of 10 (0-90) interventions compared to women with full code status with a median of 3 (0 – 42).

Figure 4. Percentage of Women with DNR by Cancer Site



Post DNR Medical Interventions

For the 83 patients with a DNR, the median duration from DNR to death was 14 days (0 -308). Among these patients, 22 (26.5%) underwent some type of medical intervention *after* the date of the DNR: 18 (21.7%) had testing, 11 (13.3%) were hospitalized, and 1 (1.2%) underwent chemotherapy. There was a significantly greater duration of time from the DNR to death for women who received medical interventions post-DNR as compared to those who did not receive medical interventions post-DNR: Median = 55.6 (1 – 308) vs. Median = 11 (0 - 289), respectively (p = 0.0001).

Hospice/Palliative Care Medicine Involvement

The majority, 84 (64.6%), had HPCM involvement during their final hospitalization; the median duration from HPCM involvement to death was 22 days (0 - 391). Of the 114 women with a documented place of death, 68 (59.6%) women died with hospice care.

Discussion

The majority of the patients with recurrent, terminal gynecologic cancers treated on our service had a DNR status; DNR status was associated with ovarian cancer, HPCM involvement, and greater overall number of medical interventions over the course of the disease. Relatively few had an advance care plan. The majority of patients were involved with hospice/palliative care medicine (e.g., consultation, etc.), and 3 in 5 died under hospice care.

Though not directly comparable, our results were highly similar to those reported in recent studies. Among women with advanced ovarian disease, Brown et. al.[7] reported a 75% rate of in-hospital DNR. We reported a 63.8% rate of DNR overall and an 88.2% rate among women with terminal, recurrent ovarian cancer. We also report 64.6% had HPCM involvement. Lefkowits et al reported 53.2% of 79 women with recurrent disease were referred to palliative care.[9]

The American Society of Clinical Oncology recommends referral to palliative care early in the diagnosis of metastatic cancer.[10] We found that median involvement with HPCM was 22 days; Zakhour et al reported a median of 28 days among the 40% of their patients with terminal gynecologic cancers involved with hospice.[11] Nevadunsky et al reported only 18% of their patients with gynecologic cancers had timely involvement defined as ≥30 days with palliative care.[12] We also reported the median time from the DNR order to a patient's death was 14 days. Lopez-Acevedo et al reported a median of 29 days prior to death for any end-of-life discussion.[8]

We report an overall rate of 26.5% for post-DNR interventions. Among women with advanced ovarian cancer, Lopez-Acevedo et. al.[8] reported a non-compliance rate of 29% for any of five end-of-life quality measures, and Brown et. al.[7] reported a 50% rate of aggressive care within the last 30 days of life. We do not know what led women or their health care power of attorneys in this study to choose post-DNR interventions; the retrospective nature of the project precluded pursuing the answer to this quandary.

It is important to note that all post-DNR interventions are not inherently inappropriate; the DNR order represents a recognition that resuscitation attempts are unlikely to be effective, but if effective, likely to lead to an unacceptable level of disability. Interventions that ease the pain and suffering of a patient and meet the patient's goals are appropriate medical care regardless of DNR status. While invasive testing and futile medical treatments are inappropriate, a procedure to bypass a bowel obstruction in a woman with advance ovarian cancer so she might be well enough to attend her grandchild's wedding may be absolutely appropriate. Herein lays the complexities of end-of-life care decisions and the need for ongoing discussion.

End-of-life care discussions are difficult. Patients, their families and oncologists do not always agree on when or how to have these conversations.[1-4, 13-16] The majority of gynecologic oncologists surveyed acknowledge these conversations typically must occur over multiple sessions.[17] However, most discussions are deferred until major changes in medical status and/or functionality present – possibly minimizing the duration of time to adequately conduct the conversation prior to death.

As difficult as these conversations are, many fellows in gynecologic oncology programs report never being observed (46%) or provided feedback specific to conducting end-of-life discussions (56%).[16] It may be assumed that this training occurred during residency, as it is an educational objective included in the obstetrics and gynecology residency program curricula.[18]

In community-based programs such as ours where we do not have a gynecologic oncology fellowship, residents are presented with unique opportunities to be highly involved with end-of-life care that are not afforded to all residents. We found our residents were documenting DNR status for a small percentage of patients – about 1 in 8. It is unclear whether this is sufficient experience to feel confident and competent to conduct difficult end-of-life conversations.

Limitations

This was a small study conducted at only one site with data available for only 38% of the recorded deaths from gynecologic cancers during our study time frame; generalization of our results is thus limited. Direct comparisons with published studies were limited by variations in methodology across studies; however, when possible, our results were quite comparable. This was a retrospective review over almost four years so we had to review multiple places with the electronic medical records for data points; we may have overlooked some documentation of DNR status or advanced care plans thus underestimating our rates. We were not able to ascertain why women with specific diseases were more or less likely to be DNR rather than full code. However, the perception of illness severity has been shown to be more important to patients than the clinical characteristics of the disease itself.[13]

Conclusion

End-of-life planning and the switching from curative to palliative care, including discussing, ordering and honoring the DNR status are difficult but important components of gynecologic oncology care. Further, the requisite skills require training and competency development. While mirroring documented achievement of the end-of-life care quality indicators for women with recurrent disease, we found room for improvement. Earlier intervention from providers or HPCM could allow for greater patient autonomy and fewer inappropriate interventions at end-of-life.

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Nate Jones, MD: Project conceptualization, data extraction and interpretation, presentation and manuscript preparation
Ashley Albers, DO: Design consultation, data interpretation, and manuscript preparation
Shelley L. Galvin, MA: All aspects from project design through manuscript completion

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