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End-of-Life Care of Women with Gynecologic Malignancies - A Pilot Study

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Abstract

Objective—There is limited data regarding the end-of-life care for women with gynecologic malignancies. We set out to generate pilot data describing the care that women with gynecologic malignancies received in last six months of life. Patient demographics, patterns of care and utilization of palliative medicine consultation services were evaluated.

Methods—100 patients who died from gynecologic malignancies were identified in our institutional database. Only patients who had received treatment with a gynecologic oncologist within one year of death were included. Medical records were reviewed for relevant information. Data were abstracted from the electronic medical record and analyses were made using Students T, and Mann-Whitney testing with SPSS software.

Results—The mean age of patients was 60 years (range 30–94 years). Racial/ethnic distribution was 38% Caucasian, 34% Black, and 15% Hispanic. 75% of patients received chemotherapy within the last six months of life, 30% received chemotherapy within the last six weeks of life. The median number of days hospitalized during the last six months of life was 24 (range 0–183 days). During the last six months of life, 19% were admitted to the Intensive Care unit, 17% were intubated, 5% had terminal extubation, and 13% had cardio-pulmonary resuscitative efforts. 64% had a family meeting, 50% utilized hospice care, and 49% had palliative medicine consultations. There was a significant difference in hospice utilization when comparison was made between patients who had 14 days from consultation until death versus patients who had 14 days or no consultation, 21 (72%) versus 29 (41%), $p=0.004$. Patients who were single were less likely to have a palliative medicine consultation, $p=0.005$.

Conclusions—End-of-life care for patients with gynecologic malignancies often includes futile, aggressive treatments and invasive procedures. It is unknown whether these measures contribute to longevity or quality-of-life. These pilot data suggest that factors for implementation of timely hospice referral, family support and legacy building should include specialists trained in palliative medicine.

Keywords

Palliative medicine; gynecologic malignancies; quality-of-life; death and dying; hospice

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Introduction

Innovations to improve end-of-life care for patients with incurable solid tumors while addressing the exponentially increasing costs of cancer and end-of-life care in the United States has become a national priority¹ It has been predicted that annual direct costs from cancer care will rise from \$104 billion in 2006 to \$173 billion in 2020.² Integration of palliative care into routine oncology care is one suggested change in attitudes and practices for health care providers managing patients with cancer.³ In 2012 the American Society of Clinical Oncology put forth a consensus statement that suggested that “combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.”⁴ The consensus opinion cited seven randomized controlled trials (RCT) demonstrating improvement in symptoms, quality-of-life, patient satisfaction, reduced caregiver burden, more appropriate referral and use of hospice, reduced use of futile intensive care and other invasive care and improved survival.^{5,6,7,8,9,10,11} Additionally there are retrospective reports that timely consultation by palliative medicine experts results in decreased metrics associated with poor end-of-life care, as well as decreased cost.^{12,13}

Concerns of changing attitudes and practices are real, as we do not know how patients, physicians or payers may be affected by these changes. Additionally, negative attitudes and misunderstanding of the role and place of palliative medicine have arisen secondary to references to “death panels” during debate regarding health care legislation. Despite these concerns, no studies to date have described patient/caregiver harm or excessive cost from early palliative care involvement and management.⁴ While the evidence from RCTs integrating standard oncology practice and palliative care are promising, the applicability of these trials to general oncology practice is yet to be tested, reproduced or proven. Additionally, the optimal method of integration of palliative medicine into standard oncology care is unknown, and at the present time, less than 1% of National Institute of Health funding is directed at research in palliative medicine.¹⁴

In reviewing end-of-life care in the last decade in the United States, a significant number of cancer patients received new chemotherapy regimens, had multiple emergency department visits, and hospitalizations including intensive care admissions at the end-of-life.^{15,16} Conversely, hospice care and palliative medicine services were under-utilized, with less than 28% of patients under hospice care at the time of death.¹⁵

An obstacle to the implementation of concurrent care is that little is known regarding clinical care guidelines for consultation with palliative medicine for women with gynecologic malignancies. The Society of Gynecologic Oncology (SGO), the parent organization for gynecologic oncologists in the US, has recently organized a Palliative Medicine Network to provide resources and educational programs to SGO members in recognition of this void. Much remains to be learned regarding the optimal treatment planning and protocols of care for these cancer patients at the end-of-life. To date there has been no standardized assessment of end-of-life care for racially and ethnically diverse women with gynecologic malignancies. The purpose of this study was to generate pilot data describing the last six months of life in women with gynecologic malignancies in a racially and ethnically diverse population. This study is designed to describe both palliative and aggressive metrics for women with gynecologic malignancies at the end-of-life at our institution.

Methods

Montefiore Medical Center is the largest hospital center in the Bronx, which has about 1.4 million persons, and is the poorest urban county in the United States. It is a 1,062 bed, urban community academic medical center. Over 27% of Bronx residents have incomes below the poverty level and 32% of the Bronx population is foreign born. Montefiore Medical Center provides medical care to a highly diverse population: 48% of its patients are identified as Latino/Hispanic, 31% as African American. English is the second language for more than half of all the inhabitants of the Bronx.

The Montefiore Medical Center Palliative Care Service was established in 2000 and currently provides care to nearly 40% of the adult patients who die at Montefiore Medical Center each year. This compares with the national norm of 13%.¹⁵ On average, there are 1800 new in-patient consultations, more than 600 in-patient unit admissions and 2000 outpatient clinic visits to the palliative care service each year. Palliative medicine at Montefiore Medical Center has developed an integrated model of care with Critical Care Medicine and Emergency Medicine.^{17,18,19}

After IRB approval, the last 100 patients who died from their primary gynecologic malignancies were identified from a comprehensive clinical database of all patients at Montefiore Medical Center. Charts were reviewed and the pathology was verified utilizing central pathology documentation. Abstracted data included patient demographics, disease status, clinical status and findings, interventions and outcomes. Data regarding the patient's date of death were abstracted from the electronic medical record as well as the on-line social security database records. Results were described and comparisons between the groups were made using chi-square, Student's T and Mann-Whitney analysis with SPSS software.

Results

Patient characteristics

Dates of patient death ranged from 6/5/2005 until 2/7/2010. Forty-nine patients had consultation with palliative medicine. There were no differences in age, race, cancer site, stage, grade or insurance carrier between patients who received palliative medicine consultation and those who did not. Table 1. There was a significant difference if the patient was not in a committed relationship (single, divorced, widowed) versus married. 38% of patients not in a committed relationship had palliative medicine consultations versus 70% of women who were married, $p < 0.005$.

Palliative consultation characteristics

The majority of consultations occurred during the last hospitalization, $n=37$ (76%). Twenty-nine patients had consultation 14 days or more before death. The median number of days from consultation to death was 16 (range 0–159 days). A minority of patients were seen less than 100 days from initial diagnosis, 6 (12%). There were no differences in the distribution of consultations amongst the referring physicians.

Aggressive Measures at the end of life

The median number of days spent in the hospital during the last six months of life was 24 (range 3–183). Thirty percent of patients had an emergency room visit and 21% of patients were admitted to the ICU. Five percent had a terminal extubation and 13% had cardiopulmonary measures performed at the end of life. Seventy-six percent of patients received chemotherapy during the last six months of life, and 30% of patients received chemotherapy during the last six weeks of life. Of the patients who received chemotherapy

within the last six months of life, 46% had uterine cancer, 26% had ovarian cancer, and 20% had cervical cancer. Of the patients who received chemotherapy within the last six weeks of life, 40% had uterine cancer, 30% had ovarian cancer and 21% had cervical cancer. The range of days from the last chemotherapy until death was from 1 day until 2280 days, median 71 days. Only thirteen patients died within 21 days of receiving chemotherapy. Forty percent of patients who received chemotherapy within 6 weeks of death and 43% of percent of patients who received chemotherapy within 6 months of death had prior exposure to 3 or more regimens of chemotherapy. Only 14 patients (18%), who received chemotherapy in the last six months were diagnosed with primary disease within the last six months of life, and 2 (5%) of patients who received chemotherapy within the last 6 weeks of life were diagnosed in the last 6 weeks of life. Sixteen patients (21%) who received chemotherapy within the last six months of life were given chemotherapeutic agents as part of a Phase I trial. Thirteen percent of patients who received chemotherapy within the last six weeks of life were participants in a Phase I trial. There was no difference in median inpatient days, emergency room admissions, intensive care admissions, terminal extubation, cardiopulmonary resuscitation and chemotherapy administration between patients who had a palliative medicine consultation and those who did not. Table 3.

Palliative Measures at the end of life

Sixty-six percent of patients were DNR/DNI, 49% enrolled in hospice (median 16 days, range 0–149 days), and 64% had a family meeting. Comparison of all patients with (n=49) and without palliative medicine consultation (n=51) showed no difference in palliative measures at the end of life including, DNR/DNI, hospice utilization, family meetings or place of death. However, subgroup analysis of those with timely palliative medicine consultation (> 14days) showed a significant increase in hospice enrollment 72% versus 41%, $p=0.004$. There was also a decrease in the number of patients who had hospice for less than three days, 7% for patients with timely consultation versus 14% for those without, $p=0.05$. Table 4

Place of death included 38% hospice, 35% hospital, 10% home, and 6% intensive care unit or emergency room. There was a non-significant trend toward death at home 21% versus 6% for patients who had consultation > 14 days versus those who did not. Additionally, there was a trend for decreased hospital deaths for patients with timely consultation 21% versus 41%.

Discussion

There is a paucity of data regarding the optimal timing for palliative medicine consultation. A longer time from referral to palliative medicine, or to enrollment in hospice has been used as a metric for measuring the quality of care at the end-of-life. In this retrospective report of data collected before the ASCO statement regarding the importance of concurrent standard oncology care and palliative care, the median of 16 days, suggests that there may be an opportunity to offer more timely consultation. The finding that the majority of patients had consultation more than 100 days after diagnosis, does not allow aggressive disease processes as an explanation for the short time period between consultation and death.

In a recent publication by Fauci et al., 70.5% of gynecologic oncology patients at the end-of-life were referred for hospice or palliative care and the median number days from hospice enrollment until death was 22 days.²² Table 5. However, the authors do not differentiate discreet time periods for consultation to palliative medicine versus hospice referral. Most publications reporting this metric do not differentiate time to referral to palliative medicine versus hospice, and this reporting methodology may speak to a misunderstanding of oncologists as to the differences between palliative medicine and hospice.

If time to hospice referral is used as a surrogate measure for referral to palliative care, median published days range from 4–24 days.^{11,22,23} A published abstract including only consultation to palliative medicine for women with gynecologic malignancies found the median number of days from consultation until death (for those patients who died) was 46 days.²⁴ While the median length of time from consultation until death at our institution falls within the ranges reported for hospice/palliative consultations at other institutions, further research regarding symptom burden, quality of life, and families experience of their loved one's death would further inform the recommended time for optimal consultation.

The finding that more consultations were made for patients who were married may indicate an increased need for supportive care at the end of life for family members, in particular spouses, of patient's dying from gynecologic malignancies. Further research into the subjective experience of these family members of the death of their spouse, and the impact of palliative medicine consultation may help gynecologic oncologists provide better bereavement care for families.

There were no differences in aggressiveness of care between patients who had palliative medicine consultation and those who did not, even after control for exposure time (i.e. 14 days) in the metrics used for evaluation by this study. Seventy-six percent of patients received chemotherapy in the last six months of life, which is similar to 82% and 64% reported by Von Gruenigen et. al. and Fauci et. al.^{22,23} Table 5. Similarly, previous reports account for 24% and 29% of patients with gynecologic malignancies receiving chemotherapy in the last six weeks of life. However, reports from national databases show that in other disease sites only 14% of patients received chemotherapy in the last 6 weeks of life.¹⁵ The high proportion of women receiving chemotherapy at the end of life may be related to the treatment patterns of some gynecologic malignancies, such as ovarian cancer, as "chronic" entity with some expectation of clinical or symptomatic response, and the use of multiple agents as potential "maintenance therapy". Almost half of the women in our study had three or more prior chemotherapy regimens. In the group receiving chemotherapy within the last 6 weeks forty-three percent of deaths occurring within 21 days of chemotherapy, may be attributed to complications of the chemotherapy, such as neutropenic sepsis. Unfortunately, the high rate of chemotherapy use at the end of life cannot be attributed to participation in Phase I (16%) clinical trials, and this may represent an area for future research and development of clinical guidelines.

There were no differences in our study between palliative measures for patients who had consultation and those who did not. However, when we accounted for adequate exposure as 14 days, per previously published reports, there was a significant difference in hospice utilization. In comparison to reports by Earle et al. and Von Gruenigen et al., the hospice utilization by our group, 45% was higher.^{15,23} Table 5. Despite the reported utilization of hospice by 50% of our patients, very few patients died in the home, 10%. In comparison, Fauci et. al., reported 60% of patients studied died in the home.²² We hypothesize that this disparity may be related to low resources for management of the dying patient at home in the impoverished, urban environment of the Bronx.

Shortcomings of our study include retrospective chart collection from a single institution. Additionally, these data reflect practices at our institution from 2005–2010, and current practices may be different.

Conclusions

Women with gynecologic malignancies undergo a multitude of aggressive interventions at the end of life, without evidence of increased longevity or improved quality-of-life. There

are difficulties in assessing the impact of palliative medicine consultation for these patients that may be related to exposure time. When there was adequate time for exposure, we reported improved hospice utilization, a recognized metric of quality end of life care. However, despite improved hospice utilization our patients often died in institutionalized settings and not at home. Our findings suggest that future research should focus on end of life care for racial/ethnically diverse women with gynecologic malignancies. We suggest that future research focus on current health care provider practice patterns and understanding of end-of-life care, palliative medicine and hospice, through surveys disseminated by nationally and internationally based societies. Additionally, research regarding the impact and role of end-of-life care as a core competency of oncology trainee curriculums may improve future hospice and palliative medicine utilization. Finally, prospective data from patient and families experiences of quality-of-life and bereavement is critical to addressing best practices and metrics for the clinical standard of care at the end-of-life.

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Table 1

Patient Characteristics

Patient Characteristics	Total Patient Cohort (N=100)	Palliative Medicine Consultation (N=49)	No Palliative Medicine Consultation (N=51)	P
Mean age at death (range)	63.5 +/- 12.3 (30-94)	60.98 +/- 11.8 (30-84)	65.8 +/- 12.4 (37-94)	
Physician				
1	44	22	22	
2	21	9	12	
3	10	4	6	
4	8	6	2	
5	17	8	9	
Disease Site				
Cervix	19	11	8	
Ovary	30	13	17	
Uterus	42	19	23	
Other	9	6	3	
Stage				
1	9	4	5	
2	15	9	6	
3	32	16	16	
4	21	8	13	
Recurrent	10	4	6	
Unknown	13	8	5	
Race				
Black	34	23	16	
Hispanic	14	3	6	
White	39	17	22	
Other	13	6	7	
Marital Status				0.02
Married	33	23	10	
Single	36	17	19	
Divorced	10	3	7	
Widowed	17	4	13	
Unknown	4	2	2	
Insurance Status				
Medicare/Medicaid	47	19	28	
Private Insurance	49	27	22	

Table 2

Characteristics of consultation

Days from Diagnosis to Consultation	
Median (range)	666 (24–5,718)
>1000 days	14 (29%)
>100–1000 days	29 (59%)
10–100 days	6 (12%)
<10 days	0 (0%)
Days from Consultation to Death	
Median (range)	16 (0–159)
>60 days	10 (20%)
>30–60 days	8 (16%)
10–30 days	12 (25%)
>1–10 days	14 (29%)
1 day	5 (10%)

Table 3

Metrics of aggressive end of life care

	All Patients (N=100)	Palliative Care (N=49)	No Palliative Care (N=51)	Adjusted Palliative Care (N=29)*	Adjusted No Palliative Care (N=71)**
Hospital Admissions in the last 6 months of life	2732 (1-7)	1473 (1-7)	1262 (1-7)	883 (1-7)	1852 (1-7)
Median number of Days in Hospital (range)	24 (3-183)	29 (5-183)	17 (3-80)	29 (5-186)	21 (3-80)
Median Number of Days in Final Hospital Admission (range)	8 (1-147)	10 (1-147)	6.5 (1-41)	12 (3-147)	7 (1-41)
ER visits in the last 6 months	30	16 (33)	14 (27)	6 (21)	22 (31)
ICU Admissions in the last 6 months	19	10 (20)	9 (18)	5 (17)	14 (20)
Median Number of Days in ICU (Range)	0 (0-18)	0 (0-18)	0 (0-17)	0 (0-18)	0 (0-17)
Chemotherapy in the last 6 months	76	39 (80)	37 (73)	21 (72)	55 (77)
Chemotherapy in last 6 weeks	30	14 (29)	16 (31)	6 (21)	24 (34)
Terminal Extubation	5	3 (6)	2 (4)	1 (3)	4 (6)
Cardiopulmonary resuscitation	13	5 (10)	8 (16)	3 (10)	10 (14)

* Patients with 14 days of palliative care

** Patients with <14 days of palliative care

Table 4

Metrics of palliative measures at the end of life care

	All Patients (N=100)	Palliative Care (N=49)	No Palliative Care (N=51)	Adjusted Palliative Care (N=29)	Adjusted No Palliative Care (N=71)**	P
DNR/DNI	66	36 (73)	32 (63)	20 (69)	48 (54)	
Hospice	50	28 (57)	22 (43)	21 (72)	29(41)	0.004
Median hospice days (range)	16 (0–149)	31 (0–149)	17 (1–113)	20 (0–113)	7 (0–149)	
Hospice < 3 days	12	8 (16)	4 (8)	2 (7)	10 (14)	0.05
Family Meeting	64	35 (71)	29 (57)	16 (55)	48 (68)	
Place of Death						
Hospital	35	18 (37)	17 (30)	6 (21)	29 (41)	
Hospice	38	20 (41)	18 (35)	12 (41)	26 (37)	
Home	10	4 (8)	6 (12)	6 (21)	4 (6)	
Unknown	11	4 (8)	7 (14)	3 (10)	8 (11)	
ICU	4	2 (4)	2 (4)	1 (3)	1 (1)	
ER	2	1 (2)	1 (2)	1 (3)	3 (4)	

* Patients with 14 days of palliative care

** Patients with <14 days of palliative care

Table 5
Comparison of metrics of palliative and aggressive care at the end of life reported in literature.

Metric	SEER/CMS Earle et al.	MGH Temel et. al.	Case Western Von Gruenigen et. al.	University of Alabama Faucit et. al.	Montefiore Medical Center
Disease site	Breast, colorectal, lung gastrointestinal	Metastatic lung cancer	Ovarian cancer	Gynecologic malignancies	Gynecologic malignancies
Chemo 6–8 months of death			82%	64%	75%
Chemo 2–6 weeks of death	14%		24%		29%
Duration of hospice		11 days 4 days	24 days (1–180)	22 days	16 days (1–149)
Hospice Utilization	28%		21%		45%
DNR/DNI			26%		64%