

Consensus development: Within general oncology practice, what constitutes high quality palliative care delivery?

Kathleen E. Bickel¹, Kristen McNiff², Jennifer Malin³, Amy Pickar Abernethy⁴, Arif Kamal⁵, Mary K. Buss⁶, Anupama Kurup Acheson⁷, Charles L. Shapiro⁸, Tracey L. Evans⁹, Dale Lupu¹⁰, Michael S. Broder¹¹, Monika K. Krzyzanowska¹²

¹White River Junction VA Medical Center, White River Junction, VT; ²American Society of Clinical Oncology, Alexandria, VA; ³WellPoint, Inc., Indianapolis, IN; ⁴Duke University Medical Center, Durham, NC; ⁵Duke Cancer Institute and Center for Learning Healthcare at Duke Clinical Research Institute, Durham, NC; ⁶Beth Israel Deaconess Medical Center, Boston, MA; ⁷Providence Oncology and Hematology Care Clinic, Portland, OR; ⁸Division of Medical Oncology, Ohio State University Medical Center and the Breast Program, Ohio State University Comprehensive Cancer Center, Columbus, OH; ⁹Abramson Cancer Center of the University of Pennsylvania, Philadelphia, PA; ¹⁰American Academy of Hospice and Palliative Medicine, Glenview, IL; ¹¹Partnership for Health Analytic Research, LLC, Beverly Hills, CA; ¹²Cancer Care Ontario, Toronto, ON

Background

- Multiple studies illustrate the benefits of combined palliative and standard cancer care, but oncology practices need guidance to fill existing gaps in the delivery of high quality palliative care to cancer patients
- To guide improvement, we m high-quality palliative care within the general oncology practice.
- What aspects of palliative care are within scope of general oncology practice?
- What aspects of palliative care are important/reasonable for oncology practices to deliver?
- For many practices, palliative care service not available
- For many practices, ancillary staff and amount of training in palliative care variable

Project Goal:

To develop a consensus definition of what constitutes the reasonably expected aspects of high-quality palliative care included as a part general adult medical oncology practice in the United States.

Aims:

- To create an actionable resource to improve the quality of palliative care provided in oncology practice.
- To create a coherent and comprehensive foundation on which to build future palliative care-related quality measurement, quality improvement, and educational initiatives for ASCO members and its constituents.

Methods

- Steering group (SG) of members from ASCO Quality of Cancer Care Committee, Clinical Practice Guidelines Committee, Clinical Practice Committee, Survivorship Committee, and the prior ASCO Palliative Care Provisional Clinical Opinion (PCO), along with members of the American Academy of Hospice of Palliative Medicine (AAHPM).
- Defined 9 Core Domains of Palliative Care in Oncology Practice:
 - Symptom Assessment and Management
 - Psychosocial Assessment and Management
 - Spiritual and Cultural Assessment and Management
 - Communication and Shared Decision-Making
 - Care Planning (including ethical and legal issues)
 - Coordination and Continuity of Care
 - Appropriate Palliative Care and Hospice Referral
 - Carer Support (family/caregiver and staff)
 - End-of-Life Care
- Panel of participants solicited from experts in both palliative care and oncology (7), oncologists in active practice (15), palliative care alone (1), and others (8 – nurse, social worker, or patient advocate).
- Consensus method used: RAND/UCLA modified Delphi process. (Shekelle PG, Kahan JP, Bernstein SJ, et al. *N Engl J Med* 1998; 338:1888-95.) Two item rating sessions, with an intervening panel discussion.
- Existing literature used by SG to develop a comprehensive list of 966 potential palliative care services or items across all of the listed domains. Items varied with respect to methods and frequency of patient assessment, complexity of management, and types of referral. Scope limited to adult patients with advanced solid tumors and/or considerable symptom burden (similar to ASCO Palliative Care PCO).
- Panelists asked to rate each item on the 3 following (1-9) scales:
 - Importance:** Within the medical oncology office, how essential is this item/service to the delivery of high-quality care to patients with advanced cancer?
1 = not important; 5 = somewhat important; 9 = essential (absolutely important)
 - Feasibility:** How feasible is it for a medical oncology practice like yours (or like the practices you interact with most) to provide this item/service?
1 = infeasible; 5 = possibly feasible; 9 = definitely feasible
 - Scope of practice:** how reasonable is it to expect that this item/service should be provided by medical oncology practices?
1 = extremely unreasonable; 5 = neither reasonable nor unreasonable; 9 = extremely reasonable
- Disagreement: At least 6 panelists rated an item in the top third of the scale (7, 8, or 9) and at least 6 panelists rated the same item in the bottom third (1, 2, or 3);
- Agreement: 'High' when an item had a median of 7-9 (or 1-3) without disagreement.
- Item Inclusion Categories:**
 - Include:** Items had High agreement (median 7-9) in all 3 scales
 - Uncertain:** Items not meeting Include or Exclude criteria
 - Exclude:** Items had High agreement (median 1-3) in all 3 scales

Results

Figure 1. Distribution of palliative care survey items by Core Palliative Care Domain and by inclusion category, in rank order of highest percentage of included items.

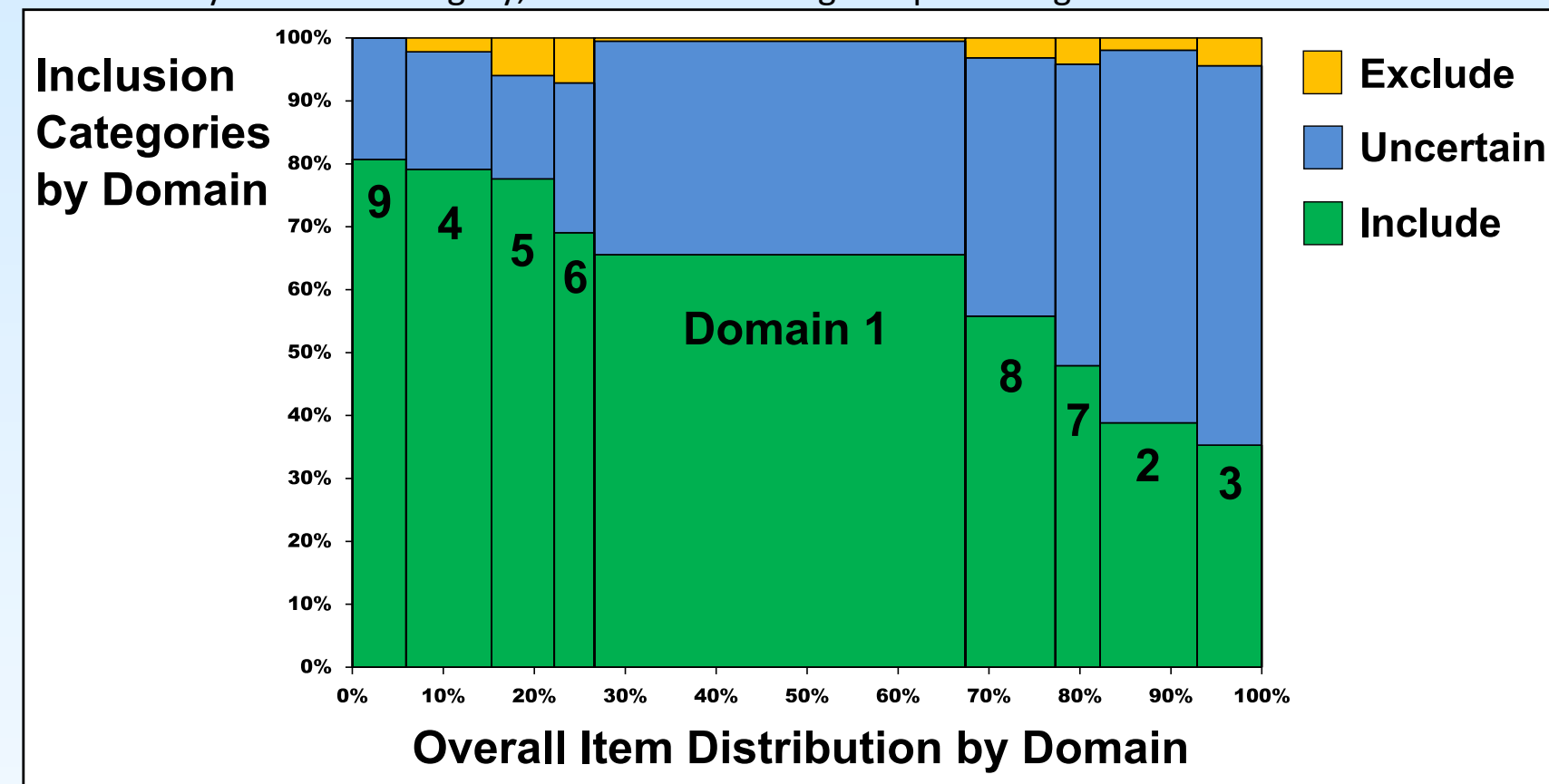


Figure 2. Distribution of palliative care survey items by item type and by inclusion categories, in rank order of highest percentage of included items.

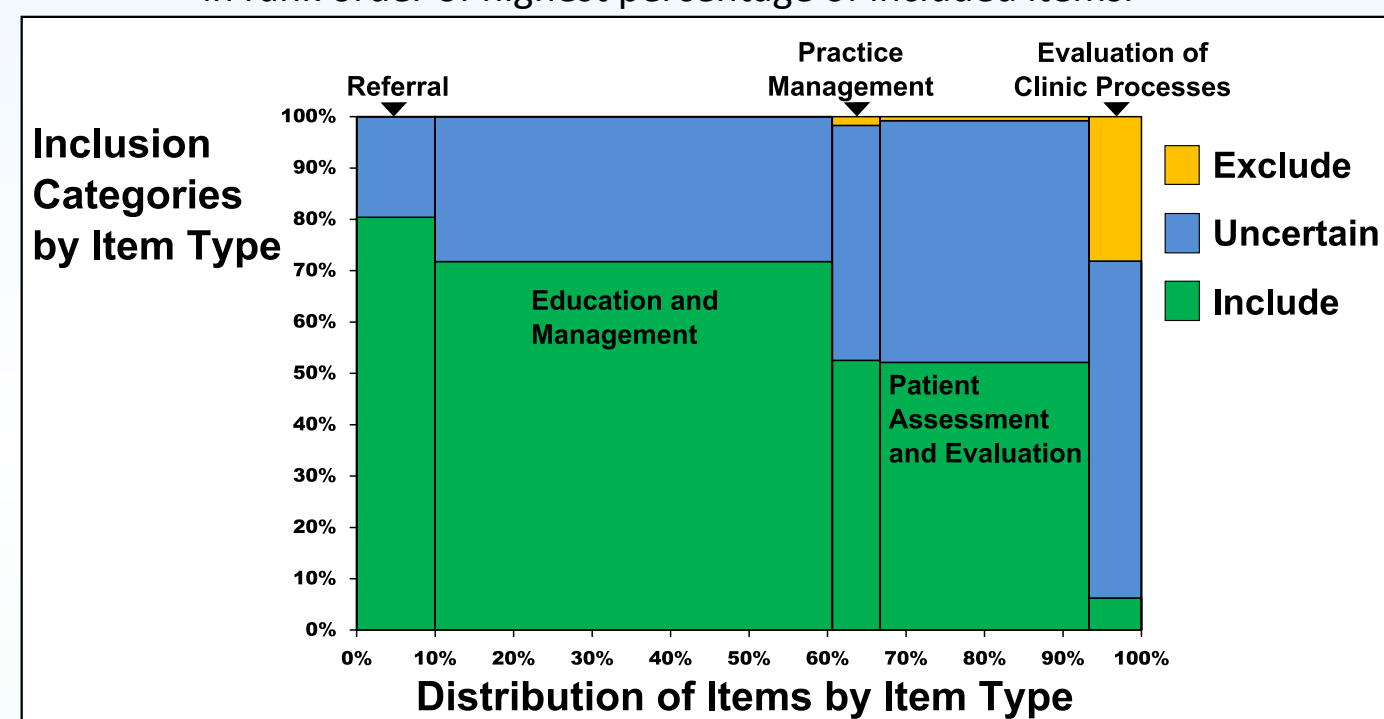


Figure 3. Distribution of palliative care survey items by item type in Domain 1: Symptom Management and Assessment, by symptom and by inclusion category, in rank order of highest percentage of included items.

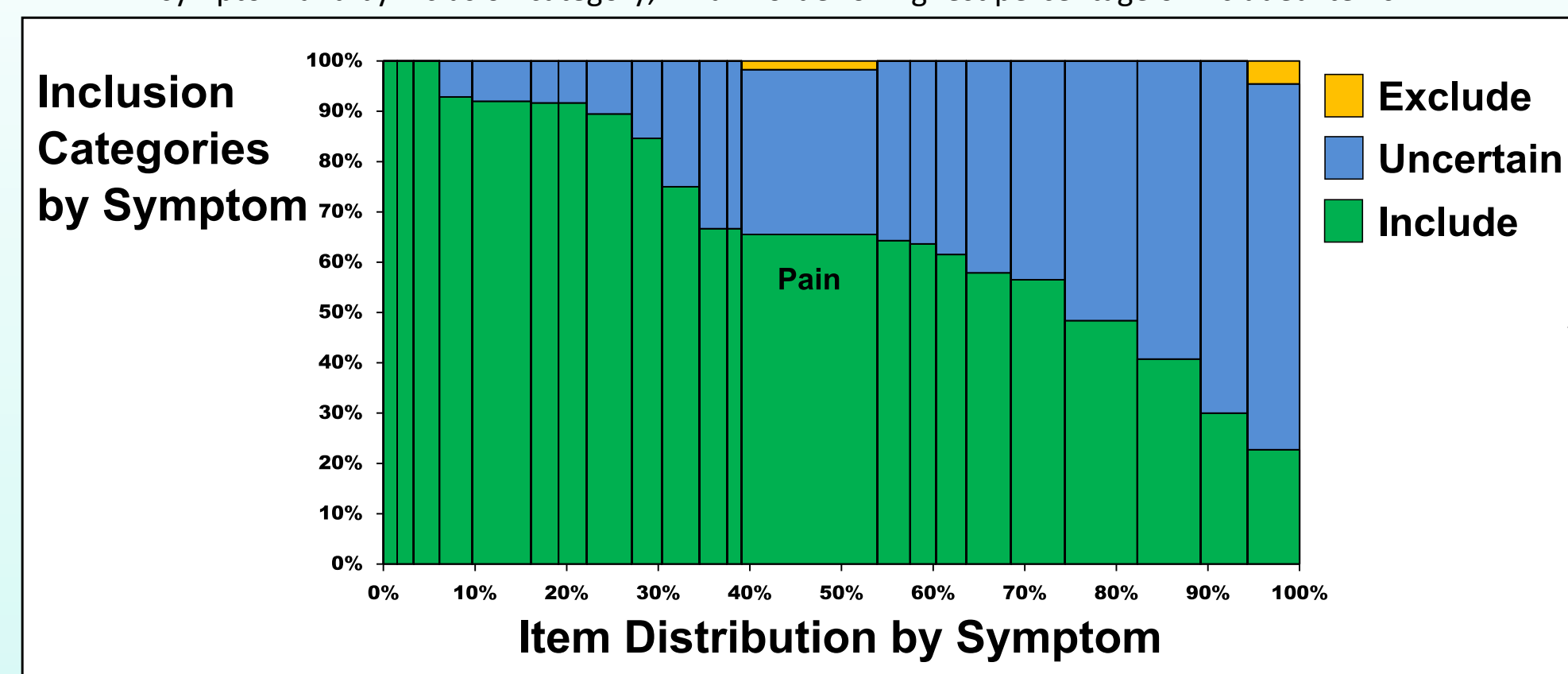


Table 1. Distribution of palliative care survey items by Core Palliative Care Domain and by inclusion category, in rank order of highest percentage of included items.

Domain (Column %)	Inclusion Category			Total Items
	Include	Uncertain	Exclude	
9. End-of-Life Care (6%)	46 (81%)	11 (19%)	0 (0%)	57
4. Communication & Shared Decision-Making (9%)	72 (79%)	17 (19%)	2 (2%)	91
5. Care Planning (7%)	52 (78%)	11 (16%)	4 (6%)	67
7. Appropriate Palliative Care & Hospice Referral (4%)	29 (69%)	10 (24%)	3 (7%)	42
1. Symptom Assessment & Management (41%)	259 (65%)	134 (34%)	2 (1%)	395
8. Carer Support (10%)	53 (56%)	39 (41%)	3 (3%)	95
6. Coordination & Continuity of Care (5%)	23 (48%)	23 (48%)	2 (4%)	48
2. Psychosocial Assessment & Management (11%)	40 (39%)	61 (59%)	2 (2%)	103
3. Spiritual and Cultural Assessment & Management (7%)	24 (35%)	41 (60%)	3 (4%)	68
Totals	598 (62%)	347 (36%)	21 (2%)	966

Table 2. Number of palliative care survey items in Domain 1: Symptom Management and Assessment in the 'Include' and 'Uncertain' categories, listed in rank order of highest percentage of included items. *Category included items with different assessment frequencies, and thus will have less 'Include' items than other symptom categories.

Symptom*	Include	Uncertain
1. Chemotherapy-related Toxicity	6	0
2. Nausea/Vomiting (not on chemo)	7	0
3. Diarrhea	11	0
4. Dyspnea	13	1
5. Cough	23	2
6. Fatigue	11	1
7. Pruritis/Rash	11	1
8. Mucositis/Dysphagia	17	2
9. Cachexia/Weight Loss	11	2
10. Nausea/Vomiting (on chemo)*	12	4
11. Constipation/Ileus/Obstruction	8	4
12. Ascites	4	2
13. Pain*	38	19
14. Delirium	9	5
15. Lymphedema	7	4
16. Insomnia	8	5
17. General Symptoms*	11	8
18. Genitourinary Symptoms	13	10
19. General Patient Function*	15	16
20. Depression	11	16
21. Anxiety	6	14
22. General Depression/Anxiety*	5	16

Table 3. List of example survey items grouped by inclusion category, categorized by Core Palliative Care Domain and item type.

Palliative Care Survey Item	Inclusion Category	Domain	Item Type
Systematically assess for pain using a validated quantitative instrument at every clinical encounter	Include	1	Patient assessment and evaluation
Assess patient for distress at initial clinical encounter	Include	2	Patient assessment and evaluation
Provide patients with a framework to consider both their hopes and medical likelihoods	Include	3	Management and education
Assess patient/family goals of care at time of diagnosis	Include	4	Patient assessment and evaluation
Explain that from a legal standpoint, there is no difference between stopping and choosing not to start any particular 'life-sustaining treatment'	Include	5	Management and education
Have a clinic protocol for sharing prognosis, treatment plan, and current illness status with other providers	Include	6	Practice management
Refer patient to hospice when median life-expectancy is 3 months or less	Include	7	Referral
Send a condolence card to the family/caregiver	Include	8	Management and education
Describe expected signs and symptoms of impending death to family and loved ones	Include	9	Management and education
In patients not appropriate for hospital admission, manage delirium with environmental modifications, such as familiar objects, normal day/night cycle, etc.	Uncertain	1	Management and education
Refer patient to complementary alternative medicine (CAM) provider for pain management	Uncertain	1	Referral
Obtain patient feedback regarding clinic process of advance care planning	Uncertain	5	Evaluation of clinic processes
Assess patient/family goals of care at each visit	Uncertain	4	Patient assessment and evaluation
Openly acknowledge and apologize for mistakes both orally and in writing	Uncertain	4	Practice management
Refer patient to hospice only when 'cancer-focused' treatment is not/no longer an option	Uncertain	7	Referral
Provide support to recently bereaved family/caregiver	Uncertain	8	Management and education
Provide palliative sedation in a patient who is imminently dying	Uncertain	9	Management and education
Have all patients receiving narcotics sign narcotic agreements	Exclude	1	Practice management
Obtain patient feedback regarding clinic process of assessing and managing spiritual and cultural issues using a standardized form at every clinical encounter	Exclude	3	Evaluation of clinic processes
Assess for changes/updates to advance care plan at every visit	Exclude	5	Patient assessment and evaluation

Conclusions

Data Summary and Process Comments

- Of 966 potential palliative care practice items, the Delphi consensus panel rated 598 (62%) items as being important, feasible and within scope of a general adult oncology practice in the United States for adult patients with advanced/metastatic solid tumors and/or considerable symptom burden.
- Only 21 (2%) of items were felt to be clearly not important, infeasible, and outside of scope of a general adult oncology practice.
- 347 items (36%) remained uncertain, falling into neither one of these categories.
- Panelists strongly considered the various types and resources of oncology practices across the country.
- Obtaining agreement on specific timing/frequency of assessment or reassessment was difficult for many of the items.
- Although the number and types of items in each Domain varied, panelists overall were less likely to rate psychiatric, psychosocial, or spiritual items highly.
- A large number of 'Include' items were practice items that oncologist panel participants were already providing as a part of their routine practice.
- Other 'Include' items were less routinely performed, and represent the potential for practice improvement in these areas.

Implications

- A summary statement of all Include items is being developed to guide improvement of palliative care delivery within a general oncology practice.
- This summary statement will be intended to form a reasonable starting place for informing primary palliative care delivery standards in oncology, but will not specify specific metrics or outcomes. However, metric development may be informed by the data from this consensus process.
- Items falling into the 'Uncertain' category through this consensus process does not imply that these items are not important or are not potentially within scope of oncology practice. Instead these items suggest additional areas for exploration and/or may represent items that are more experience or resource dependent.