

Palliative Care: Science, perceptions and the patient experience

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Disclosures

The following faculty and planning committee staff have no financial disclosures:

| Name | Institution |
|----------------------|--|
| Eric Roeland, MD | University California San Diego Moores Cancer Center |
| Areej El-Jawahri MD | Blood and Marrow Transplant Program Massachusetts General Hospital |
| Effie Petersdorf, MD | University of Washington, Fred Hutchinson Cancer Research Center |
| Thomas LeBlanc, MD | Duke Cancer Institute |
| Ellen Denzen, MS | National Marrow Donor Program/Be The Match |
| Christa Meyer, MS | National Marrow Donor Program/Be The Match |

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| Christina Ullrich, MD, MPH | Boston Children's Hospital / Dana-Farber Cancer Institute Harvard Medical School | Schulman IRB |

Learning objectives

At the conclusion of this session, attendees will be able to:

- Synthesize the evidence-base for palliative and supportive care in HCT
- Discuss HCT physicians' perceptions of and attitudes on the gaps in delivering palliative and supportive care
- Recognize the collaborative role of the multi-disciplinary care team in meeting palliative and supportive care needs of HCT patients
- Discover barriers to palliative and supportive care and the patient/caregiver experience

Integration of Palliative Care into the Care of Hematopoietic Stem Cell Transplantation Patients

Eric Roeland, MD, FAAHPM

Oncology & Palliative Care

UC San Diego Moores Cancer Center

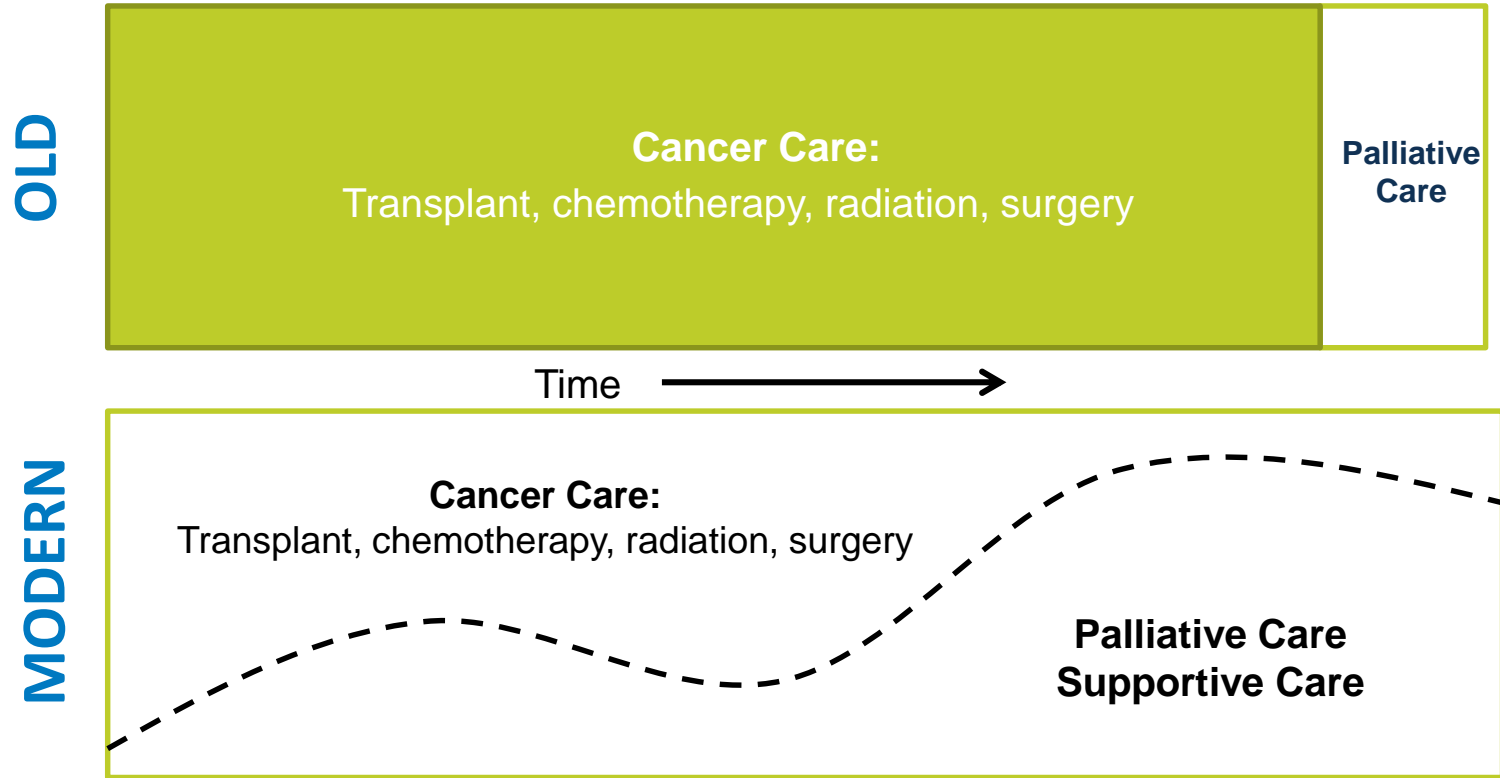
Outline

- Discuss the difference between palliative care and hospice care
- Briefly review the data regarding palliative care integration into solid tumor cancer care
- Review palliative care needs in hematologic malignancies
- Review SHIELD palliative care study

Palliative Care Compared to Hospice



Palliative Care: Old & New Approaches



Integrative Palliative Care Studies in Oncology

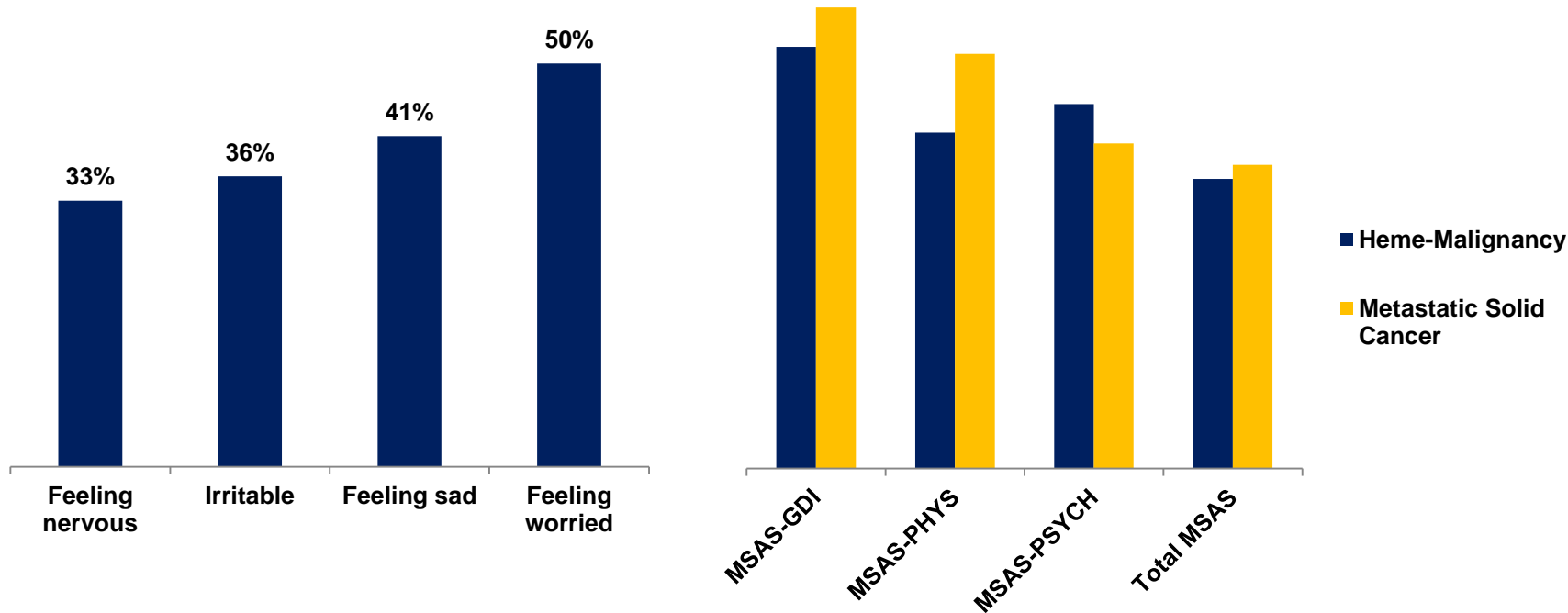
- 7 randomized controlled trials
 - Bakitas et al, 2009 ENABLE II study
 - Temel et al, 2010
 - Zimmerman et al, 2014
 - Bakitas et al, 2015 ENABLE III study
 - Grudzen et al, 2016
 - Temel et al, 2016
 - **El-Jawahri et al, 2016**
- Reference slides attached to end of presentation as a resource
- **No study to date has shown harm**

Professional Society Recommendations

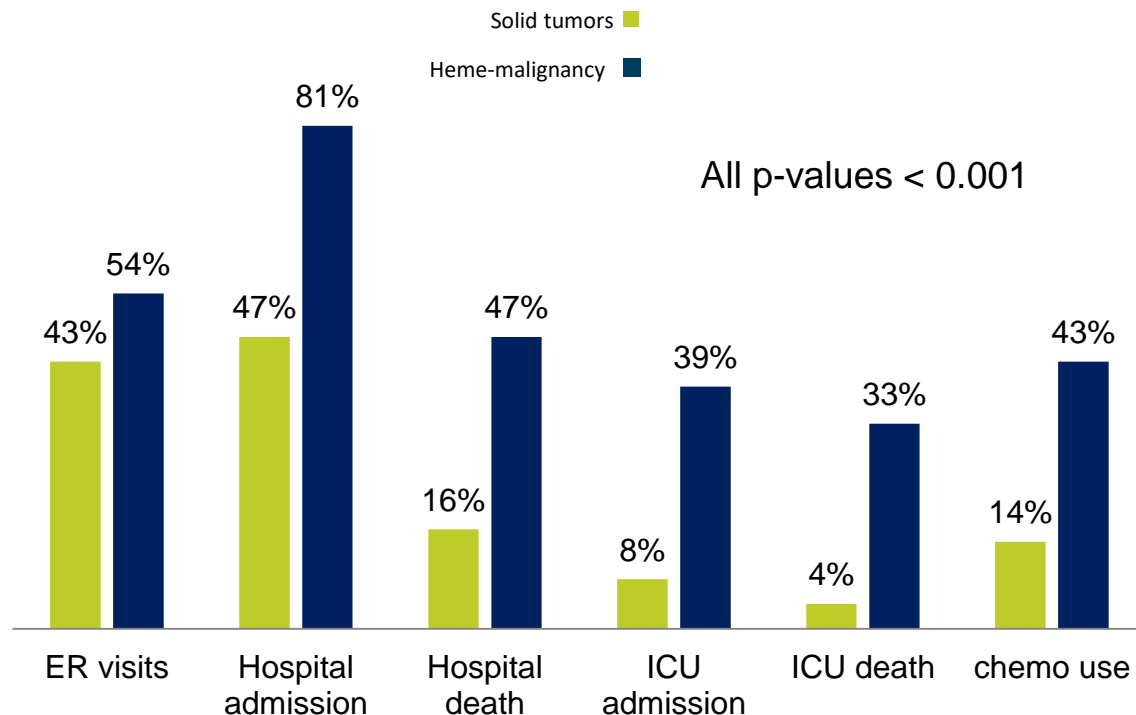
- **American Society of Clinical Oncology**
 - “any patient with metastatic cancer \pm high symptom burden”
- **American College of Surgeons, Commission on Cancer**
 - “required to offer palliative care either on site or by referral”
- **National Comprehensive Cancer Network**
 - “develop processes for integrating palliative care into cancer care, both as part of usual oncology care and for patients with specialty palliative care needs”
- **Oncology Nursing Society**
 - “All patients with cancer benefit from palliative care
 - “Palliative care should begin at time of diagnosis”

What about hematopoietic stem cell transplantation (HSCT)?

High Symptom Burden in Hematologic Malignancies



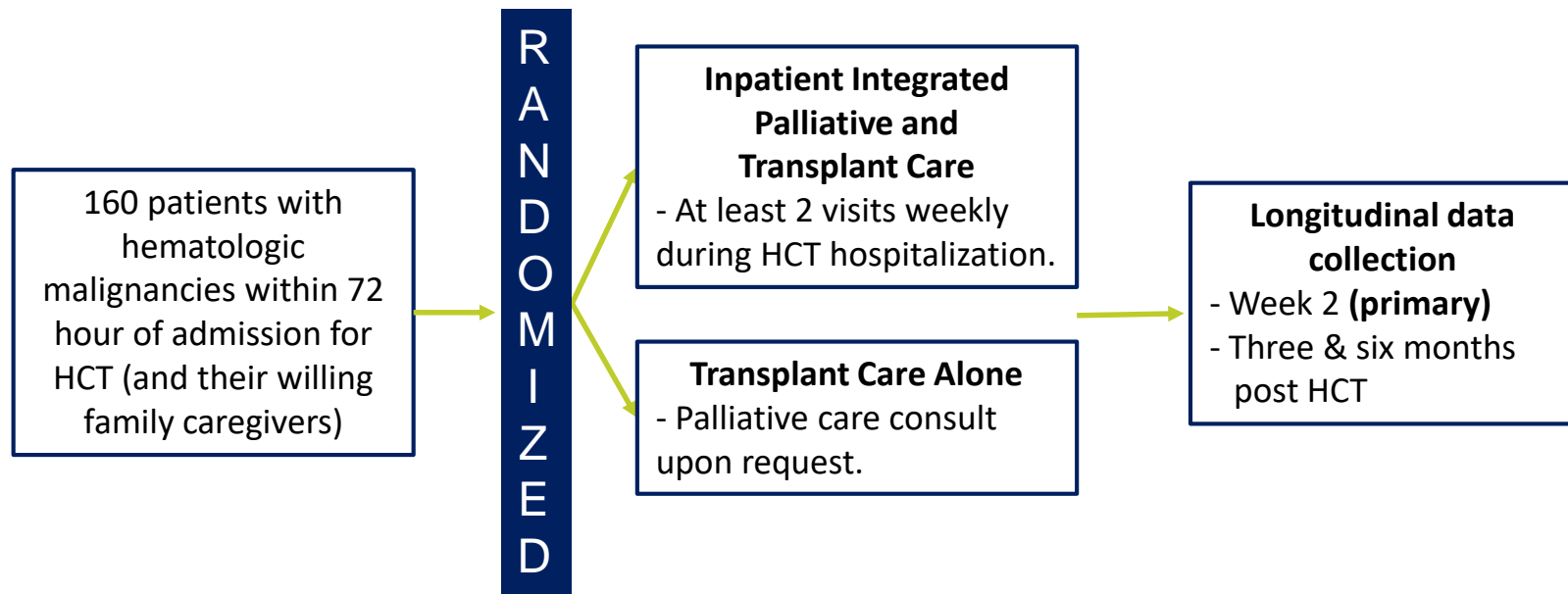
Unmet End-of-Life Needs in Hematologic Malignancies



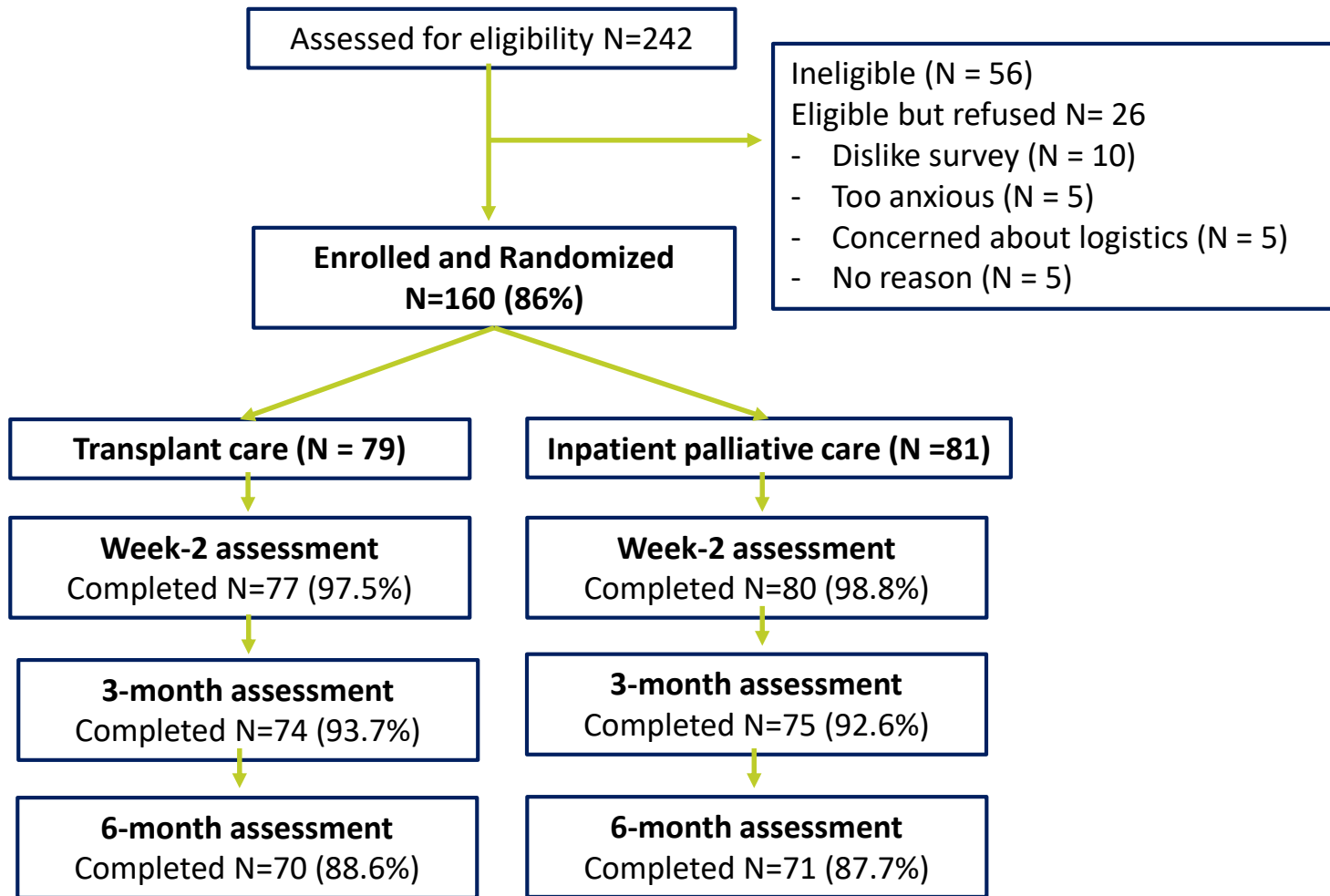
Hematologic Malignancies: Unmet Palliative Care Needs

- Patients with hematologic malignancies have substantial unmet palliative care needs throughout their illness trajectory
 - Psychological trauma of unexpected diagnosis
 - Intensive therapies leading to significant symptom burden
 - Unmet end-of-life care needs
 - Survivors struggle with long-term complications

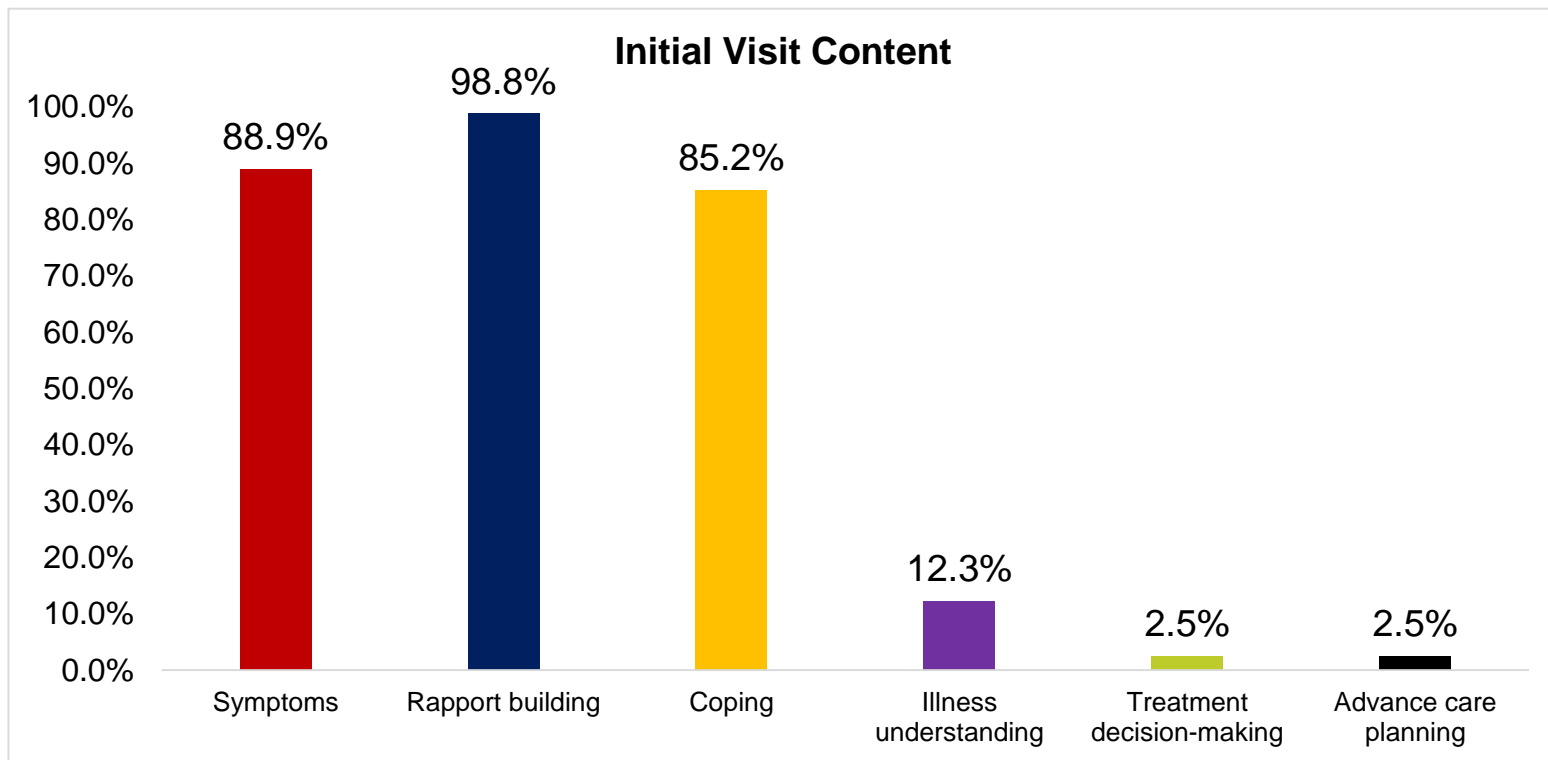
SHIELD: Study Design



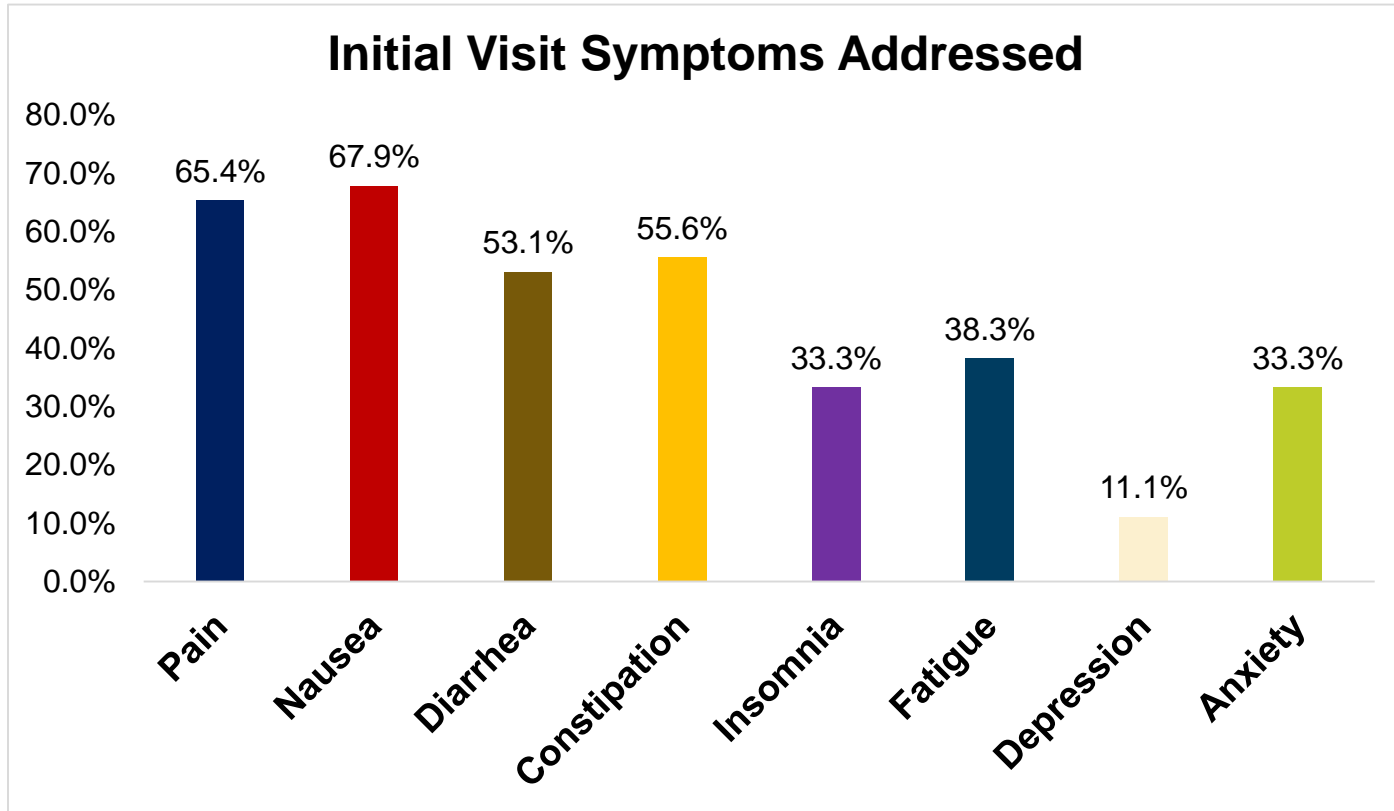
SHIELD: Study Schema



SHIELD: Palliative Care Intervention



SHIELD: Palliative Care Intervention



SHIELD: Patient Week-2 Outcomes

| Week-2 Outcomes | Adjusted Mean Difference | 95% CI | P- Value |
|----------------------------|--------------------------|-----------------|------------------|
| FACT – BMT | 7.73 | 1.27 to 14.19 | 0.019 |
| FACT – Fatigue | 3.88 | 0.21 to 7.54 | 0.038 |
| ESAS – Symptom Burden | -6.26 | -11.46 to -1.05 | 0.019 |
| HADS – Depression symptoms | -1.74 | -3.01 to -0.47 | 0.008 |
| HADS – Anxiety symptoms | -2.26 | -3.22 to -1.29 | <0.001 |
| PHQ-9 – Depression | -1.28 | -2.82 to 0.27 | 0.104 |

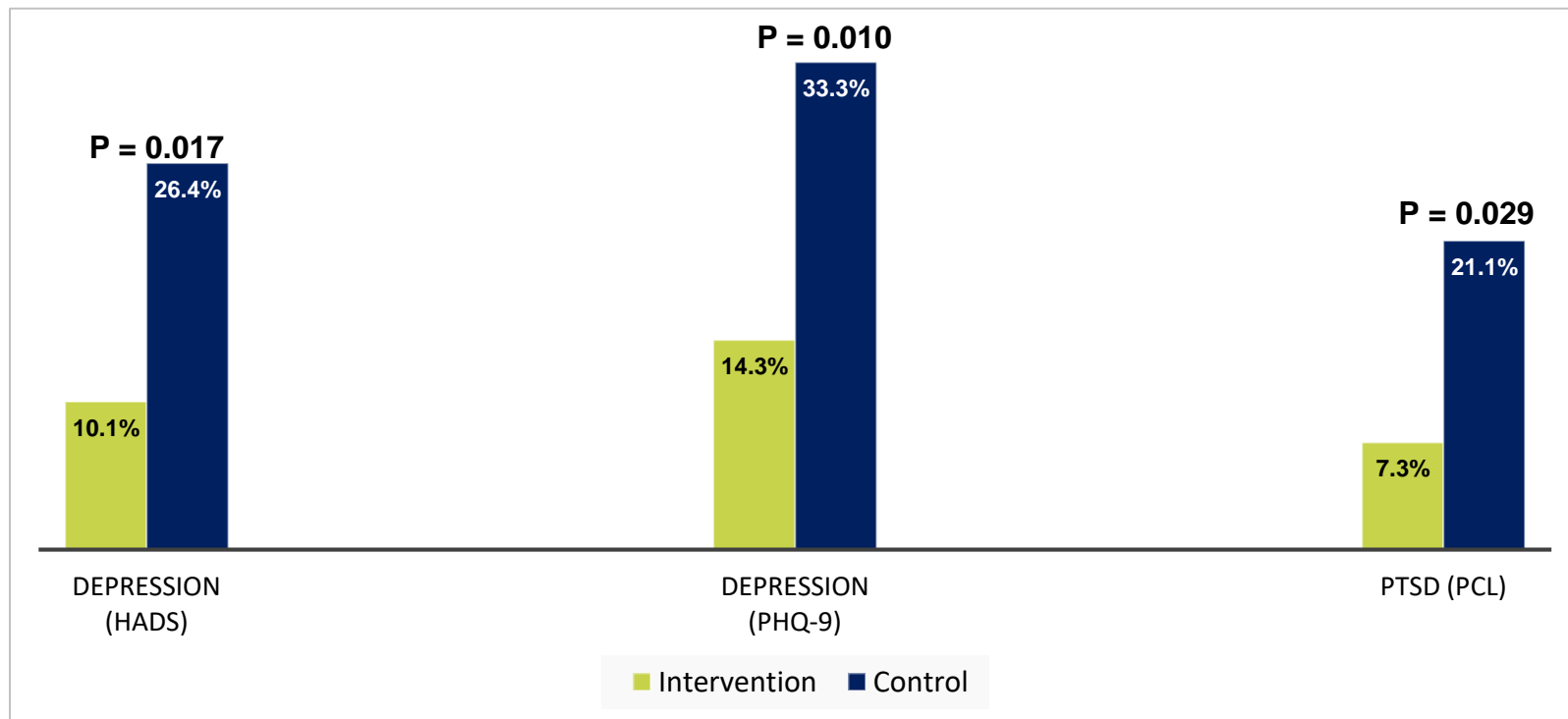
SHIELD: Patient 3-Month Outcomes

| 3-Month Outcomes | Adjusted Mean Difference | 95% CI | P- Value |
|----------------------------|--------------------------|----------------|--------------|
| FACT – BMT | 5.34 | 0.04 to 10.65 | 0.048 |
| FACT – Fatigue | 2.00 | -1.08 to 5.09 | 0.202 |
| ESAS – Symptom Burden | -2.44 | -6.29 to 1.41 | 0.212 |
| HADS – Depression symptoms | -1.70 | -2.75 to -0.65 | 0.002 |
| HADS – Anxiety symptoms | -0.76 | -1.73 to 0.23 | 0.130 |
| PHQ-9 – Depression | -2.12 | -3.42 to -0.81 | 0.002 |
| PCL – PTSD Symptoms | -4.35 | -7.12 to -1.58 | 0.002 |

SHIELD: Patient 6-Month Outcomes

| 6 Month Outcomes | Adjusted Mean Difference | 95% CI | P- Value |
|-------------------------|--------------------------|----------------|--------------|
| FACT – BMT | 2.72 | -2.96 to 8.39 | 0.346 |
| FACT – Fatigue | 0.10 | -3.38 to 3.58 | .957 |
| HADS – Depression | -1.21 | -2.26 to -0.16 | 0.024 |
| HADS – Anxiety symptoms | -0.61 | -1.69 to 0.47 | 0.267 |
| PHQ-9 – Depression | -1.63 | -3.08 to -0.19 | 0.027 |
| PCL – PTSD Symptoms | -4.02 | -7.18 to -0.86 | 0.013 |

SHIELD: Psychological Distress at 6-Months



SHIELD: Caregiver Outcomes

| 2-week Caregiver Outcomes | Adjusted mean difference | 95% CI | P-value |
|---------------------------|--------------------------|----------------|--------------|
| HADS-Depression | -1.65 | -3.01 to -0.29 | 0.018 |
| HADS-Anxiety | -0.14 | -1.56 to 1.27 | 0.84 |
| QOL | 3.38 | -1.59 to 8.35 | 0.180 |

- **Improvement in two domains of QOL**
 - **Coping:** adjusted mean difference = 1.01, **P = 0.009**
 - **Administrative/finances:** adjusted mean difference = 0.67, **P = 0.029**

SHIELD: Palliative care in HSCT Summary

- Inpatient palliative care improved QOL, symptom burden, depression, and anxiety symptoms in patients with hematologic malignancies undergoing HCT.
- Caregivers also experienced improvement in certain domains of QOL and lower depression symptoms.
- A relatively brief inpatient palliative care intervention led to remarkable sustained improvements in patient depression and post-traumatic stress 3 & 6 months post-HCT.
- First study showing the benefits of palliative care for patients with hematologic malignancies undergoing curative therapy.

Where Do We Go from Here?

- Further need for proof-of-principal trials in novel populations of patients with hematologic malignancies
- Developing palliative care models that are tailored to the need of patients and their families
- Understanding mechanism of the benefits of palliative care
- Who benefits the most from early palliative care integration?
- Developing less resource-intensive models/ telemedicine
- Developing primary palliative care interventions

Palliative Care & Oncology Studies

| Study | Population | Intervention | Control | QOL /mood | Healthcare utilization | Survival | Caregiver outcomes |
|----------------|--|---|---------------------|-----------|------------------------|----------|--------------------|
| Bakitas 2009 | Advanced stage solid tumor with prognosis 1 year | n=161 Telephone-based, manualized, nursing-led multicomponent psychoeducational intervention | n=161 Usual care | ↑ | -- | -- | -- |
| Temel 2010 | Patients with newly diagnosed metastatic lung cancer | n=77 Early integrated PC with monthly outpatient PC clinic visits | n=74 Usual care | ↑ | ↓ | ↑ | -- |
| Zimmerman 2014 | Patients with stage III/IV lung, GI, GU, gynecologic cancer with prognosis 6-24 months | n=228 PC consultation and at least monthly follow-up in PC clinic | n=233 Usual care | ↑ | ↓ | -- | -- |

Palliative Care & Oncology Studies...

| Study | Population | Intervention | Control | QOL/ mood | Healthcare utilization | Survival | Caregiver outcomes |
|-----------------|--|--|--|--------------|---------------------------|--|-----------------------|
| Bakitas 2015 | Patients with advanced stage solid tumor or hematologic malignancy (n=10, 4.8%) with prognosis 6-24 months | n=104 Early initiation of PC (within 30-60 days of diagnosis) Involving outpatient in-person PC consult, 6 weekly telephone coaching session by advanced practice nurse using manual | n=103 Delayed initiation of PC (3 months after diagnosis) | -- | -- | One-year survival: yes Overall survival: no | ↑ |
| Grudzen 2016 | Patients with advanced stage solid tumor in the emergency department | n=69 PC consultation by inpatient team, refer to outpatient PC clinic if appropriate | n=67 Usual care | ↑ | ↓ | ↓ | -- |

Palliative Care & Oncology Studies...

| Study | Population | Intervention | Control | QOL/ mood | Healthcare utilization | Survival | Caregiver outcomes |
|-----------------|---|---|----------------------|---------------------------------------|---------------------------|----------|-----------------------|
| Temel 2016 | Patients with newly diagnosed incurable lung or noncolorectal GI cancer | n=175 Early integrated PC with monthly outpatient PC clinic visits | n=175 Usual care | Lung cancer : ↑ GI cancer : -- | | -- | pending |
| El-Jawahri 2016 | Caregivers of patients with new diagnosis of incurable lung or non-colorectal GI cancer | n=137 PC visit for patient within 4 weeks of enrollment and at least monthly until death. Caregivers encouraged, but not required to attend. | n= 138 Usual care | ↑ | -- | -- | ↑ |

Integrative Palliative Care Studies in Oncology Citations for Reference

1. 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*. 2009;302(7):741-749.
2. El-Jawahri A, Podgurski LM, Eichler AF, et al. Use of video to facilitate end-of-life discussions with patients with cancer: a randomized controlled trial. *Journal of Clinical Oncology*. 2010;28(2):305-310.
3. Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *The Lancet*. 2014;383(9930):1721-1730.
4. Bakitas MA, Tosteson TD, Li Z, et al. Early versus delayed initiation of concurrent palliative oncology care: Patient outcomes in the ENABLE III randomized controlled trial. *Journal of Clinical Oncology*. 2015;33(13):1438-1445.
5. El-Jawahri A LT, VanDusen H, et al. Effect of inpatient palliative care on quality of life 2 weeks after hematopoietic stem cell transplantation: a randomized clinical trial. *Jama*. 2016.
6. Ferrell BR, Temel JS, Temin S, et al. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of Clinical Oncology*. 2016;JCO. 2016.2070. 1474.
7. Grudzen CR, Richardson LD, Johnson PN, et al. Emergency Department–Initiated Palliative Care in Advanced Cancer: A Randomized Clinical Trial. *JAMA oncology*. 2016.



Transplant Physicians' Perspectives on Palliative Care

Areej El-Jawahri MD
Blood and Marrow Transplant
Program

Massachusetts General Hospital



MASSACHUSETTS
GENERAL HOSPITAL
CANCER CENTER



CANCER
OUTCOMES
RESEARCH

Outline

- Barriers to Palliative Care Integration
- Transplant Physicians' Perspectives on Palliative Care: A National Survey
- Overcoming Barriers with Successful Models of Integration
- Insights from Palliative Care and Transplant Physicians on a Model of Early Palliative Care Integration
- Where do we go from here?

Barriers to Palliative Care Integration

- Substantial unmet palliative and supportive care needs for patients undergoing HCT
 - Prior to transplant
 - During the acute hospitalization for HCT
 - Survivorship and chronic GVHD
 - End of life
- Barriers to palliative care utilization
 - Illness specific barriers
 - System based barriers
 - Cultural barriers

Illness Specific Barriers

- Patients with Hematologic Conditions are just different:
 - Prognostic uncertainty
 - Absence of clear transition between curative phase and palliative phase of treatment
 - Rapid and unpredictable trajectory of decline at the EOL
 - Complications at the EOL are also different:
 - Need for blood product support
 - Infectious complications
 - Bleeding complications

System-Based Barriers

- Lack of access to high-quality palliative care services
- Lack of Infrastructure for outpatient palliative care
- Difficulty managing GVHD complications in this population
- EOL care delivery models → not developed for this population
- Lack of understanding of what death looks like for a heme-malignancy patients
- Lack of preparation for family

El-Jawahri, Curr. Hematol 2016

El-Jawahri, JOP 2017



Cultural Barriers

- Misperceptions equating palliative care with just EOL care.
- Lack of exposure to palliative care – mistrust.
- Palliative care services have not been exposed enough to this population.

Leblanc, JOP 2015
El-Jawahri, JOP 2017



Transplant Physicians Survey

- Current access and collaboration with palliative care
- Physicians' sense of ownership over addressing palliative care issues
- Attitudes & perceptions of palliative care
- Perceived barriers to palliative care utilization
- Perceived unmet palliative care needs in this population

Transplant Physicians Survey

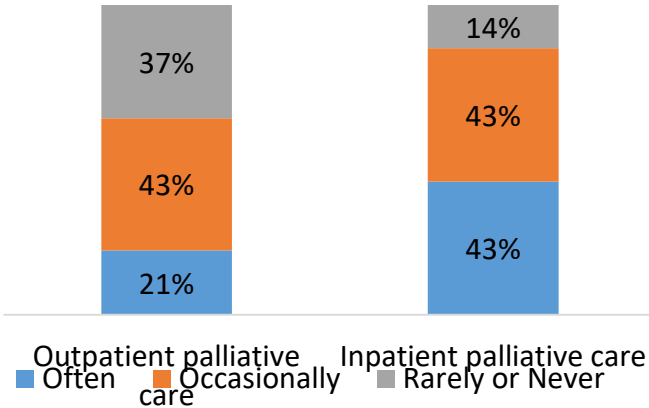
| Participant Characteristics N(%) | N = 277 |
|--|-----------|
| Male gender | 179 (65%) |
| Hispanic | 22 (8%) |
| Race | |
| White | 194 (70%) |
| Asian | 51 (21%) |
| African American | 7 (3%) |
| Other | 19 (7%) |
| US region of practice | |
| Midwest | 89 (32%) |
| South Atlantic | 53 (19%) |
| South Central | 50 (18%) |
| Northeast | 33 (12%) |
| Mountain | 27 (10%) |
| Pacific | 25 (9%) |
| Years of clinical practice since completing training | |
| < 10 years | 101 (36%) |
| 10-20 years | 80 (29%) |
| > 10 years | 96 (35%) |

Transplant Physicians Survey

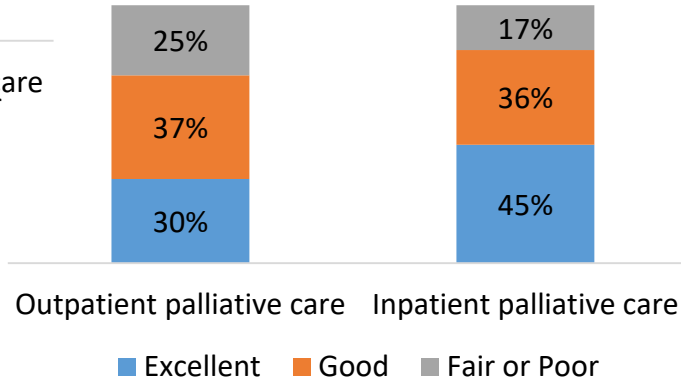
| Participant Characteristics N(%) | N = 277 |
|---|-----------|
| What patient age group do you provide care | |
| Adults only | 179 (65%) |
| Pediatrics only | 77 (28%) |
| Adults and Pediatrics | 21 (8%) |
| For what patient population do you provide care | |
| Both non-transplant and transplant patients | 159 (57%) |
| Transplant patients only | 118 (43%) |
| Number of adult transplants performed at your center | |
| < 50 total transplants per year | 13 (6%) |
| 50-200 transplants per year | 98 (42%) |
| > 200 transplants per year | 123 (52%) |
| Don't know | 1 (0%) |
| Training in palliative care | |
| Attended CME courses & educational lectures | 128 (46%) |
| No training | 102 (37%) |
| Rotation during residency or fellowship | 81 (29%) |
| 6 months or more of formal training | 4 (1%) |

Collaboration & Quality of PC Services

Collaboration with Palliative Care

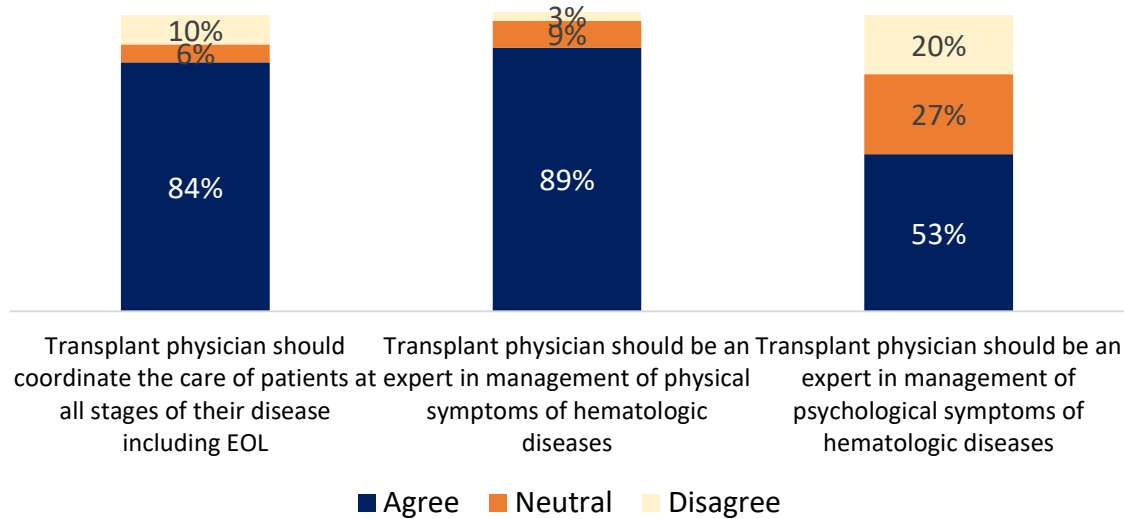


Quality of Palliative Care Services



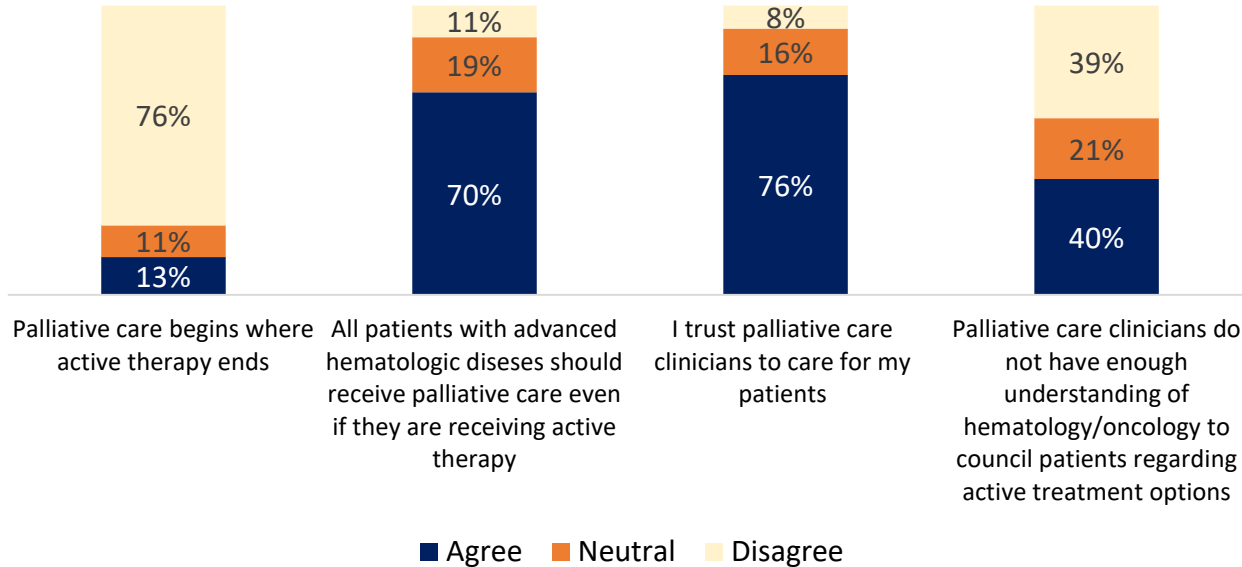
Ownership over PC Issues

Transplant Physicians' Ownership over Palliative Care Issues



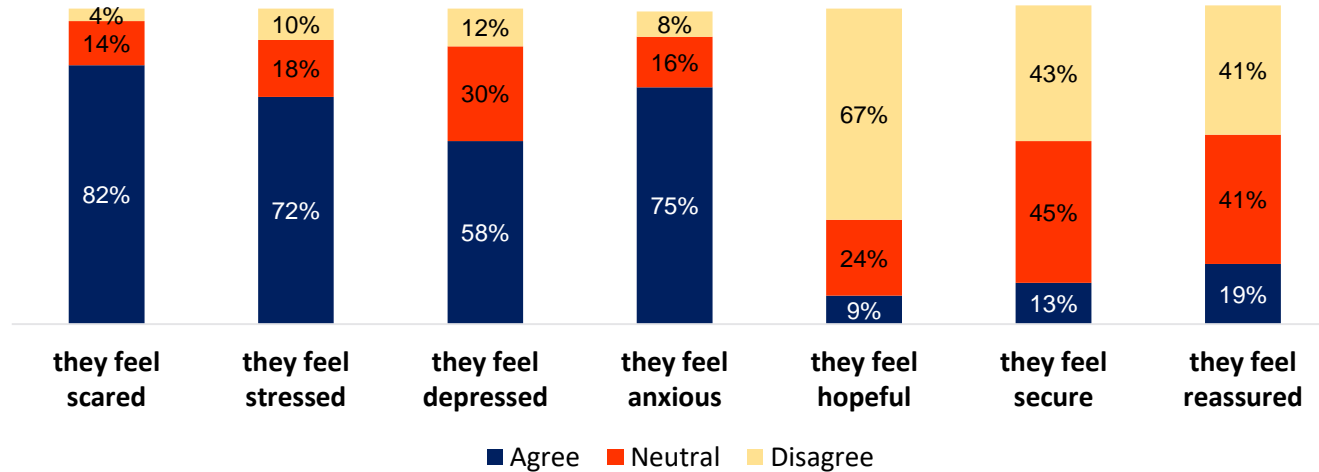
Attitudes about PC

Transplant Physicians' Attitudes towards Palliative Care



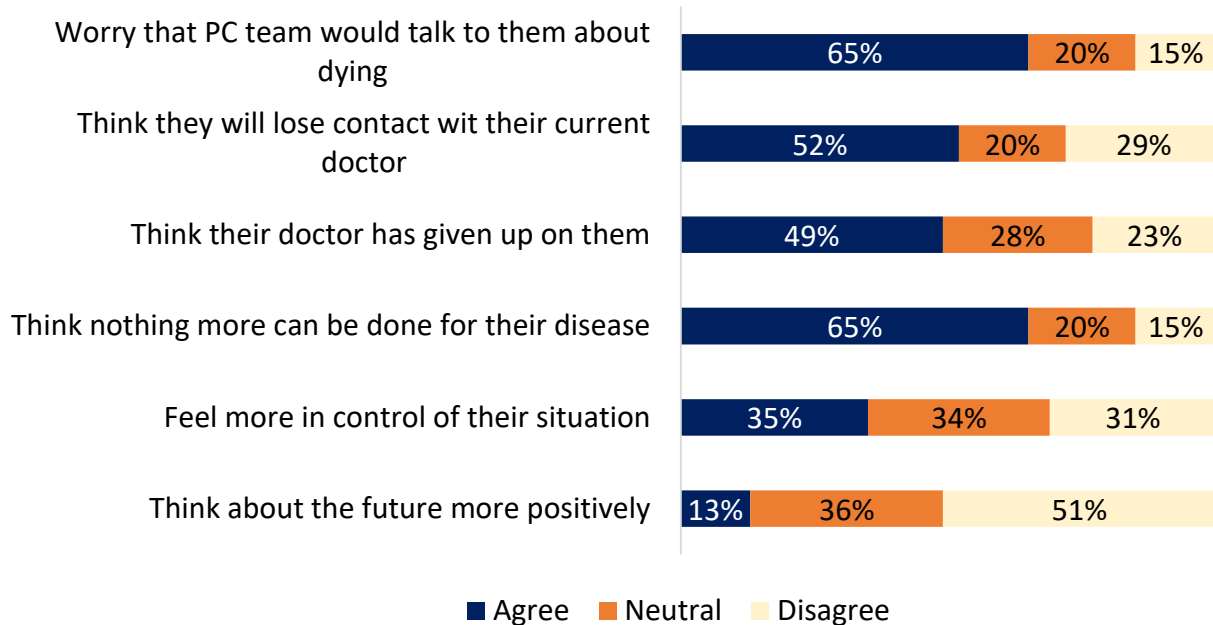
Attitudes about PC

Physicians' perceptions: "When patients hear the term palliative care"



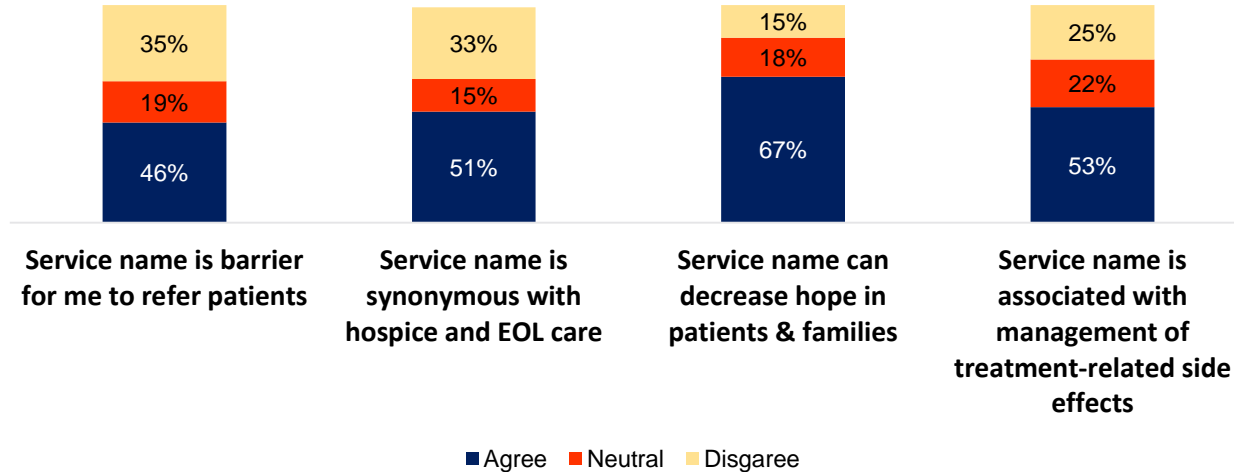
Attitudes about PC

If a palliative care referral is suggested for a patient, they might:



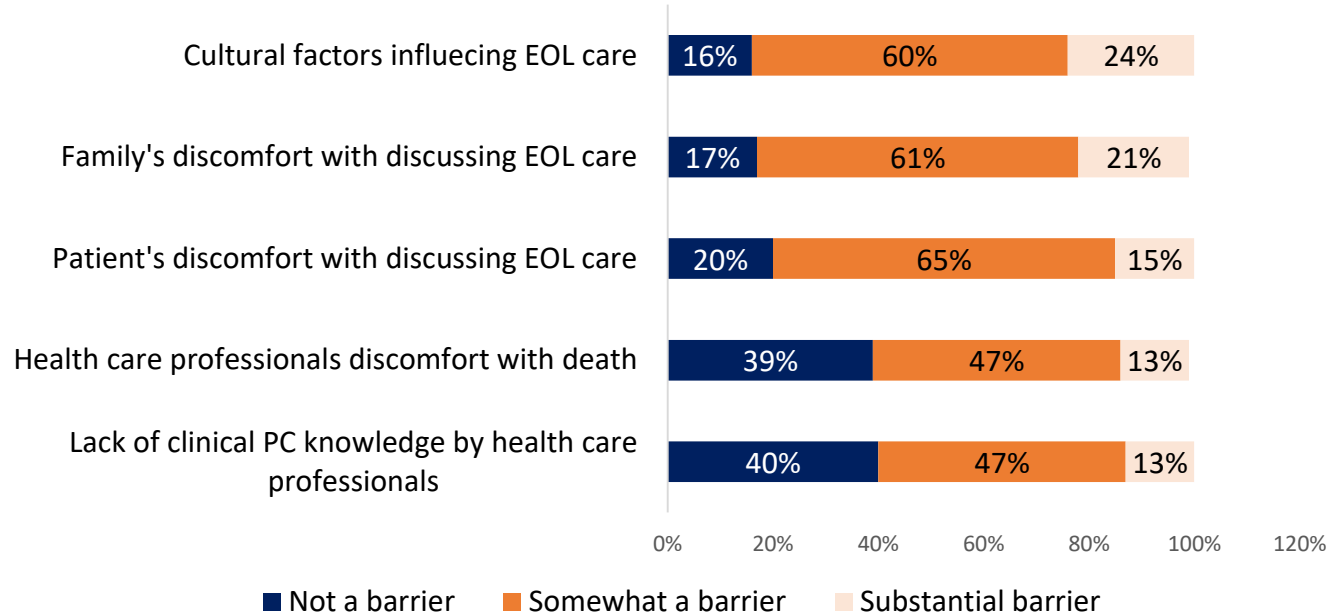
Barriers to PC Utilization

Regarding "Palliative Care"



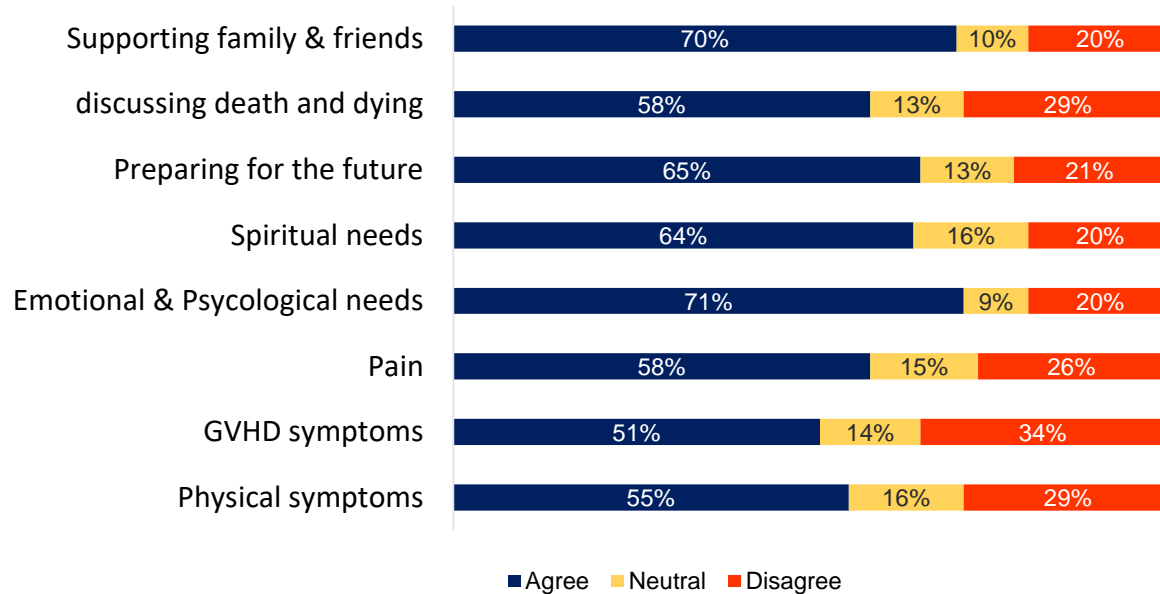
Barriers to PC Utilization

Perceived Barriers to Palliative Care Utilization



Perceived Unmet Palliative Care Needs

Perceived Unmet Palliative Care Needs



Summary of Findings

- Access to high-quality palliative care services continue to be limited, especially in the outpatient setting
- Transplant physicians can trust & collaborate with PC clinicians, but feel like PC clinicians need more exposure to HCT
- Transplant physicians have major concerns regarding patients' reaction to palliative care
- Patient, provider, and cultural barriers to PC identified
- There are immense unmet PC needs in this population

Integration Strategies

- Rigorous studies targeting the needs of patients undergoing HCT.
- Identify the role of early palliative care for patients with certain hematologic conditions.
- Build trust & break down misperceptions about palliative care.
- Focus first on how palliative care can help HCT survivors to break down misperceptions about EOL care
- Increase access to inpatient and outpatient palliative care services → innovative delivery models

- Collaborative engagement: BMT clinicians, nursing, palliative care, and patients & families
- Focus on the science and rationale in cultivating trust
- Start by breaking misperceptions about palliative care
 - First palliative care intervention → focused on symptoms management
 - Building trust

Early PC: Insights from Oncology

- Palliative care has more tools in their toolbox for symptom management.
- Palliative care clinicians have expertise in helping patients cope/accept/adapt to their illness.
- Patients do not have a negative perception of palliative care.
- **Palliative care is not just about end of life care.**

Early PC: Insights from Palliative Care

- Palliative care must learn the unique needs of a particular population of patients with cancer.
 - Understand chemo regimen
 - Side effect profiles
 - Illness trajectory
- Deeper understanding of prognostic uncertainty in patients with hematologic malignancies & those receiving curative therapy.
- Importance of establishing trusting relationship with oncology.

Where Do We Go from here?

- Patient survey of attitudes and perceptions of palliative care
- More research & clinical care models integrating palliative care for HCT patients
 - Collaborative care models
 - Consultative models
 - Embedded care models
- Developing palliative care models that are tailored to the need of patients and their families.
- Developing less resource-intensive models/ telemedicine.
- Developing primary palliative care interventions.

Panel Discussion

Moderator:

Christina Ullrich, MD, MPH: Boston Children's Hospital / Dana-Farber Cancer Institute
Harvard Medical School

Panel:

Eric Roeland, MD: University California San Diego Moores Cancer Center
Areej El-Jawahri MD: Blood and Marrow Transplant Program Massachusetts General Hospital

Evaluation Reminder

Please complete the Council Meeting 2017 evaluation in order to receive continuing education credits and to provide suggestions for future topics.

We appreciate your feedback!