

Current State of Palliative Care within Malignant Hematology

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Disclosures

- I have no financial disclosures or conflicts of interest

Outline

- Overview of End of Life challenges
- Palliative Care Role
- Barriers to Palliative Care and Hospice

Hematologic Malignancies - Challenges

- **Unpredictable illness trajectory**
 - Long lasting disease vs death within a few days of diagnosis
 - Difficult to predict disease progression
- **High symptom burden**
 - Similar to solid malignancies however fatigue more common
- **Transfusion Dependence**
 - No clear definition on frequency of transfusion
- **Healthcare Utilization**
 - High rates of hospitalization in last 30 days, ICU admissions, ED visits
 - Short hospice durations

End-of-life Care Quality Outcomes among Medicare Beneficiaries with Hematologic Malignancies

Patients with blood cancers receive
aggressive end of life care

Hospice use in solid tumor malignancies is
associated with improved EOL care
quality

Hospice use among patients with blood cancers was
associated with:

Decreased inpatient deaths

Decreased ICU admissions and chemotherapy use

Decreased Medicare spending at EOL



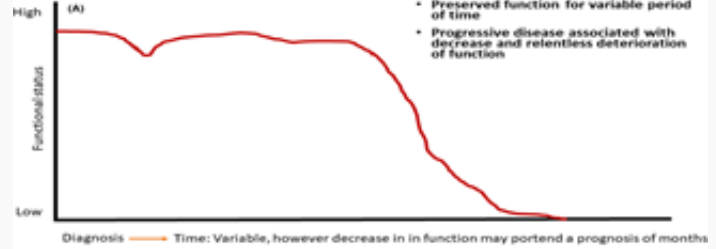
We analyzed hospice use among
Medicare beneficiaries who died of blood
cancers in 2008-2015

Only 57% of decedents enrolled on
hospice at the EOL

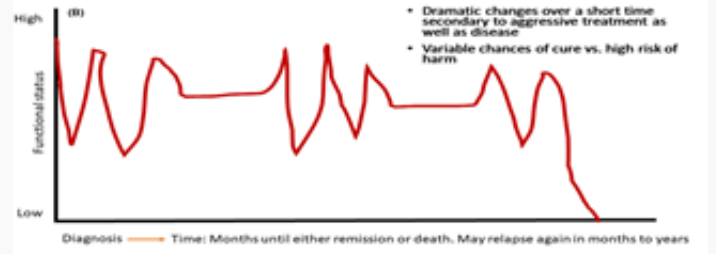
Hematologic Illness Trajectories

- Less predictable than typical solid tumor trajectory
- Have possibility of transforming between trajectories
- Leads to clinician uncertainty when discussing prognosis

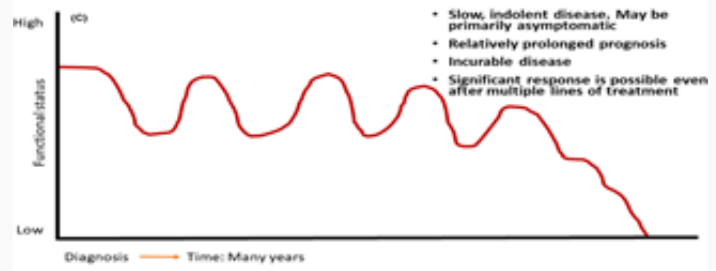
Solid Tumor



Aggressive HM: The Rollercoaster



Indolent HM: War of Attrition



Bone Marrow Failure: Transfusion Tether



Patient Prognostic Misconceptions

- Misperceptions about treatment risks/benefits
 - 90% of elderly AML patients believed they had somewhat or very likely chance of cure whereas hematologists estimated chance of cure 31%
- Patients want to know their prognosis/information
 - However awareness of poor prognosis has led to high psychologic symptoms



Current situation of care

- Less likely to receive palliative care consult and hospice care than solid oncology
- Given heterogeneity of diseases, unclear trigger for palliative care involvement
- Hematologic malignancies account for 9.5% of cancer deaths however only 0.4% published studies regarding end of life care

	Palliative care	Hospice care	End of life care	Hospital care
Haematological malignancies	155	31	50	5
Blood cancer	146	17	26	6
Cancer	42 280	2732	3032	584

Table 1: Number of studies identified via PubMed using different search terms

Timing of “Goals of Care” conversations

- Late in the game typically
 - 42.5% address code status preferences in acute hospital stay or when death is imminent
 - ~25% address hospice for 1st time when death is imminent
- Racial disparities
 - Lower likelihood of having GOC discussions → increased aggressive EOL care



Potential Sign-Posts for GOC/Prognosis

- Relapsed/refractory disease
- Central nervous system involvement of disease
- Worsening performance status



Palliative Care Role in Hematologic Malignancies

	Disease trajectory	Types of disease	Suggestion for start of palliative care involvement	Reference
Indolent lymphoma, and chronic lymphocytic leukaemia	Low symptom burden, long course of the disease and low mortality	Indolent lymphoma, and chronic lymphocytic leukaemia	Symptomatic progress	EJawahri et al (2020) ³³
Multiple myeloma	Intermediate symptom burden, intermediate course of the disease and mortality	Multiple myeloma	Intermittent addition, based on reporting of patient-reported outcomes	Ramsenthaler et al (2019) ³⁴
Chronic graft versus host disease	High symptom burden, intermediate course of the disease and mortality	Chronic graft versus host disease	Integration at the time of diagnosis	El-Jawahri et al (2018) ³⁵
Acute myeloid leukaemia	High symptom burden, high mortality	Acute myeloid leukaemia	Early integration at the time of diagnosis	El-Jawahri et al (2021) ³⁸
Aggressive lymphoma	High symptom burden, high mortality	Aggressive lymphoma	Integration at the time of recurrent or refractory disease or when non-curative treatment is initiated	Odejide et al (2020) ³⁶

Table 2: When to start palliative care in treatment strategies for diseases with different progression trajectories

Palliative Care Integration and HSCT

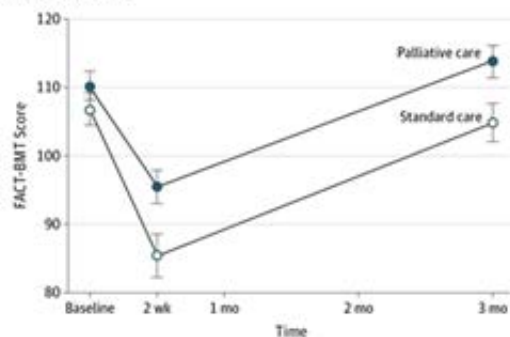
- HSCT
 - Long hospitalization (3-4 weeks typically) with physical symptoms and psychological symptoms
 - Physical symptoms predominantly include nausea, pain/mucositis, fatigue, sleep disturbances, constipation, and depression
 - Psychological symptoms of isolation and trauma in both patient and caregivers

Palliative Care and HSCT

- Randomized clinical trials looking at patients undergoing HSCT with standard of care vs integrated palliative care
 - Single center at MGH from 2014-2016
 - Evaluated both autologous (80 patients) and allogeneic (80 patients) transplants
 - Integrated palliative care service included *at least 2* visits a week focused primarily on symptoms

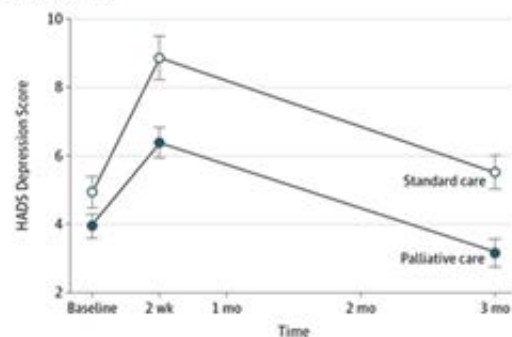
Figure 2. Patient-Reported Quality of Life, Depression, Anxiety, and Symptom Burden Outcomes Across All Time Points by Treatment Group

A Patient quality of life



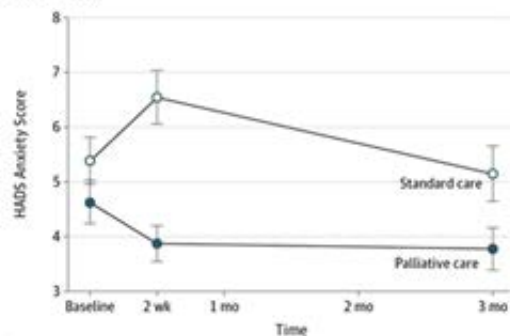
No. of patients			
Palliative care	81	80	75
Standard care	79	77	74

B Patient depression



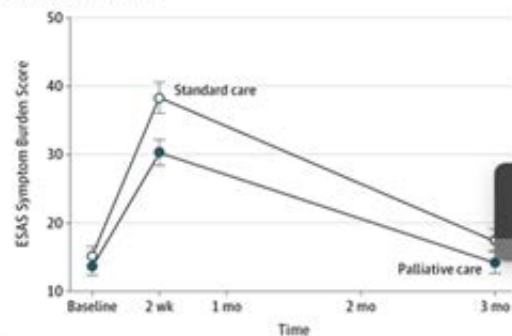
No. of patients			
Palliative care	81	80	74
Standard care	79	77	74

C Patient anxiety



No. of patients			
Palliative care	81	80	74
Standard care	79	77	74

D Patient symptom burden



No. of patients			
Palliative care	77	75	69
Standard care	79	77	71

Palliative Care Syringe

Table 2. Visit Content and Symptoms Addressed During Palliative Care Visits

Visit Content and Symptoms Addressed	No. (%)	
	Initial Palliative Care Consultation Visit (n = 81 Visits)	Subsequent Palliative Care Visits (n = 268 Visits)
Visit content		
Rapport building	80 (98.8)	182 (67.9)
Symptoms	72 (88.9)	237 (88.4)
Coping	69 (85.2)	170 (63.4)
Illness understanding	10 (12.3)	22 (8.2)
Treatment decision making	2 (2.5)	4 (1.5)
Advance care planning	2 (2.5)	8 (3.0)
Symptoms addressed		
Nausea	55 (67.9)	187 (69.8)
Pain	53 (65.4)	142 (53.0)
Diarrhea	43 (53.1)	102 (38.1)
Constipation	45 (55.6)	34 (12.7)
Fatigue	31 (38.3)	55 (20.5)
Insomnia	27 (33.3)	36 (13.4)
Anxiety	27 (33.3)	25 (9.3)
Depression	9 (11.1)	7 (2.6)



But wait.....

Palliative Care Integration and HSCT

- Inpatient palliative care integration led to improvements in PTSD and depression at 6 months
 - Associated with decreased symptom burden and anxiety during HSCT

Table 2. Effect of the Inpatient Palliative Care Intervention on Patient-Reported Outcomes at 6 Months Post-Transplant

Assessment	Adjusted Mean Score*	95% CI	Adjusted Mean Difference Between Groups	95% CI	P
HADS-D (n = 141)					
Control	4.66	3.93 to 5.38	-1.21	-2.26 to -0.16	.024
Intervention	3.45	2.70 to 4.19			
HADS-A (n = 141)					
Control	4.74	3.99 to 5.49	-0.61	-1.69 to 0.47	.267
Intervention	4.13	3.36 to 4.90			
PHQ-9 depression symptoms (n = 142)					
Control	5.58	4.57 to 6.60	-1.63	-3.08 to -0.19	.027
Intervention	3.95	2.93 to 4.96			
PCL (n = 134)					
Control	26.18	23.96 to 28.39	-4.02	-7.18 to -0.86	.013
Intervention	22.15	19.91 to 24.40			
FACT-BMT (n = 141)					
Control	109.39	105.38 to 113.41	2.72	-2.96 to 8.39	.346
Intervention	112.11	108.12 to 116.10			
FACT fatigue (n = 143)					
Control	37.38	34.64 to 39.83	0.10	-3.38 to 3.58	.957
Intervention	37.48	35.01 to 39.94			

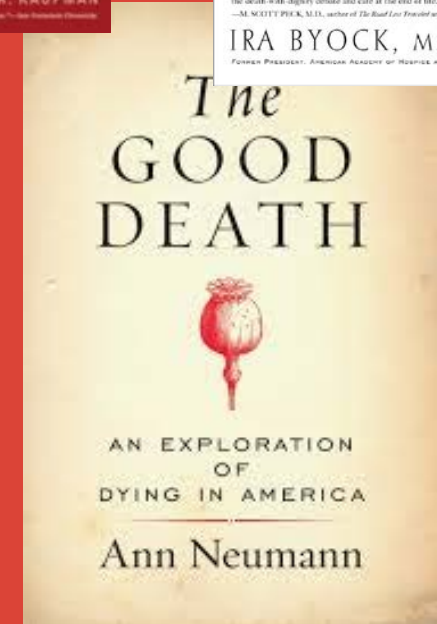
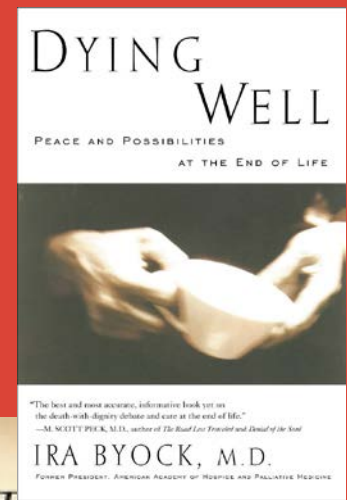
NOTE: Boldface indicates significant $P < .05$.
 Abbreviations: FACT-BMT, Functional Assessment of Cancer Therapy–Bone Marrow Transplant; HADS-A, Hospital Anxiety and Depression Scale anxiety subscale; HADS-D, Hospital Anxiety and Depression Scale depression subscale; PCL, Post-Traumatic Stress Disorder Checklist; PHQ-9, Patient Hospital Questionnaire 9.
 *The adjusted mean score is the predicted outcome score at the average baseline value for all participants.

El-Jawahri A, Traeger L, Greer JA, et al. Effect of Inpatient Palliative Care During Hematopoietic Stem-Cell Transplant on Psychological Distress 6 Months After Transplant: Results of a Randomized Clinical Trial. *Journal of Clinical Oncology*. 2017 Nov 10;35(32):3714-3721. doi: 10.1200/JCO.2017.73.2800. Epub 2017 Sep 19.

SCOPE-Leukemia

- Primary vs Specialty Palliative Care
 - Caveat hematologists receiving additional palliative care training
- Randomized Hospitals (not patients)
- Patient Inclusion Criteria
 - Hospitalized patients (age ≥ 18 years) with **high-risk AML**
- Outcomes
 - Primary: Quality of Life
 - Secondary: Anxiety/Depression, PTSD, EOL communication, EOL care, Caregiver QOL

What is a “Good Death”?



Barriers to Palliative Medicine and Hospice

Illness-Specific Barriers

- Illness trajectory that often requires intensive treatments with significant morbidity and mortality
- Absence of a clear transition between curative and palliative phase of treatment
- Prognostic uncertainty

Cultural Barriers

- Misperceptions that equate palliative care with just EOL care
- Oncologists' reluctance to involve other providers in their patients' care
- Lack of knowledge with regard to the potential role of palliative care

Barriers to Palliative Care Integration

System-Based Barriers

- Exclusion of patients with hematologic malignancies from prior palliative care intervention trials in oncology
- Inadequate outpatient palliative care infrastructure and shortage of palliative care clinicians

Illness-Specific Barriers

- Unpredictable illness course with cure as possibility of treatment
- Significant symptoms associated with disease and treatment



Cultural Barriers

- Hematologists tend to be lone cancer providers vs team based approach in solid malignancies
- View palliative care as end-of-life care
- Issues relate to treatment goals, loss of control, trust, and disease characteristics
- Infrequent prognosis discussions with 1 in 5 hematologists not discussing after initial consultation

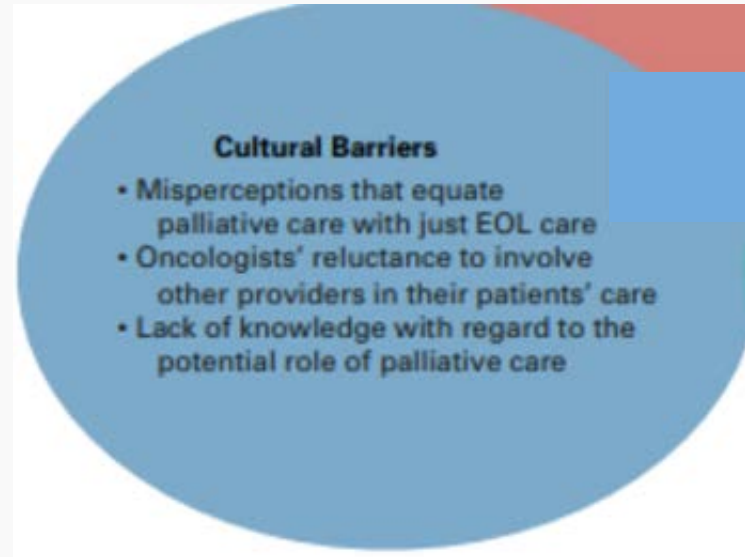


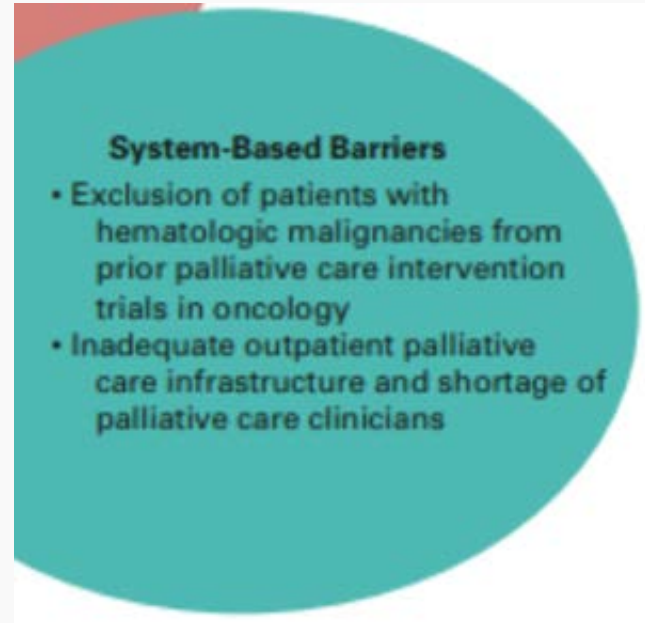
Table 3. Predominant Views of Palliative Care by Oncologist Type

Oncologist Type	Comment
Hematologic malignancy	
Palliative care is end-of-life care	"When you talk about palliative care, [you're] really gonna stop any treatments."
Palliative care is solely end-of-life care	"Well, I generally don't refer very many people to palliative care, at least not early on, because I think for many patients that's a signal that they're not going to do well. And so I tend to wait until there's . . . you know, until there's some indication—both medically as well as from the patient—that <u>they're willing to accept the fact that their course may not be ideal.</u> "
Either/or: palliative versus cancer care	"How I usually come to the decision of a palliative care referral is: it can either be for patients for whom active oncologic treatment isn't really indicated anymore, either because they've sort of failed all available treatments or they're becoming progressively more symptomatic and their performance status is declining and/or they just don't wish to pursue treatment." "The patient has the right to hear that option when the probability of survival is low, when there's nothing else that they could be offered, that they are imminently dying, they should have the option of having a palliative care consult."
Solid tumor	
Specialist palliative care	"When you're referring for symptoms, it's usually pretty easy, actually. I'll say, "You know, there's a service here: they're internists who specialize in dealing with symptoms associated with cancer. I feel like we could use their help in taking better care of you."
Palliative care includes symptom management specialty expertise	"I had very positive experiences co-managing patients with them. . . I think that the important thing for patients to understand is that it's not a substitution for cancer care, it's really an adjunct and a value-added piece to cancer care."
Palliative care can be offered concurrently with cancer care (concept of comanagement)	"I think a lot of patients associate that with terminal disease, so I try to minimize that association for them. . . I tell them it's really about symptom management; it doesn't really have to do with the disease course."

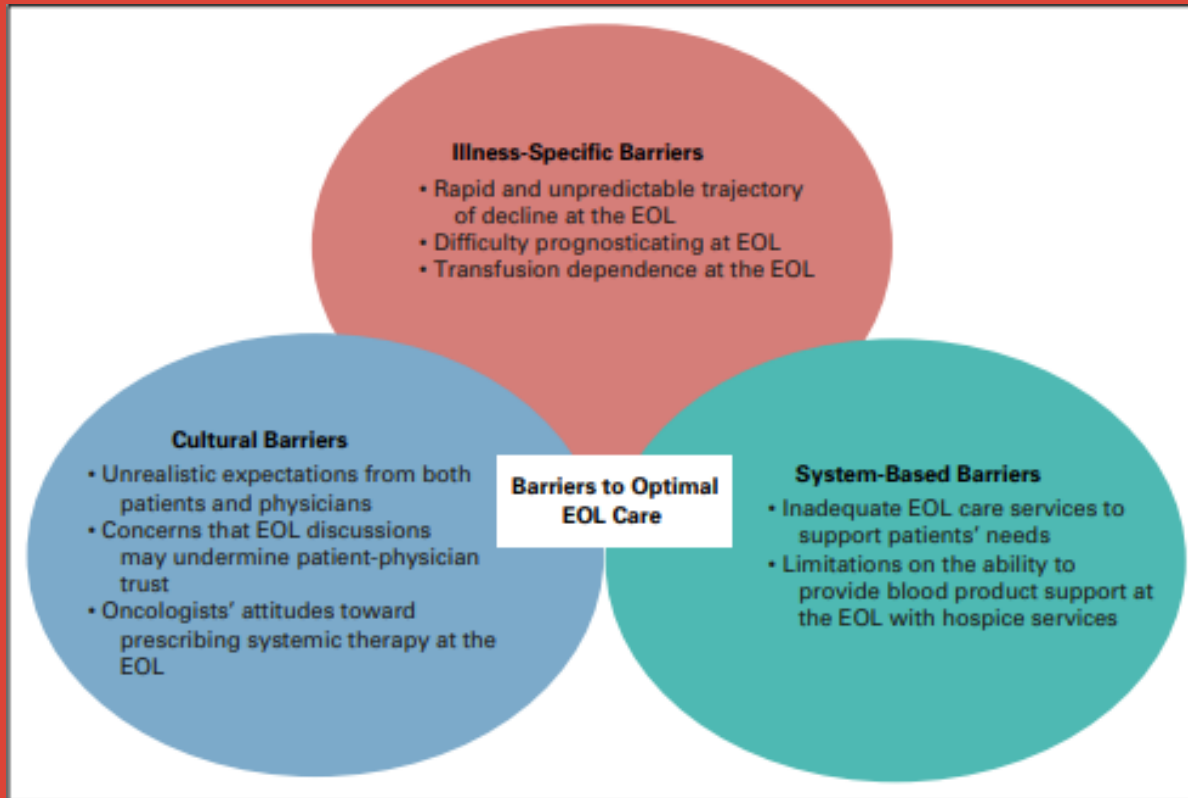
- Surveyed 23 hematologists and 43 solid tumor oncologists across multiple institutions

System-Based Barriers

- Unclear triggers
 - The extent of prognostic uncertainty in patients with hematologic malignancies makes the identification of triggers for palliative care use rather challenging if only patients with incurable disease are referred for these services
- 52% of transplant specialists viewed palliative as only end of life
 - Curative treatment does not align with palliative care

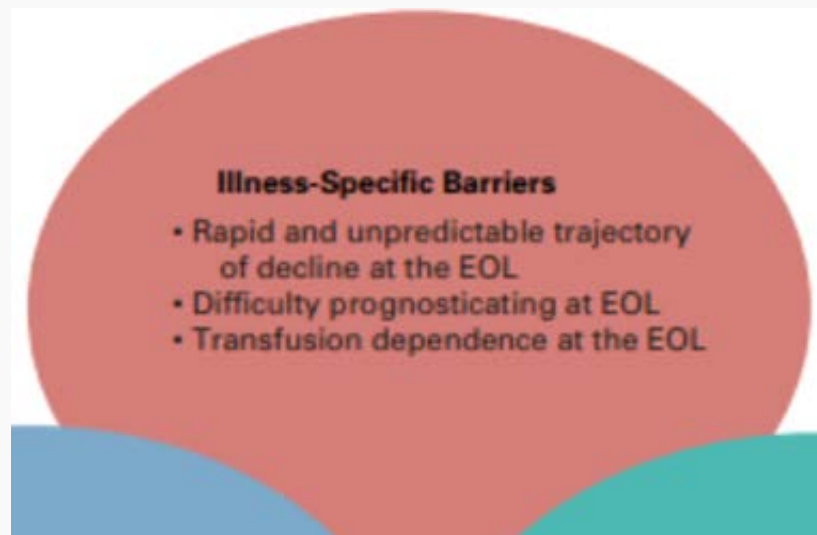


End of Life Barriers



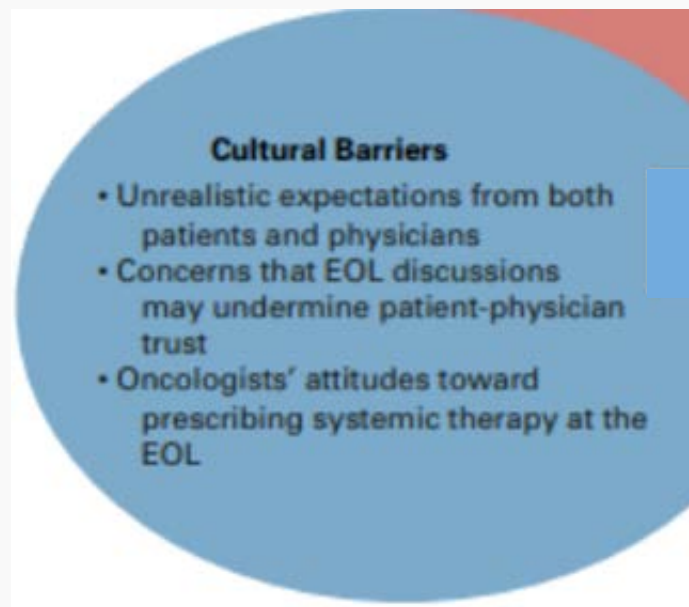
Illness-Specific Barriers to Hospice

- One review showed 50% of hematologic malignancy patients survive ICU admission
- Patients' and caregivers' comfort in inpatient setting given previous treatment related hospitalizations



Cultural Barriers to Hospice

- Less likely to be taking opioids at time of hospice enrollment
- Unrealistic patient (97.3%) and clinician (59%) expectations about disease prognosis, including treatment options and outcomes
- Clinicians' concerns about taking away hope from patients (71.3%)



Barriers to Hospice Care for Patients with Blood Cancers

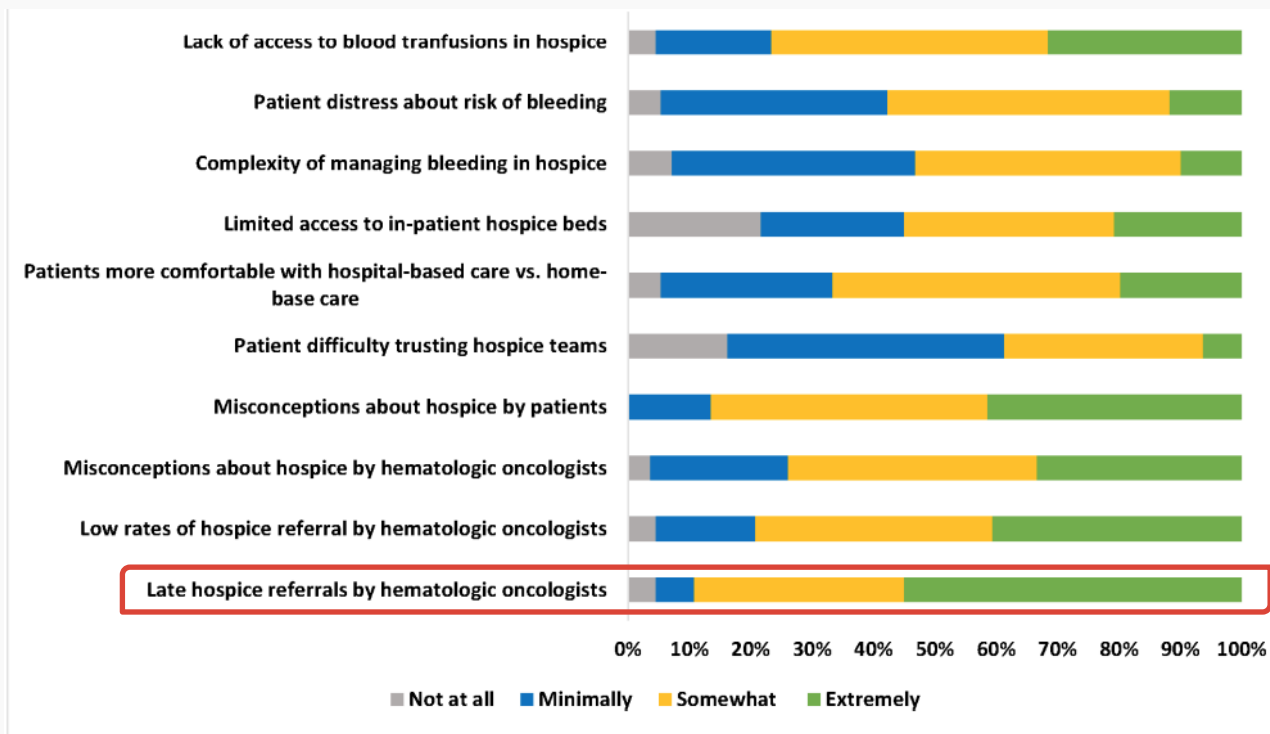
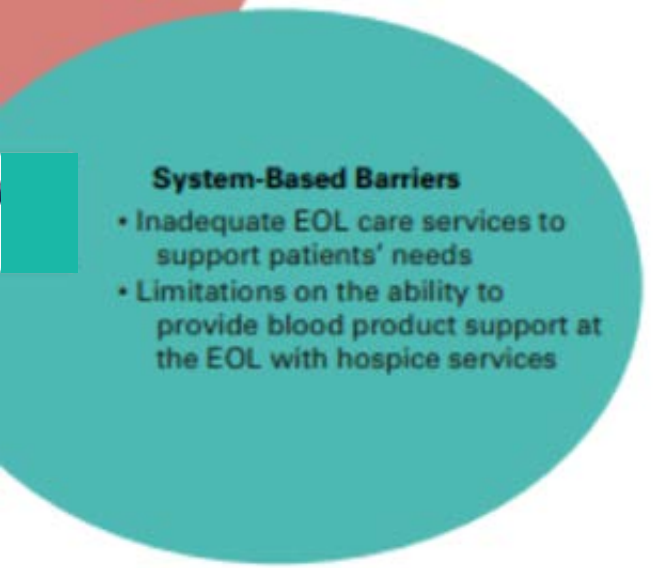


Figure 2. Barriers to Hospice Care for Patients with Blood Cancers.

“To what extent do you think each of the following is a barrier to hospice care for patients with blood cancers?”

System-Based Barriers to Hospice

- Late hospice referrals= short stays
 - Difficulties in mobilizing care
 - Financial difficulties for hospice companies
- Difficulty maintaining previous symptom relief treatments such transfusions and antibiotics



System-Based Barriers

- Inadequate EOL care services to support patients' needs
- Limitations on the ability to provide blood product support at the EOL with hospice services

Hospice Providers Perceived Barriers to Transfusions

- Characteristics of “pro”-friendly
 - Non-profit
 - Larger
 - Associated freestanding hospice facility

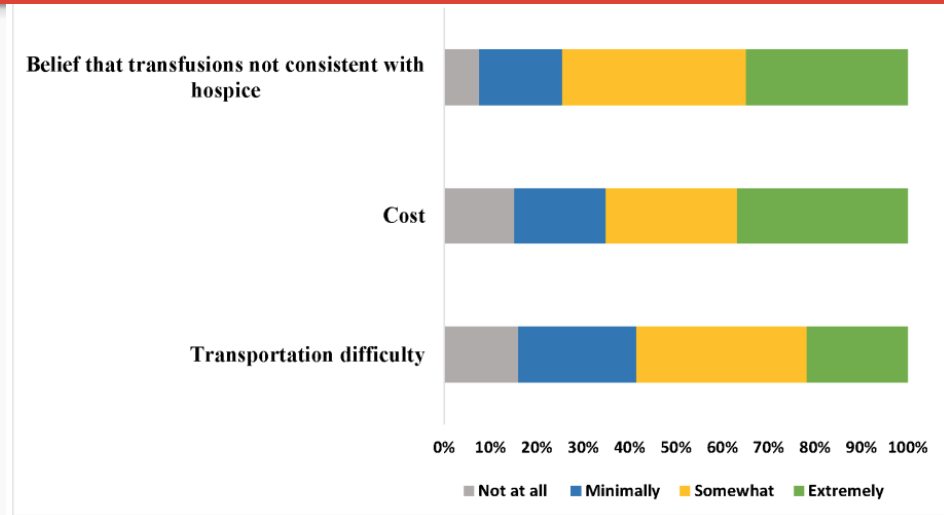


Figure 1. Barriers to availability of blood transfusions for blood cancer patients in hospice.

“To what extent do the following factors contribute to lack of availability of blood transfusions for blood cancer patients enrolled in your hospice?”

Assessed among 106 participants who noted that transfusions were never or only sometimes offered to patients with blood cancers enrolled in their hospice and answered all 3 questions about barriers to transfusions

Hematologic Oncologist Providers Perceived Barriers/Benefits to Transfusions

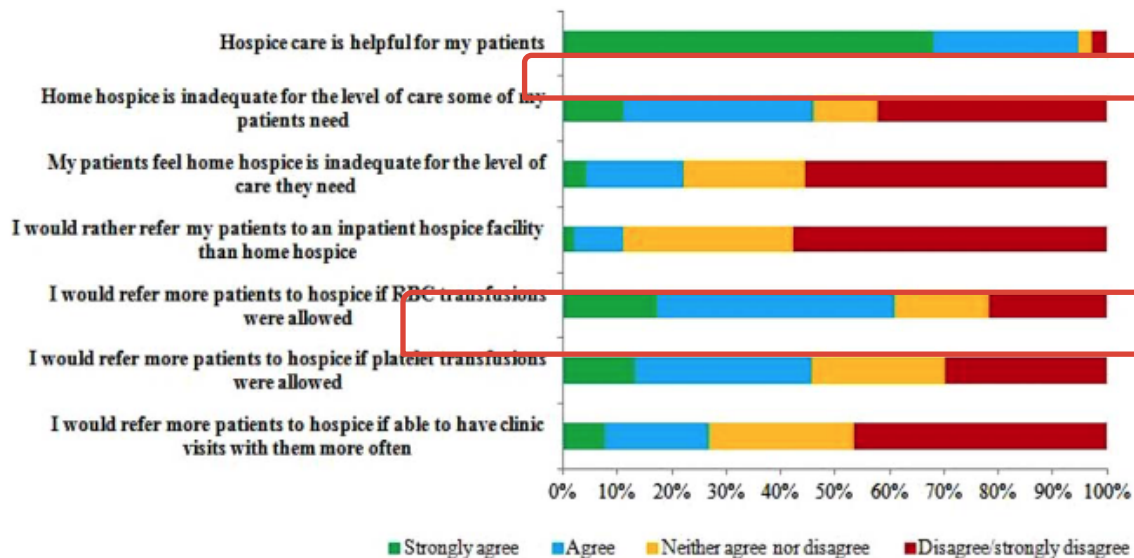


Figure 1. Hematologic oncologists' perspectives regarding hospice care for patients with hematologic cancers at the end of life (n = 332). RBC indicates red blood cell.

Strategies to Improve EOL Care

Policy

- Receipt of disease-directed treatment on hospice
- Higher hospice reimbursement
- Innovative hospice and payment models

Team Interactions

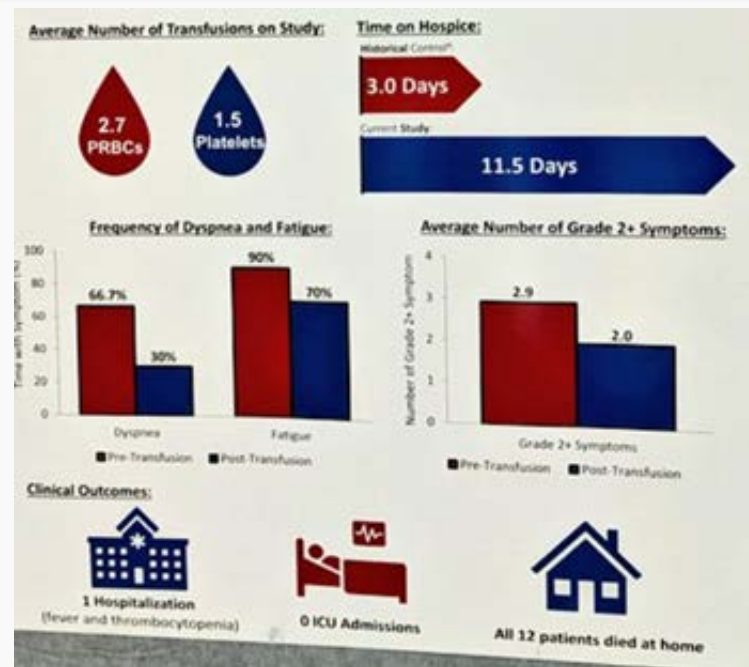
- Enhanced collaboration among hematology, palliative care, and hospice
- Early engagement of palliative care
- Involvement of multidisciplinary team members and families

Patient-oncologist Communication

- Early discussion of prognosis
- Exploration of patient goals and preferences throughout the illness trajectory
- Communication skills training and effective communication

Potential solutions to hospice problem

- Removing transfusion dependence as barrier
 - Home-based transfusion models
 - No hospice revocations
 - Few number of actual transfusions needed with improved symptoms



Questions

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