



A Letter to Your Care Providers: Implementation and Analysis of a Letter-based Advance Care Planning Initiative for Gynecologic Oncology Patients

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Abstract

To determine the impact of a letter-based advance care planning (ACP) healthcare improvement (HI) initiative on rates of ACP conversations and documentation among gynecologic oncology (GO) inpatients. An HI initiative was implemented from January to December 2020 to improve ACP documentation among GO inpatients. Patients admitted to the GO service were given ACP packets with a letter-based ACP worksheet. GO inpatients who were interested in learning more about ACP were visited by medical students trained to lead ACP conversations. ACP documentation rates in the EMR (electronic medical record) pre- and post-intervention were evaluated. Descriptive statistics were calculated. Associations between sociodemographic characteristics and ACP documentation were analyzed using logistic regression. There were 172 patients admitted in 2019 (pre-implementation cohort). Of these, 45/172 patients (26%) had an advance directive (AD) documented in their electronic medical record (EMR). Following the implementation of the ACP HI in 2020, 55/168 patients (33%) had an AD documented in their EMR. This was a 7% absolute increase and 27% relative increase from pre-intervention AD documentation rates. Increasing age was associated with an increased likelihood of having an AD in the chart ($p=0.004$). Married women were less likely to have an AD in their chart ($p=0.05$). An HI utilizing a letter-based ACP packet given to GO inpatients improved AD documentation in the EMR. This HI offers a unique method for introducing ACP to patients. More work is needed to improve the occurrence and documentation of ACP conversations.

Keywords Advance care planning · Advance directives · Gynecologic cancer · Gynecologic oncology · Cancer · Palliative care

Introduction

Advance care planning is an ongoing, reflective process that allows patients to share their personal values regarding end-of-life care with their caregivers. Advance care planning encompasses a variety of end-of-life care topics including discussions regarding goals of care, resuscitation/life support preferences, palliative care, hospice, and identification of surrogate decision-makers [1]. Advance care planning initiatives have been shown to increase concordance between patient preferences for care and delivered care [2], decrease cost of care at the end of life [3], and decrease utilization of intensive medical care at the end of life [4]. As a result, the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN) recommend that standard care for patients with advanced

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cancer includes advance care planning discussions early in a patient's disease course [5, 6].

Many patients with gynecologic malignancies are ultimately diagnosed with a terminal illness and as a result must navigate end-of-life care topics with their caregivers. Prior research evaluating end-of-life care among gynecologic oncology patients at our institution demonstrated that over 40% of gynecologic oncology patients experienced aggressive end-of-life care and up to 50% did not have advance care planning documents in their electronic medical record (EMR) at the time of death [7]. This is similar to rates experienced at other institutions [7]. Given the impact these discussions can have on both the individual patient and on the overarching utilization of healthcare resources, we identified a need to improve advance care planning discussion and documentation among gynecologic oncology patients at our institution.

To address this need, we designed and implemented a year-long healthcare improvement initiative to increase advance care planning discussions and documentation in the gynecologic oncology patient population at our institution using a letter-based advance care planning packet. The primary aim of this healthcare improvement initiative was to improve advance care planning documentation in the EMR from our baseline. Secondary aims were encouraging patients to discuss advance care planning with their physicians and their family members or other loved ones. Our hypothesis was that this advance care planning initiative would be associated with an increase in advance care planning documentation among our patients.

Methods

This health care improvement initiative study was approved as exempt by our Institutional Review Board (IRB). This manuscript has been prepared in accordance with the Standards for Reporting Implementation Studies (StaRI) guidelines [8], and the Institute for Healthcare Improvement's (IHI) methodology of Plan, Do, Study, Act (PDSA) cycles were used for the development and analysis of this HI intervention [9].

Context/Intervention

Our institution is a tertiary care academic medical center. A multidisciplinary team within the Division of Gynecologic Oncology was assembled including gynecologic oncologists, medical students, a palliative care physician, a research data analyst, and a nurse practitioner (NP). This team conducted both the pre-intervention review of pertinent data and the design and implementation of the healthcare improvement initiative. This team developed the following intervention.

1. Patients admitted to the gynecologic oncology inpatient service from January 2020 to December 2020 who did not have an advance directive documented in their EMR were approached by an inpatient NP (RRL) and given an advance care planning packet. An effort was made to give every admitted patient an advance care planning packet, but due to limitations in staffing on weekends, COVID restrictions, and patients' preferences (patients could decline the packet), not all eligible patients received a packet. Advance care planning packets included an official Tennessee advance care planning document and a letter-based advance directive worksheet that was modified with permission from the Stanford University Department of Medicine's Letter Project [10]. This advance care planning worksheet was included because prior studies have shown that the letter-based format of this worksheet is preferred by patients over traditional advance directives because patients find these worksheets easier to read and understand. Patients also feel that these worksheets more accurately reflect what matters most to them when compared to traditional advance directives [11]. These encounters were intended to happen on the day of admission or the following day.
2. After receiving an advance care planning packet, patients were invited to participate in one-on-one follow-up discussions with a student team member trained to lead advance care planning discussions. These conversations were not intended to occur at a specific time during the hospital stay but instead were based on patient preference. They lasted anywhere from 30 min to an hour and involved the student team member walking the patient through the letter-based advance directive worksheet and answering any related questions. Unfortunately, from March to September 2020, students were unavailable to facilitate in-person advance care planning conversations due to COVID-19 restrictions. Student team members participated in advance care planning training including a 90-min orientation session and multiple faculty-mentored interactions with admitted patients where students led advance care planning discussions utilizing the letter-based advance directive worksheet. The orientation included an overview of advance care planning and its role in the clinical environment and an introduction to the letter-based advance directive worksheet. Students then participated in role play activities wherein each student administered the letter-based advance directive worksheet to a partner under faculty supervision. After the orientation, students participated in faculty-supervised interactions in the inpatient palliative care setting during which they were able to independently lead advance care planning discussions with patients by guiding them through the letter-based advance directive worksheet.

- After completion of the advance care planning packet, the documents were scanned into the EMR with patient permission.

The healthcare improvement initiative was approved by the faculty in the Division of Gynecologic Oncology in December of 2019, and notification of the intervention was provided to all gynecologic oncology team members during a divisional meeting. Updates regarding compliance were discussed at quarterly divisional meetings as indicated.

Outcome/Analysis

Pre-implementation data was retrospectively collected on all gynecologic oncology patients admitted to our institution from January to December 2019. Data for the post-implementation period from January to December 2020 was collected prospectively. The pre-intervention time period was chosen as it marked the period prior to the initiation of discussions regarding the importance of improving advance directive documentation in the EMR within our division and the formation of a research group to improve divisional documentation of advance directives in the EMR. The post-intervention period was chosen to begin after the completion of educational outreach to the division.

All patients admitted to the gynecologic oncology inpatient service who were ≥ 18 years of age and were fluent in English were included in this study. We obtained demographic data including age, race, oncologic history including type of cancer and stage, education level, and comfort completing medical forms as listed in the EMR.

The primary outcome of this healthcare improvement intervention was the presence of an advance directive in the EMR. An advance directive was defined as the presence of a living will, medical power of attorney, code status order, or physician orders for scope of treatment (POST/POLST form). This outcome was assessed by retrospective analysis of the presence of an advance directive in the code status and advance care planning section of patients' EMRs. Our aim was to improve advance directive documentation from our baseline over a one-year period. Process measures included (1) percentage of distribution of advance care planning packets to eligible patients and (2) percentage of follow-up conversations with patients who desired them. Outcome and process measures were collected and managed using HIPAA-compliant interfaces including Box and Research Electronic Data Capture (REDCap) hosted at Vanderbilt University Medical Center. REDCap is a secure, web-based software platform designed to support data capture for research studies, providing (1) an intuitive interface for validated data capture, (2) audit trails for tracking data manipulation and export procedures, (3) automated export procedures for seamless data downloads to common

statistical packages, and (4) procedures for data integration and interoperability with external sources [12, 13].

IBM SPSS Statistics 27 was used for statistical analyses. Descriptive statistics were calculated. Multivariate logistic regressions were completed within the pre- and post-intervention cohorts to assess sociodemographic factors that may impact the presence of an advance directive in the EMR. The dependent variable for the regressions was the presence of an advance directive in the EMR (Y/N). Independent variables included categorical variables of cancer diagnosis (Y/N), married (Y/N), uninsured (Y/N), education of college level or above (Y/N), and white race (Y/N).

Results

Baseline

Prior to the implementation of this healthcare improvement initiative, 45 out of the 172 unique patients (26%) who were admitted to the gynecologic oncology service at our institution between January and December 2019 had an advance directive documented in their EMR. Demographic information for all admitted patients is summarized in Table 1, and oncologic characteristics of patients with cancer diagnoses are summarized in Table 2.

Post-intervention

Following the implementation of our healthcare improvement initiative, we identified 168 unique patients who were admitted to the gynecologic oncology service at our institution between January and December 2020. The median age of inpatients was 57 years old (IQR 44–66 years old). Most patients identified as white ($N=139$, 83%) and not Hispanic, Latino/a, or Spanish origin ($N=157$, 94%), and the majority of patients had a cancer diagnosis ($N=117$, 70%). Demographic information for all admitted patients is summarized in Table 1. Oncologic characteristics are summarized in Table 2. Demographic and oncologic characteristics were similar between baseline (2019) and post-intervention (2020) patients.

Of the 168 patients who were admitted in 2020, 34/168 (20%) had an AD in their chart at the time of initial admission and did not receive the study intervention; 102/168 (61%) had no advance directive in their EMR prior to admission and received an advance care planning packet during their admission. Please note that some patients did not have an AD in their EMR and did not receive a packet due to patients declining a packet or due to service constraints that limited packet distribution. Of those 102 patients who received an advance care planning packet, 21/102 (21%) uploaded an advance care planning document into their chart

Table 1 Patient demographics and clinical characteristics

	Baseline (<i>N</i> = 172)	Post-intervention (<i>N</i> = 168)
Age in years, median (IQR)	58 (44–67)	57 (44–66)
Race, <i>N</i> (%)		
White	134 (78%)	139 (83%)
Black	25 (15%)	25 (15%)
Asian	6 (3%)	1 (<1%)
Other/unknown	7 (4%)	3 (2%)
Ethnicity, <i>N</i> (%)		
Non-Hispanic	160 (93%)	157 (94%)
Hispanic	11 (6%)	10 (6%)
Unknown	1 (<1%)	1 (<1%)
Insurance status, <i>N</i> (%)		
Private	60 (35%)	62 (37%)
Medicare	57 (33%)	62 (37%)
Medicaid or pending Medicaid	27 (16%)	25 (15%)
Other governmental	17 (10%)	12 (7%)
Uninsured	11 (6%)	7 (4%)
Education, <i>N</i> (%)*		
Advanced degree	10 (6%)	9 (5%)
Completed or some college	82 (48%)	68 (40%)
Completed or some high school	54 (31%)	52 (31%)
Less than or equal to 8th grade	7 (4%)	3 (2%)
Other/unknown	12 (7%)	13 (8%)
Marital status, <i>N</i> (%)		
Single	40 (23%)	39 (23%)
Married	84 (49%)	83 (49%)
Significant other	4 (2%)	1 (<1%)
Divorced	21 (2%)	22 (13%)
Widowed	22 (13%)	21 (13%)
Legally separated	1 (<1%)	1 (<1%)
Other	0 (0%)	1 (<1%)
Cancer diagnosis, <i>N</i> (%)		
Yes	119 (69%)	117 (70%)
No	53 (31%)	51 (30%)
Advance care plan in EMR, <i>N</i> (%)		
Yes	45 (26%)	55 (33%)
No	127 (74%)	113 (67%)
Type of advance care plan, <i>N</i> (%)**		
Living will	27 (16%)	27 (16%)
Power of attorney	31 (18%)	31 (19%)
POLST or POST form	18 (10%)	15 (9%)
DNR/DNI code status	23 (13%)	22 (13%)

*Missing education level for 7 baseline patients and 23 post-intervention patients

**Some patients had more than one type of advanced care plan

IQR, interquartile range

Table 2 Patient oncologic characteristics

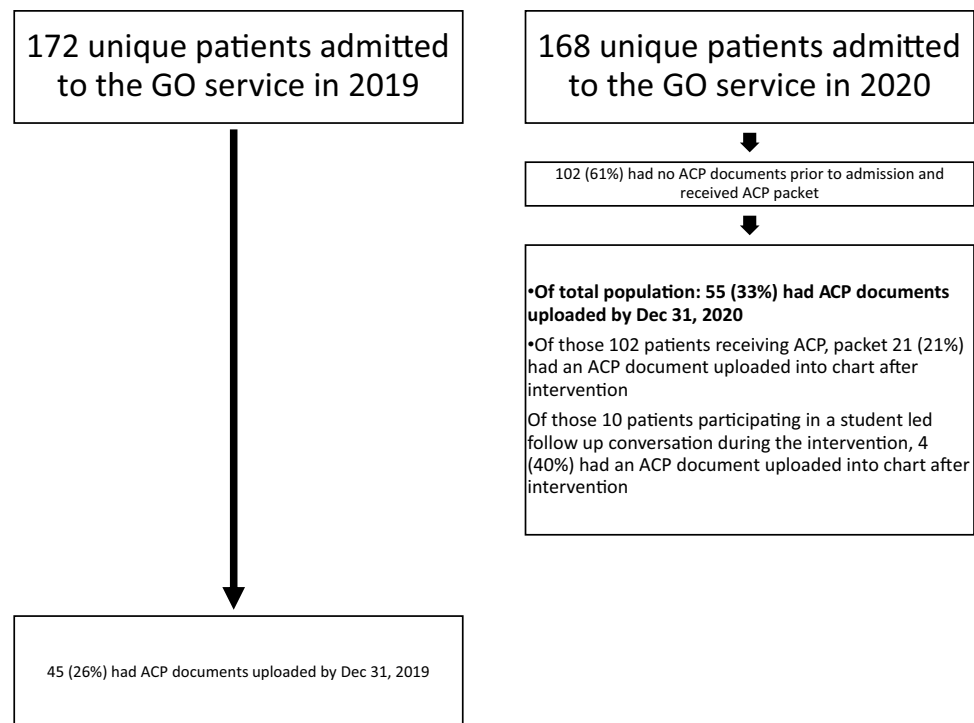
	Baseline (<i>N</i> = 119)	Post-intervention (<i>N</i> = 117)
Primary cancer site, <i>N</i> (%)		
Cervical	20 (17%)	19 (16%)
Uterine	32 (27%)	34 (29%)
Ovarian*	54 (45%)	51 (44%)
Gestational trophoblastic neoplasm	2 (2%)	3 (3%)
Vaginal/vulvar	9 (7%)	7 (6%)
Non-GYN cancer	3 (3%)	5 (4%)
Other/unknown	2 (2%)	4 (3%)
Cancer stage, <i>N</i> (%)		
Stage I	28 (24%)	25 (21%)
Stage II	18 (15%)	14 (12%)
Stage III	38 (32%)	42 (36%)
Stage IV	27 (23%)	27 (23%)
Unknown	8 (7%)	9 (8%)
Advance care plan in EMR, <i>N</i> (%)		
Yes	40 (34%)	44 (38%)
No	79 (66%)	71 (61%)
Type of advance care plan, <i>N</i> (%)**		
Living will	24 (20%)	21 (18%)
Power of attorney	27 (23%)	24 (21%)
POLST or POST form	17 (14%)	13 (11%)
DNR/DNI code status	23 (19%)	19 (16%)

*Ovarian cancer includes individuals with primary peritoneal and fallopian tube cancer

**Some patients had more than one type of advanced care plan

ACP, advance care plan; DNR, do not resuscitate; DNI, do not intubate; EMR, electronic medical record; POLST, Physician Orders for Life-Sustaining Treatment; POST, Physician Orders for Scope of Treatment

after the intervention. See Fig. 1. Due to COVID constraints, a limited number of patients (10/102) were able to participate in advance care planning conversations with students after receipt of the initial advance care planning packet. Eleven patients in total requested this conversation. Of those patients who had extended conversations with students, 4/10 (40%) uploaded an advance care planning document into their chart after the intervention. See Fig. 1. In total, fifty-five patients (33%) out of the 168 unique patients admitted during 2020 had an advance directive documented in their EMR. This number included both patients who already had ADs in their chart and did not undergo the intervention ($n = 34$) and those patients who received the intervention and subsequently uploaded an AD in their chart ($n = 21$). This reflected an absolute increase of 7% and a relative increase of 27% in advance directive documentation among our

Fig. 1 Advance care plan intervention and documentation rates

patient population when compared to the year 2019 (26% rate of completion in 2019 and 33% rate of completion in 2020). See Table 1 for details regarding the types of advance directives.

Multivariate logistic regression was performed to ascertain the effects of age, race, marital status, insurance status, education, and cancer diagnosis on the likelihood that patients had an advance directive documented in their EMR. Increasing age was associated with an increased likelihood of having advance directive documentation (OR 1.04; 95% CI [1.013, 1.068]). Married women were less likely to have an advance directive (OR 0.48; 95% CI [0.24, 0.997]). Race, insurance status, education level, and cancer diagnosis were not associated with advance directive completion rates.

Subgroup Analysis

A subgroup analysis was then performed for patients who had a confirmed diagnosis of gynecologic cancer. Prior to the implementation of this healthcare improvement initiative, 40 out of the 119 unique cancer patients (34%) who were admitted to the gynecologic oncology service at our institution between January and December 2019 had an advance directive documented in their EMR. In 2020, the year of our healthcare improvement initiative implementation, there were 117 unique patients admitted to the gynecologic oncology service at our institution who had confirmed diagnoses of gynecologic cancer ($N=117$). The median age of these patients was 62 years (IQR 51–69 years). Most

patients identified as white ($N=94$, 80%) and not Hispanic, Latino/a, or Spanish origin ($N=108$, 92%). The most common cancer types were ovarian ($N=44$, 38%), uterine ($N=34$, 29%), and cervical ($N=19$, 16%). Most patients had advanced stage disease ($N=69$, 59%).

Of the 117 patients with gynecologic malignancies who were admitted in 2020, 31/117 (26%) had an AD in their chart at the time of initial admission and did not receive the study intervention; 61/117 (52%) had no advance directive in their EMR prior to admission and received an advance care planning packet during their admission. Please note that some patients did not have an AD in their EMR and did not receive a packet due to patients declining a packet or due to service constraints that limited packet distribution. Of those 61 patients who received an advance care planning packet, 15/61 (25%) uploaded an advance care planning document into their chart after the intervention. In total, 46 patients (39%) out of the 117 unique cancer patients admitted during 2020 had an advance directive documented in their EMR. This number included both patients who already had ADs in their chart and did not undergo the intervention ($n=31$) and those patients who received the intervention and subsequently uploaded an AD into their chart ($n=15$). Among cancer patients, this reflected an absolute increase of 5% and a relative increase of 15% in advance directive documentation among our cancer patient population when compared to the year 2019 (34% rate of completion in 2019 and 39% rate of completion in 2020). The types of advance directives are listed in Table 2. Multivariate logistic regression within this

subgroup again revealed that increasing age was associated with an increased likelihood of having an advance directive (OR 1.05; 95% CI [1.01–1.08]) and there was a trend toward married women being less likely to have an advance directive (OR 0.47; 95% CI [0.21,1.06]). Again, race, insurance status, education level, and cancer diagnosis were not associated with advance directive completion rates.

Discussion

The usage of a letter-based advance care planning packet improved advance directive documentation in the EMR among patients admitted to our gynecologic oncology service. Within our entire population, we noted a 7% absolute increase and 27% relative increase in advance directive documentation after our health improvement intervention. Twenty-one percent of those patients who received the advance care planning packet during their admission went on to upload an advance directive to their EMR after admission. This rate was 25% among our cancer patient population. This health improvement intervention was easy to implement and provides the foundation for a protocol to encourage discussion of EOLC topics among admitted gynecologic oncology patients.

Further development of such interventions is paramount given the undesirably low rates of advance care planning discussions and documentation. Prior research has found that one barrier to patients completing advance care planning documents is the cumbersome nature of many advance care planning documents. Our healthcare improvement initiative sought to utilize advance care planning tools that incorporated patients' values and used patient-friendly language as such tools have shown promise in increasing patient understanding of and engagement in the advance care planning process [11, 14]. An advance care planning packet that included a letter-based format was chosen as our intervention because research comparing letter advance directives to traditional advance directives showed that letter advance directives were preferred by study participants because they were easier to understand, better-reflected participant values, stimulated thinking about end-of-life care, and facilitated communication with providers and loved ones about end-of-life care preferences [11].

In addition to cumbersome advance directive forms that are challenging for patients to understand, another barrier to increased advance directive completion are physician time constraints. Utilization of multidisciplinary teams including social workers, NPs, and/or lay health care workers is one approach that may be utilized to address this barrier and improve patient engagement with advance care planning [15, 16]. Our healthcare improvement initiative utilized an inpatient NP and medical students to encourage patients

to consider end-of-life care issues and complete advance directives. Unfortunately, medical student involvement with patient interactions was limited due to COVID-19 restrictions. Future iterations of this healthcare improvement initiative may benefit from the incorporation of additional lay healthcare team members who are trained to lead and document advance care planning conversations and preferences.

Strengths and Limitations

The strengths of our study include buy-in from the entire gynecologic oncology division. This allowed us to seamlessly implement our intervention even as personnel changed in the inpatient service.

There are several limitations to our study. The COVID-19 pandemic interrupted the planned implementation of the intervention in several ways. First, by restricting student involvement, therefore limiting the team's ability to conduct one-on-one, follow-up conversations from March to September 2020. Secondly, visitor restrictions during the peak of COVID may have impacted patients' willingness to complete advance directives without family members at the bedside. These restrictions likely impacted our rates of AD completion following the intervention. Additionally, this study compared a 2019 gynecologic oncology inpatient cohort to a 2020 inpatient cohort. The temporal nature of this comparison limited our ability to control for confounding factors and as such limits our ability to determine causation. Another limitation of our project is the relatively small number of gynecologic oncology patients admitted to our institution each year. This limited the power of our study. Lastly, the introduction of advanced care planning concepts can be distressing to patients, especially young patients or patients with new diagnoses of terminal illness who have not had time to emotionally process their diagnosis. These patients may have declined packets.

Contextual Changes and Adaptations

Adaptations made to the intervention throughout the study period in accordance with PDSA cycles included documentation within the EMR that a patient had been given a packet during their admission.

Implications/Future Directions

Advance directive documentation rates remain low, likely owing to several patient and provider factors. Our results suggest that the implementation of a multidisciplinary team approach to distribute a letter-based advance care planning packet improved advance directive documentation in the EMR. This allowed our division to improve compliance with ASCO and NCCN recommendations

regarding advance care planning. Further directions for research include utilizing the EMR to encourage patients to bring copies of their advance directives to post-hospitalization outpatient appointments with their providers and distribution of advance care planning packets in the outpatient setting.

Conclusion

We demonstrated that a letter-based advance care planning healthcare improvement initiative implemented by a multidisciplinary team was effective at increasing advance directive documentation in the gynecologic oncology inpatient population. Providing end-of-life care that is concordant with personal preferences is a critical component of patient-centered care. Increasing the documentation of patient's wishes is a step toward the goal of increasing patient-centered care at the end of life. Further studies are necessary to examine whether this increased documentation correlates to increased concordance with personal advance care planning preferences at end-of-life.

Author Contribution CNZ: conceptualization, methodology, investigation, writing – original draft, review, and editing, visualization.

AC: conceptualization, methodology, investigation, writing – original draft, review, and editing, visualization.

RRL: methodology, investigation, data curation, review of manuscript.

SGL: writing – original draft, review, and editing.

SCR: writing – original draft, review, and editing.

MAR: software, data curation, writing – review and editing.

MK: conceptualization, methodology, writing – review and editing.

LSP: conceptualization, methodology, writing – review and editing.

AJB: conceptualization, methodology, formal analysis, writing – original draft, review, and editing, supervision. All authors reviewed, edited, and approved the manuscript.

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Data Availability Deidentified data can be made available upon request.

Code Availability Data collected and managed using HIPAA-compliant interfaces including Box and Research Electronic Data Capture (REDCap) hosted at Vanderbilt University Medical Center. IBM SPSS Statistics 27 was used for statistical analyses.

Declarations

Ethics Approval This health care improvement initiative study was approved as exempt by our Institutional Review Board (IRB).

Consent to Participate Not applicable.

Consent for Publication Not applicable.

Conflict of Interest The authors certify that we have no affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

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