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Defining High-Quality Palliative Care in Oncology Practice: An American Society of Clinical Oncology/American Academy of Hospice and Palliative Medicine Guidance Statement

Kathleen E. Bickel, MD, MPhil, Kristen McNiff, MPH, Mary K. Buss, MD, MPH, Arif Kamal, MD, MHS, Dale Lupu, MPH, PhD, Amy P. Abernethy, MD, PhD, Michael S. Broder, MD, Charles L. Shapiro, MD, Anupama Kurup Acheson, MD, Jennifer Malin, MD, PhD, Tracey Evans, MD, and Monika K. Krzyzanowska, MD, MPH

White River Junction VA Medical Center; Geisel School of Medicine at Dartmouth, White River Junction, VT; Dana-Farber Cancer Institute; Beth Israel Deaconess Medical Center, Boston, MA; Duke University Medical Center, Durham, NC; American Academy of Hospice and Palliative Medicine, Glenview, IL; Partnership for Health Analytic Research, Beverly Hills, CA; Mt Sinai Ichan School of Medicine, New York, NY; Providence Cancer Center, Portland, OR; Anthem, Indianapolis, IN; Abramson Cancer Center of the University of Pennsylvania, Philadelphia, PA; and Princess Margaret Cancer Centre, Toronto, Ontario, Canada

Corresponding author: Kathleen E. Bickel, MD, MPhil, White River Junction VA Medical Center, 215 N Main St, Mail Code GEC 003, White River Junction, VT 05091; e-mail: kathleen.bickel@outlook.com.

Disclosures provided by the authors are available with this article at jop.ascopubs.org.

QUESTION ASKED: What are the specific elements of basic “primary palliative care” that general medical oncology practices in the United States should be reasonably expected to provide for adult patients with advanced cancer or high symptom burden?

SUMMARY ANSWER: The panel endorsed a substantial proportion (598 of 966 [62%]) of specific palliative care service items. Three hundred forty-seven items (36%) fell into the Uncertain category, and 21 items (2%) were excluded. Oncology providers wishing to enhance palliative care delivery may find this information useful to inform operational changes and quality improvement efforts.

WHAT WE DID: An expert steering committee created a list of 966 palliative care service items in nine domains, describing elements of palliative care for oncology patients. Thirty-one multidisciplinary panelists then used modified Delphi methodology to rate these items according to three separate constructs: importance, feasibility, and scope of medical oncology practice.

WHAT WE FOUND: Domains with the highest proportion of items endorsed (Include category) were End-of-Life Care (81%); Communication and Shared Decision Making (79%); and Advanced Care Planning (78%). The lowest proportions were in Spiritual and Cultural Assessment and Management (35%) and Psychosocial Assessment and Management (39%). In the largest domain, Symptom Assessment and Management, there was consensus that all symptoms should be assessed and managed at a basic level, with more comprehensive management for common symptoms such as nausea, vomiting, diarrhea, dyspnea, and pain. Within the Appropriate Palliative Care and Hospice Referral domain, there was consensus that oncology practices should be able to describe the difference between palliative care and hospice to patients and refer patients appropriately.

BIAS, CONFOUNDING FACTOR(S), REAL-LIFE IMPLICATIONS: Despite the panel size and a rigorous attempt to compose a representative panel, one third of the panelists self-identified as both medical oncologists and palliative care physicians. As they were not a majority, this group could not completely influence the Include category because it required a median rating of 7 to 9 without disagreement in all three constructs. However, this group likely made it more difficult to completely exclude certain items, thereby creating a larger Uncertain category. In addition, the panel was not asked to endorse any standardized tools, prioritize areas for improvement, or suggest performance benchmarks, which would be useful for further implementation. Lastly, with only US-based panelists, these findings cannot be generalized elsewhere. Our findings demonstrate that primary palliative care continues to be essential for all medical oncology clinicians caring for seriously ill patients, despite variation in settings and resources. This statement represents the first clearly itemized consensus definition of what elements should be a part of primary palliative care delivery within medical oncology practice in the United States. Because of the wide range of oncology practice settings and resources, the intent is to allow practices flexibility in choosing



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improvement areas based on local context, feasibility, and interest. No one specific area has been prioritized, no benchmarks have been set or recommended, and no mandates have been proposed, because the evidence is still lacking. However, we hope that this statement will serve as a starting point—along with appropriate education, evaluation, and reimbursement models—toward operationalizing and improving primary palliative care delivery in medical oncology practice. **JOP**

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American Society of Clinical Oncology

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ASSOCIATED CONTENT



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Abstract

Purpose

Integrated into routine oncology care, palliative care can improve symptom burden, quality of life, and patient and caregiver satisfaction. However, not all oncology practices have access to specialist palliative medicine. This project endeavored to define what constitutes high-quality primary palliative care as delivered by medical oncology practices.

Methods

An expert steering committee outlined 966 palliative care service items, in nine domains, each describing a candidate element of primary palliative care delivery for patients with advanced cancer or high symptom burden. Using modified Delphi methodology, 31 multidisciplinary panelists rated each service item on three constructs: importance, feasibility, and scope within medical oncology practice.

Results

Panelists endorsed the highest proportion of palliative care service items in the domains of End-of-Life Care (81%); Communication and Shared Decision Making (79%); and Advance Care Planning (78%). The lowest proportions were in Spiritual and Cultural Assessment and Management (35%) and Psychosocial Assessment and Management (39%). In the largest domain, Symptom Assessment and Management, there was consensus that all symptoms should be assessed and managed at a basic level, with more comprehensive management for common symptoms such as nausea, vomiting, diarrhea, dyspnea, and pain. Within the Appropriate Palliative Care and Hospice Referral domain, there was consensus that oncology practices should be able to describe the difference between palliative care and hospice to patients and refer patients appropriately.

Conclusion

This statement describes the elements comprising high-quality primary palliative care for patients with advanced cancer or high symptom burden, as delivered by oncology practices. Oncology providers wishing to enhance palliative care delivery may find this information useful to inform operational changes and quality improvement efforts.

INTRODUCTION

Integrating specialist palliative care into routine cancer care can lead to better patient and caregiver outcomes, including improvement in symptoms, quality of life, satisfaction, caregiver burden, and survival.¹⁻⁹ However, studies also indicate that palliative care delivery in medical oncology practice requires improvement.^{10,11} Consequently, ASCO and others recommend integrating palliative care early into the usual care of patients with advanced cancer or high symptom burden.^{1,3,12-15} Although specialist palliative care teams deliver care focused on symptoms, care planning, and quality of life, it is not feasible for all patients with cancer to be cared for by these teams.^{11,16,17} Oncologists and their clinic teams remain the primary providers of palliative care for the majority of patients with cancer in the United States,¹¹ and ASCO has long recognized and acknowledged the aspects of palliative care inherent in oncology practice.^{3,12-14,18} A distinction between primary palliative care (ie, skills that all clinicians should have) and specialist palliative care has been described by many,^{17,19-21} but the exact elements of primary palliative care in medical oncology practice have not been defined. To improve primary palliative care delivery, medical oncology practices require guidance, practical resources, and assistance in overcoming barriers.

To develop more detailed guidance, ASCO representatives partnered with representatives from the American Academy of Hospice and Palliative Medicine (AAHPM) to

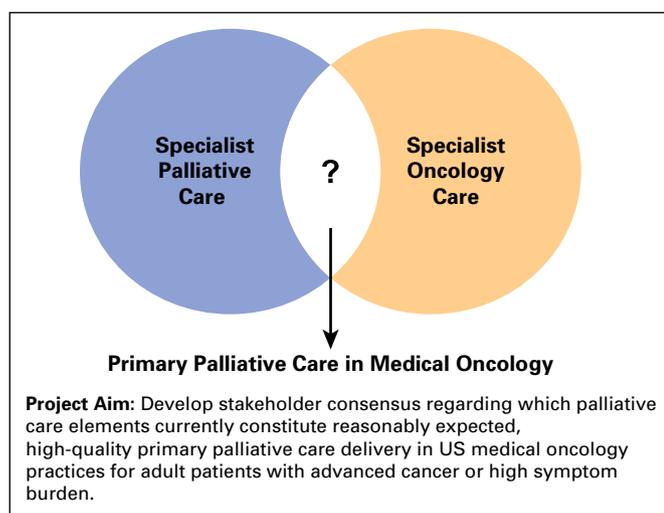


FIG 1. Conceptual model of the project aim: Defining high-quality primary palliative care in medical oncology.

form a project steering group. The project goal was to use a formal consensus process to define what elements currently constitute reasonably expected, high-quality palliative care delivery in US medical oncology practices for adult patients with advanced cancer or high symptom burden, hereafter referred to as primary palliative care in medical oncology (Fig 1). Specifically, we aimed to (1) create an actionable resource for improving the quality of palliative care provided in medical oncology practices; (2) build a foundation on which future palliative care-related quality measures, quality improvement initiatives, and educational activities could be constructed; and (3) identify areas of uncertainty to stimulate conversation among both disciplines.

METHODS

We used the RAND/UCLA-modified Delphi process²² to develop consensus on which elements of palliative care should be provided within medical oncology practices in the United States to deliver high-quality primary palliative care.

Steering Group and Project Structure

The steering group (authors) consisted of representatives from ASCO's Quality of Care, Clinical Practice, Clinical Practice Guidelines, and Survivorship Committees; representatives from AAHPM; and an impartial process expert. This group adapted previously published frameworks^{1,23} to create the project's scope and structure, resulting in nine domains: Symptom Assessment and Management, Psychosocial Assessment and Management, Spiritual and Cultural Assessment and Management, Communication and Shared Decision Making, Advance Care Planning, Appropriate Palliative Care and Hospice Referral, Coordination and Continuity of Care, Carer Support, and End-of-Life Care. Scope was limited to US adult patients with advanced cancer or high symptom burden, in concordance with the ASCO provisional clinical opinion regarding integration of palliative care into oncology care.³

Delphi Panelists

Professional organizations, including state medical oncology societies, the Oncology Nursing Society, the Association of Oncology Social Work, as well as oncology patient advocate groups (to represent the patient perspective), were approached to nominate individuals to participate in the panel. The goal was to have experts representing medical oncology practice from

different regions, practice types, and practice sizes. Although chaplains play an important role in the provision of palliative care, they are not common members of medical oncology practices, and thus were not included as panel members. To avoid academic bias, there was no publication requirement for panelists.

The resulting 31-member multidisciplinary panel was larger than standard Delphi methodology panel size (nine to 12 members); however, the steering group considered adequate stakeholder engagement to be essential. Twenty-two members were physicians, self-identified as palliative care ($n = 1$), medical oncology ($n = 10$), or medical oncology and palliative care ($n = 11$). Years of board certification ranged from 3 to 35 years for medical oncology (average, 17.8 years) and from 1 to 5 years for palliative care (average, 3.2 years), because 2008 was the first year the current palliative care board examination was offered. The other nine members were patient advocates ($n = 3$), social workers ($n = 2$), nurses ($n = 2$), and nurse practitioners ($n = 2$). Physicians were either in academic practice ($n = 8$), hospital-based practice ($n = 5$), or private practice ($n = 9$). Represented practices were located across the United States and Puerto Rico (64% urban, 36% suburban), with staff sizes ranging from four to 2,500 people. Steering group members did not participate in the Delphi process.

Development of Rating Document

Content experts in the steering group reviewed the results of a literature search and developed a comprehensive list of 966 palliative care service items, reflecting the array of palliative care services that should be available in the health care system for patients with advanced cancer or significant symptom burden. The steering group did not preliminarily remove any service items potentially inappropriate for medical oncology practice. Furthermore, when appropriate, multiple items were developed to capture implementation distinctions, such as method or frequency, within the same palliative care service (eg, pain assessment using a standardized scale at every clinical encounter *v* only as needed). Within each domain, service items were further grouped into the following subcategories of patient care and clinical practice: Patient Assessment and Evaluation, Education and Management, Practice Management, Referral, and Evaluation of Clinic Processes.

Three separate constructs, each on a scale from 1 to 9, were developed for panelists to rate each service item (Data Supplement). The constructs were related to the importance of delivering the service as part of high-quality medical

oncology care (1 = not important, 9 = essential), the feasibility of doing so (1 = infeasible, 9 = definitely feasible), and whether it was reasonable (within scope) to expect medical oncology practices caring for patients with advanced cancer and/or high symptom burden to provide the service (1 = extremely unreasonable, 9 = extremely reasonable).

Delphi Process and Analysis

Panelists participated in an introductory webinar, followed by a pilot round, to gauge panelists' understanding of the constructs and the rating process. Clarifications and definitions (Data Supplement) were reviewed before the first full round. Panelists received summarized results of the first round of ratings, followed by a face-to-face meeting conducted by a professional facilitator without ties to oncology or palliative care (M.S.B.). The meeting discussion focused on the service items with a composite rating of Uncertain and areas of disagreement. Afterward, panelists rerated the service items using the same three constructs.

For analysis, we made an a priori decision to modify standard Delphi methodology definitions of agreement and disagreement,²² accounting for the larger panel size. Disagreement was defined to exist when at least six panelists rated the service item in the top one third of a construct scale (7, 8, or 9) and at least six panelists rated the same service item in the bottom one third of the same construct scale (1, 2, or 3); agreement was considered high when a service item had a median rating of 7 to 9 without disagreement (or a median of 1 to 3 without disagreement).

A composite rating across all three constructs was also created for each service item, with each categorized as Include (ie, reasonably within the scope of practice), Uncertain, or Exclude (ie, typically beyond the scope of practice). Service items were in the Include category if the median was 7 to 9 for all three constructs (importance, feasibility, and scope) without disagreement, in the Exclude category if the median was 1 to 3 for all three constructs without disagreement, and called Uncertain otherwise. All classifications (eg, agreement, disagreement, Include, Exclude, and Uncertain) and summary statistics (ie, medians and standard deviations) were summarized descriptively for pilot-, first-, and second-round responses. All data and statistical analyses were performed using SAS version 8.2 (SAS Institute, Cary, NC).

RESULTS

Figure 2 summarizes the final composite ratings. Detailed results are presented in the Data Supplement. Overall, 62%

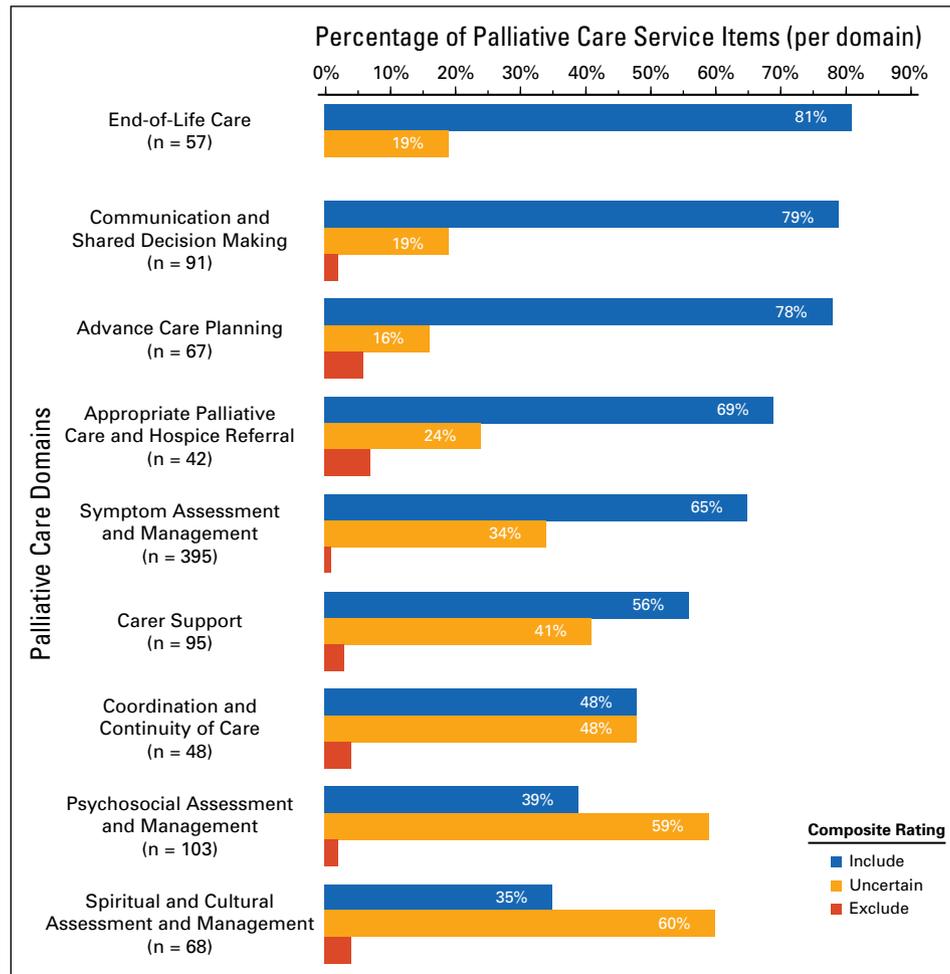


FIG 2. Distribution of palliative care service items by domain and by composite rating category, rank ordered by percentage of service items with an Include composite rating.

(n = 598) of the 966 palliative care service items were compositely rated as Include, 2% (n = 21) as Exclude, and the remainder fell into the Uncertain category. The distribution of composite ratings varied by domain. For example, the majority of service items in the End-of-Life Care domain were rated as Include, compared with the Spiritual and Cultural Assessment and Management domain, where most items were rated as Uncertain.

Table 1 provides examples of the palliative care service items considered to be within the scope of medical oncology practice (Include), beyond the scope of medical oncology practice (Exclude), and those in between (Uncertain), based on each service item’s composite rating. Given the extent of data, in this section we describe representative service items from each domain, focusing on those with an Include composite rating. The majority of Exclude service items focused on standardized patient assessments at regular time intervals (eg, every visit).

Domain 1: Symptom Assessment and Management

This was the largest section, with 395 service items divided into 22 different symptom-related categories (Table 2). The percentage of service items rated as Include ranged from 100% for nausea/vomiting and diarrhea to 23% for items related to general depression and anxiety. Panelists agreed that in this patient population (ie, those with advanced cancer or high symptom burden), a general symptom assessment using a validated quantitative instrument should be conducted at least monthly. Practices should also perform the following: (1) educate patients about the cause and management of existing symptoms, (2) instruct patients how and when to contact the clinic during and after hours for new or worsening/poorly controlled symptoms, and (3) assess the effectiveness of adjusted medication by the next clinical encounter. All symptoms should be assessed and managed at a basic level, with more comprehensive

Table 1. Example of Palliative Care Service Items in Each Palliative Care Domain by Composite Rating Category

Palliative Care Domain	Composite Rating Category		
	Include (within scope)	Uncertain	Exclude (not within scope)
1. Symptom Assessment/ Management	<ul style="list-style-type: none"> Systematically assess for pain using a validated quantitative instrument at every clinical encounter 	<ul style="list-style-type: none"> Treat a patient with moderate to severe uncomplicated pain, who is using medical marijuana, with opioids 	<ul style="list-style-type: none"> Have all patients receiving opiates sign opiate agreements
2. Psychosocial Assessment/ Management	<ul style="list-style-type: none"> Obtain a basic psychosocial history at initial clinical encounter 	<ul style="list-style-type: none"> Assist with applications for insurance (eg, Medicare, Medicaid) 	<ul style="list-style-type: none"> Obtain patient feedback regarding clinic process of assessing and managing psychosocial issues using a standardized form at every clinical encounter
3. Spiritual and Cultural Assessment/ Management	<ul style="list-style-type: none"> Assess and record current faith group, if any, in medical record 	<ul style="list-style-type: none"> Perform screening for possible spiritual issues 	<ul style="list-style-type: none"> Obtain patient feedback regarding clinic process of assessing and managing spiritual and cultural issues using a standardized form at every clinical encounter
4. Communication and Shared Decision Making	<ul style="list-style-type: none"> Determine patient/family understanding of prognosis 	<ul style="list-style-type: none"> Discuss potential cost to patient/family of any potential treatment, acknowledging the effects that cost may have on family finances and future plans* 	<ul style="list-style-type: none"> Obtain patient feedback regarding clinic process of communication and shared decision making using a standardized form at every clinical encounter
5. Advance Care Planning	<ul style="list-style-type: none"> Explain the difference between "code status" and an advance directive 	<ul style="list-style-type: none"> Complete the advance care planning process before starting any cancer-directed treatments 	<ul style="list-style-type: none"> Assess for changes/updates to advance care plan at every visit
6. Coordination and Continuity of Care	<ul style="list-style-type: none"> Communicate current prognosis to primary care 	<ul style="list-style-type: none"> Have a clinic protocol on when to refer patient back to primary care 	<ul style="list-style-type: none"> Obtain family/surrogate feedback regarding clinic process of coordination and continuity of care using a standardized form at every clinical encounter
7. Appropriate Palliative Care and Hospice Referral	<ul style="list-style-type: none"> Assess patient's need for hospice referral at time of diagnosis of incurable malignancy 	<ul style="list-style-type: none"> Refer patient to palliative care if you would "not be surprised if the patient died in the next 12 months" 	<ul style="list-style-type: none"> Obtain patient feedback regarding clinic process of palliative care and hospice referral using a standardized form at every clinical encounter
8. Carer Support	<ul style="list-style-type: none"> Assess family/caregiver for distress (when he or she accompanies patient to clinical encounter) 	<ul style="list-style-type: none"> Assess distressed family/caregiver for causes of distress 	<ul style="list-style-type: none"> Obtain family/caregiver feedback regarding clinic process of family/caregiver support using a standardized form at every clinical encounter
9. End-of-Life Care	<ul style="list-style-type: none"> Describe expected signs and symptoms of impending death to family and loved ones 	<ul style="list-style-type: none"> Obtain family/surrogate feedback regarding clinic involvement in patient's end-of-life care 	<ul style="list-style-type: none"> NA

Abbreviation: NA, not applicable.

*As an example, the simpler version of this service item, "Discuss potential cost to patient/family of any potential treatment" without the italicized words was rated as an 'Include' item. Only 'Included' items qualified as part of the consensus definition for high-quality primary palliative care in medical oncology practice.

Table 2. Palliative Care Service Items by Symptom Category in the Symptom Assessment and Management Domain, Rank Order by Percentage of Service Items With an Include Composite Rating

Symptom Category	Service Items	Composite Rating Category, Row % (No. of patients)	
		Include	Uncertain
Chemotherapy-related toxicity	6	100 (6)	0 (0)
Nausea/vomiting (not on chemotherapy)	7	100 (7)	0 (0)
Diarrhea	11	100 (11)	0 (0)
Dyspnea	14	93 (13)	7 (1)
Cough	25	92 (23)	8 (2)
Fatigue	12	92 (11)	8 (1)
Pruritus/rash	12	92 (11)	8 (1)
Mucositis/dysphagia	19	89 (17)	11 (2)
Cachexia/weight loss	13	85 (11)	15 (2)
Nausea/vomiting (on chemotherapy)*	16	75 (12)	25 (4)
Constipation/ileus/obstruction	12	67 (8)	33 (4)
Ascites	6	67 (4)	33 (2)
Pain*	58	66 (38)	33 (19)
Delirium	14	64 (9)	36 (5)
Lymphedema	11	64 (7)	36 (4)
Insomnia	13	62 (8)	38 (5)
General symptoms*	19	58 (11)	42 (8)
Genitourinary symptoms	23	57 (13)	43 (10)
General patient function*	31	48 (15)	52 (16)
Depression	27	41 (11)	59 (16)
Anxiety	20	30 (6)	70 (14)
General depression/anxiety*	22	23 (5)	73 (16)
Totals	391	66 (257)	33 (132)

NOTE: Table does not include the four service items describing Evaluation of Clinic Processes for this domain, or the two items in the Exclude category, one each in Pain and in General Depression/Anxiety. Only items in the Include category are part of the consensus definition of high-quality primary palliative care in medical oncology practice.

*Category included duplicate service items with varying implementation, such as methods of assessment or frequency (eg, every visit *v* every 3 months).

management for common symptoms such as nausea, vomiting, diarrhea, dyspnea, and pain. Patients with uncontrolled/poorly controlled symptoms should be referred to specialist palliative care or other specialty as indicated. However, during discussion, panelists commented that referral is often limited by availability of specialist providers.

Domain 2: Psychosocial Assessment and Management

Panelists agreed that practices should conduct at minimum an initial, basic psychosocial assessment and a distress assessment. Distress should also be systematically assessed with a validated quantitative instrument after any clinical change (eg,

new areas of metastatic disease). Panelists agreed that distress should be managed at a basic level with supportive, empathetic statements and validation of the patient's experience. Otherwise, patients should be referred.

Domain 3: Spiritual and Cultural Assessment and Management

Although only two spiritual assessment items (documentation of a patient's faith and differentiation of a grief reaction from depression) were rated as Include, multiple basic spiritual support elements were rated as Include, such as providing patients with a framework to consider their goals and hopes along with the likely medical outcome(s) of their illnesses and supporting those goals. During discussion, panelists encouraged more frequent referrals to outside spiritual providers (because they may be underutilized). Culturally, preferences for communication and language should be assessed and documented, and at the minimum, telephone translation services should be provided.

Domain 4: Communication and Shared Decision Making and Domain 5: Advance Care Planning

Panelists endorsed most of the service items in these domains. Patients and families should be assessed for preferences regarding (1) how they want to receive information regarding the patient's cancer, prognosis, treatment risks/benefits, treatment plan, and bad news; and (2) who participates in the decision making and to what extent. Oncology practices should provide oral and written documentation of the treatment plan to the patient and family with specific details regarding (1) expectations for disease control, (2) expected effects on symptoms and quality of life, (3) expected length and frequency of treatment, and (4) the frequency of and rationale for disease reassessment. The patient's and family's understanding of the patient's illness, prognosis, and goals of care should be assessed at diagnosis, at disease progression, and with changes in the treatment plan. Mistakes should be openly acknowledged and addressed as soon as they are noticed.

The process of advance care planning in this patient population should begin at the diagnosis of advanced cancer, and should start with assessing the patient's and family's readiness to discuss advance care planning and any concerns they might have. Panelists agreed that code status, living wills, advanced directives, health care surrogate, and out of hospital "do not resuscitate" orders should be discussed, completed,

and documented for all patients as soon as possible. However, as discussed by the panel, completing all aspects of advance care planning may be complicated by patient/family avoidance, patient illness, lack of time during a regular outpatient clinic visit, and shortage of needed support staff.

Domain 6: Coordination and Continuity of Care

Panelists registered strong agreement (Include) for care coordination with primary care, hospice, hospital, and nursing home, but were Uncertain about having clinic protocols for referring back to primary care or tracking utilization (emergency clinic visits, emergency room visits, or hospitalizations).

Domain 7: Appropriate Palliative Care and Hospice Referral

Oncology practices should describe the difference between hospice and palliative care, with the benefits and limitations of each, to patients and families as soon as possible after an advanced cancer diagnosis. Routine patient assessments should be conducted to determine need for palliative care or hospice referral. Although rated as Uncertain, during discussion panelists thought that ideally, practices would have protocols to facilitate these assessments, and that practices would maintain rosters of patients receiving palliative/comfort care and hospice care for purposes of improvement and outcomes tracking. There was strong consensus (Include) that patients with a prognosis of 3 months or less and/or an Eastern Cooperative Oncology Group performance status of three to four be referred for hospice and that referrals be collaboratively agreed upon between the patient/family and the oncology team. However, during discussion, panelists acknowledged the patient-centered exceptions to these and other service items, advocating benchmarking over absolute measurement.

Domain 8: Carer Support

The term "carer" was chosen to encompass all people caring for the patient—both the patient's caregivers (family and loved ones) and oncology clinic staff. Panelists agreed that practices should obtain permission to speak with primary caregiver(s) and to include them in conversations about the patient's care. Caregivers attending clinic visits with patients should be assessed for distress at least once. Caregivers should know how to contact the clinic in both routine and emergency situations, and they should have information about local and online caregiver resources. Other than assisting with Family Medical Leave Act paperwork (Include), most caregiver needs are likely

met by referrals to other providers (eg, social worker, counselor, or their own physicians). Bereaved caregivers should get a phone call and/or condolence card from the clinic and receive information regarding local bereavement resources. To care for staff, the clinic environment should be supportive and allow for open communication, respect, growth, and self-care.

Domain 9: End-of-Life Care

The panel endorsed the majority of these service items as being important, feasible, and within the scope of medical oncology practice. Practices should have processes to evaluate patient symptoms, advise medication changes to patients and family, and provide on-call coverage 24 hours per day, 7 days per week whether hospice is involved or not. For patients on hospice, practices should collaborate with the hospice team for questions and issues.

DISCUSSION

Comprehensive palliative care assessment and management encompasses a large breadth and depth of services for patients and their families. Using the three constructs of importance, feasibility, and scope of practice, an interdisciplinary panel of medical oncology practice stakeholders endorsed 62% of the 966 palliative care service items as being reasonably within the scope of medical oncology practice (the Include composite rating). These items in the Include category (Data Supplement) represent our consensus definition of high-quality primary palliative care within medical oncology practice. The highest proportions were in the domains of End-of-Life Care, Communication and Shared Decision Making, and Advance Care Planning. Panelists were less certain about service items within the Psychosocial and Spiritual care domains, but did support basic supportive service items, such as maximizing patient independence and patient autonomy whenever possible. In the largest domain, Symptom Assessment and Management, there was consensus that all symptoms should be assessed and managed at a basic level, with more comprehensive management for common symptoms such as nausea, vomiting, diarrhea, dyspnea, and pain.

The panel's recommendations corroborate prior studies illustrating that medical oncologists consider palliative care services to be within the scope of quality medical oncology practice^{13,20} and use primary palliative care skills.^{19,24} Thus, it is not surprising that the panel endorsed many basic palliative care service items, comprising a large proportion of the Include category. Indeed, there is a large overlap between the

service items in the Include category herein and measures in the American Board of Internal Medicine Palliative Care for Primary Care and Subspecialist Physicians Practice Improvement Module,²⁵ which is also intended to improve primary palliative care delivery.

Rather than devaluing the importance or need for specialist palliative medicine, our findings reiterate that primary palliative care skills, such as symptom assessment and management, with honest and compassionate communication about treatment options and their limits in advanced disease,²⁶ have been and continue to be essential for all clinicians caring for seriously ill patients. ASCO embraces the need for palliative care to be “emphasized in oncology training, certification, and continuing medical education,”¹⁴ and a framework for the delivery of primary versus specialist palliative care has been proposed.¹⁷ Separate work has identified potential indicators for palliative care and oncology integration.^{27,28} However, our work offers more granular guidance regarding discrete elements of primary palliative care within medical oncology practice itself, which was previously lacking.

Despite purposeful inclusion of complex care elements considered by our steering group members to be within the realm of specialist palliative medicine, only 2% of service items were in the Exclude category. Many of these service items were excluded because of frequency, eg, advance care planning was endorsed but not “at every visit.” Despite the panel's size and a rigorous attempt to compose a representative panel, a high proportion of physician panelists self-identified as both medical oncologists and palliative care physicians. These panelists may have been biased toward providing more palliative care services than the average oncologist, making it more difficult to completely exclude certain service items and creating a larger Uncertain category. However, only comprising approximately one third of the panel, this group likely had less influence over the Include category (the primary focus of this guidance statement) because it required a median rating of 7 to 9 without disagreement in all three constructs.

Our findings are also limited because we did not ask the panel to endorse any specific standardized tools (such as “The Distress Thermometer”²⁹) to specify which individual(s) within medical oncology practice should provide each service item, prioritize areas for improvement, or suggest performance benchmarks, because adding these topics would have required more resources. Some service items could have arguably been placed in a different domain, altering our summative findings, but the rating for each item remains the

same regardless of domain (eg, having bereavement items in the Carer Support domain rather than the End-of-Life Care domain). The service items are intended to be generally representative; not every possibility was considered. Lastly, with only US-based panelists, our findings cannot be generalized elsewhere, and they are subject to change as practice patterns and evidence evolve.

One of the main project goals was to create an actionable resource by outlining the elements of high-quality primary palliative care within the context of medical oncology practice. Some improvement and educational resources exist (Data Supplement), but have not been incorporated into routine care by many medical oncology practices for various reasons,³⁰ including lack of training and unclear level of responsibility.³¹ Improvement is difficult without clear definitions. The granularity of these recommendations allows interested medical oncology practices to consider incorporating some of these service items as internal process goals and begin closing local gaps in end-of-life care. We acknowledge that although some service items are already routine, others are more aspirational, especially given the limitations of the current patient care systems in which many medical oncology practices exist. However, compared with the service items in the Uncertain category, our panelists believed that many of the service items in the Include category were achievable, low-hanging fruit.

This statement acknowledges the wide range of medical oncology practice settings and resources. Its intent is to allow practices flexibility in choosing improvement areas based on local context, feasibility, and interest; as such, one area has not been prioritized over others. Practices strong in some areas, such as specialty tumor-based clinics, may already provide service items in the Uncertain category that are in their areas of strength. Although the scope of this work was limited to medical oncology practice, palliative care issues are cross-cutting, and other oncology disciplines may also find this statement relevant. Meanwhile, specialist palliative care teams may find this statement useful as they work to build effective collaborations with oncology, offering their services as a resource for clinical expertise and education regarding primary palliative care.

Further research could address current literature gaps,¹⁰ including better methods to identify the palliative care needs of patients with cancer and their families, how best to standardize palliative care delivery in oncology,

priorities for improvement, validated quality metrics, and benchmark goals. Such efforts need to be coupled with the identification of appropriate reimbursement models to facilitate provision of high-quality palliative care for patients with cancer.

In summary, this statement represents a rigorous consensus definition reached by an interdisciplinary panel of medical oncology and palliative care experts regarding what elements of palliative care constitute high-quality primary palliative care delivery by medical oncology practices for adult patients with advanced cancer or high symptom burden in the United States at this time (Fig 1). However, it is neither a clinical practice guideline nor a set of standards, because the evidence base is yet lacking for the creation of such a directive, and no benchmarks or mandates have been proposed in this statement. Our findings demonstrate that primary palliative care skills are endorsed within medical oncology practice, recognizing that, despite variation in practice settings and resources, medical oncology practices shoulder significant responsibility for delivering primary palliative care. Having specialist palliative care teams provide all palliative care is not feasible in most cases.¹⁶ However, with appropriate education, evaluation, and reimbursement models, this statement can guide the medical oncology community toward operationalizing and improving primary palliative care delivery in medical oncology practice. **JOP**

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Author Contributions

Conception and design: Kathleen E. Bickel, Kristen McNiff, Mary K. Buss, Arif Kamal, Dale Lupu, Amy P. Abernethy, Charles L. Shapiro, Anupama Kurup Acheson, Jennifer Malin, Tracey Evans, Monika K. Krzyzanowska

Administrative support: Dale Lupu

Collection and assembly of data: Kathleen E. Bickel, Kristen McNiff, Mary K. Buss, Arif Kamal, Dale Lupu, Amy P. Abernethy, Charles L. Shapiro, Anupama Kurup Acheson, Jennifer Malin, Tracey Evans, Monika K. Krzyzanowska

Data analysis and interpretation: All authors

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Kathleen E. Bickel, MD, MPhil, White River Junction VA Medical Center, 215 N Main St, Mail Code GEC 003, White River Junction, VT 05091; e-mail: kathleen.bickel@outlook.com.

References

1. Gaertner J, Wolf J, Hallek M, et al: Standardizing integration of palliative care into comprehensive cancer therapy—A disease specific approach. *Support Care Cancer* 19:1037-1043, 2011
2. Shaw KL, Clifford C, Thomas K, et al: Review: Improving end-of-life care: A critical review of the Gold Standards Framework in primary care. *Palliat Med* 24:317-329, 2010
3. Smith TJ, Temin S, Alesi ER, et al: American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care. *J Clin Oncol* 30:880-887, 2012
4. Waller A, Girgis A, Currow D, et al: Development of the palliative care needs assessment tool (PC-NAT) for use by multi-disciplinary health professionals. *Palliat Med* 22:956-964, 2008
5. Weissman DE, Meier DE: Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the Center to Advance Palliative Care. *J Palliat Med* 14:17-23, 2011
6. Bakitas M, Lyons KD, Hegel MT, et al: Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *JAMA* 302:741-749, 2009
7. Gade G, Venohr I, Conner D, et al: Impact of an inpatient palliative care team: A randomized control trial. *J Palliat Med* 11:180-190, 2008
8. Temel JS, Greer JA, Muzikansky A, et al: Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363:733-742, 2010
9. Zimmermann C, Swami N, Rodin G, et al: Cluster-randomized trial of early palliative care for patients with metastatic cancer. *J Clin Oncol* 30, 2012 (suppl; abstr 9003)
10. Institute of Medicine: Dying in America: Improving quality and honoring individual preferences near the end of life. National Academies Press, Washington, DC, 2015
11. Levit L, Balogh E, Nass S, et al: (eds). *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*. National Academies Press, Washington, DC, 2013
12. Ferris FD, Bruera E, Cherny N, et al: Palliative cancer care a decade later: Accomplishments, the need, next steps—From the American Society of Clinical Oncology. *J Clin Oncol* 27:3052-3058, 2009
13. Partridge AH, Seah DS, King T, et al: Developing a service model that integrates palliative care throughout cancer care: The time is now. *J Clin Oncol* 32:3330-3336, 2014
14. Peppercorn JM, Smith TJ, Helft PR, et al: American Society of Clinical Oncology statement: Toward individualized care for patients with advanced cancer. *J Clin Oncol* 29:755-760, 2011
15. Cherny N, Catane R, Schrijvers D, et al: European Society for Medical Oncology (ESMO) Program for the Integration of Oncology and Palliative Care: A 5-year review of the Designated Centers' incentive program. *Ann Oncol* 21:362-369, 2010
16. Lupu D; American Academy of Hospice and Palliative Medicine Workforce Task Force: Estimate of current hospice and palliative medicine physician workforce shortage. *J Pain Symptom Manage* 40:899-911, 2010
17. Quill TE, Abernethy AP: Generalist plus specialist palliative care—Creating a more sustainable model. *N Engl J Med* 368:1173-1175, 2013
18. Cancer care during the last phase of life. *J Clin Oncol* 16:1986-1996, 1998
19. Cheng MJ, King LM, Alesi ER, et al: Doing palliative care in the oncology office. *J Oncol Pract* 9:84-88, 2013
20. Hoffman MA, Raftopoulos H, Roy R: Oncologists as primary palliative care providers. *J Clin Oncol* 30:2801-2802, author reply 2802, 2012
21. von Gunten CF: Secondary and tertiary palliative care in US hospitals. *JAMA* 287: 875-881, 2002
22. Shekelle PG, Kahan JP, Bernstein SJ, et al: The reproducibility of a method to identify the overuse and underuse of medical procedures. *N Engl J Med* 338: 1888-1895, 1998
23. National Consensus Project for Quality Palliative Care: Clinical practice guidelines for quality palliative care (ed 2). Pittsburgh, PA, National Consensus Project for Quality Palliative Care, 2009, pp 80
24. Parikh RB, Kirsh RA, Smith TJ, et al: Early specialty palliative care—Translating data in oncology into practice. *N Engl J Med* 369:2347-2351, 2013
25. American Board of Internal Medicine. ABIM Palliative Care for Primary Care and Subspecialist Physicians PIM™ Practice Improvement Module Measures Catalogue. Philadelphia, PA, American Board of Internal Medicine, 2014
26. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force: Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Intern Med* 174:1994-2003, 2014
27. Hui D, Bansal S, Strasser F, et al: Indicators of integration of oncology and palliative care programs: An international consensus. *Ann Oncol* 26:1953-1959, 2015
28. Hui D, Kim YJ, Park JC, et al: Integration of oncology and palliative care: A systematic review. *Oncologist* 20:77-83, 2015
29. Roth AJ, Kornblith AB, Batel-Copel L, et al: Rapid screening for psychologic distress in men with prostate carcinoma: A pilot study. *Cancer* 82:1904-1908, 1998
30. Davis MP, Bruera E, Morganstern D: Early integration of palliative and supportive care in the cancer continuum: Challenges and opportunities. *Am Soc Clin Oncol Educ Book* 33:144-150, 2013
31. Cherny NI, Catane R; European Society of Medical Oncology Taskforce on Palliative and Supportive Care: Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer: Report on a survey by the European Society of Medical Oncology Taskforce on Palliative and Supportive Care. *Cancer* 98:2502-2510, 2003

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**Defining High-Quality Palliative Care in Oncology Practice: An American Society of Clinical Oncology/American Academy of Hospice and Palliative Medicine Guidance Statement**

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Kathleen E. Bickel

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Mary K. Buss

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Arif Kamal

Consulting or Advisory Role: Insys Therapeutics

Dale Lupu

Other Relationship: AAHPM, Coalition for Supportive Care of Kidney Patients

Amy P. Abernethy

Employment: Flatiron Health, AthenaHealth, Orange Leaf Associates

Stock or Other Ownership: AthenaHealth, Flatiron Health

Consulting or Advisory Role: Bristol-Myers Squibb, Helsinn Therapeutics, Genentech

Michael S. Broder

Other Relationship: Partnership for Health Analytic Research; Amgen; Bristol-Myers Squibb; Boston Scientific; Celgene; Eisai; Ethicon; Genentech; Jazz Pharmaceuticals; Novartis; Otsuka; Roche

Charles L. Shapiro

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Anupama Kurup Acheson

No relationship to disclose

Jennifer Malin

Employment: Anthem

Stock or Other Ownership: Anthem

Tracey Evans

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