Palliative Care: Science, perceptions and the patient experience

Moderator – Christina Ullrich, MD, MPH
Assistant Professor in Pediatrics, Harvard Medical School
Pediatric Hematology/Oncology and Palliative Care, Boston Children's Hospital/ Dana Farber Cancer Institute
Disclosures
The following faculty and planning committee staff have no financial disclosures:

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
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<tr>
<td>Eric Roeland, MD</td>
<td>University California San Diego Moores Cancer Center</td>
</tr>
<tr>
<td>Areej El-Jawahri MD</td>
<td>Blood and Marrow Transplant Program Massachusetts General Hospital</td>
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<tr>
<td>Effie Petersdorf, MD</td>
<td>University of Washington, Fred Hutchinson Cancer Research Center</td>
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<tr>
<td>Thomas LeBlanc, MD</td>
<td>Duke Cancer Institute</td>
</tr>
<tr>
<td>Ellen Denzen, MS</td>
<td>National Marrow Donor Program/Be The Match</td>
</tr>
<tr>
<td>Christa Meyer, MS</td>
<td>National Marrow Donor Program/Be The Match</td>
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<td>Christina Ullrich, MD, MPH</td>
<td>Boston Children's Hospital / Dana-Farber Cancer Institute Harvard Medical School</td>
<td>Schulman IRB</td>
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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
Supportive Care

Hospice
Palliative Care: Old & New Approaches

OLD

Cancer Care:
Transplant, chemotherapy, radiation, surgery

Palliative Care

MODERN

Cancer Care:
Transplant, chemotherapy, radiation, surgery

Supportive Care

Palliative Care

Time
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 ± 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

- Feeling nervous: 33%
- Irritable: 36%
- Feeling sad: 41%
- Feeling worried: 50%

Bar charts showing symptom burden in hematologic malignancies and metastatic solid cancer.
Unmet End-of-Life Needs in Hematologic Malignancies

All p-values < 0.001

- ER visits: 43%
- Hospital admission: 47%
- Hospital death: 16%
- ICU admission: 8%
- ICU death: 4%
- Chemo use: 14%

Solid tumors
Heme-malignancy

Hui, Cancer 2014
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

160 patients with hematologic malignancies within 72 hour of admission for HCT (and their willing family caregivers)

Randomized

Inpatient Integrated Palliative and Transplant Care
- At least 2 visits weekly during HCT hospitalization.

Transplant Care Alone
- Palliative care consult upon request.

Longitudinal data collection
- Week 2 (primary)
- Three & six months post HCT
SHIELD: Study Schema

Assessed for eligibility N=242

- Ineligible (N = 56)
  - Eligible but refused N= 26
    - Dislike survey (N = 10)
    - Too anxious (N = 5)
    - Concerned about logistics (N = 5)
    - No reason (N = 5)

Enrolled and Randomized N=160 (86%)

- Transplant care (N = 79)
  - Week-2 assessment
    - Completed N=77 (97.5%)
  - 3-month assessment
    - Completed N=74 (93.7%)
  - 6-month assessment
    - Completed N=70 (88.6%)

- Inpatient palliative care (N =81)
  - Week-2 assessment
    - Completed N=80 (98.8%)
  - 3-month assessment
    - Completed N=75 (92.6%)
  - 6-month assessment
    - Completed N=71 (87.7%)
SHIELD: Palliative Care Intervention

Initial Visit Content

- Symptoms: 88.9%
- Rapport building: 98.8%
- Coping: 85.2%
- Illness understanding: 12.3%
- Treatment decision-making: 2.5%
- Advance care planning: 2.5%
SHIELD: Palliative Care Intervention

Initial Visit Symptoms Addressed

- Pain: 65.4%
- Nausea: 67.9%
- Diarrhea: 53.1%
- Constipation: 55.6%
- Insomnia: 33.3%
- Fatigue: 38.3%
- Depression: 11.1%
- Anxiety: 33.3%
## SHIELD: Patient Week-2 Outcomes

<table>
<thead>
<tr>
<th>Week-2 Outcomes</th>
<th>Adjusted Mean Difference</th>
<th>95% CI</th>
<th>P- Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACT – BMT</td>
<td>7.73</td>
<td>1.27 to 14.19</td>
<td>0.019</td>
</tr>
<tr>
<td>FACT – Fatigue</td>
<td>3.88</td>
<td>0.21 to 7.54</td>
<td>0.038</td>
</tr>
<tr>
<td>ESAS – Symptom Burden</td>
<td>-6.26</td>
<td>-11.46 to -1.05</td>
<td>0.019</td>
</tr>
<tr>
<td>HADS – Depression symptoms</td>
<td>-1.74</td>
<td>-3.01 to -0.47</td>
<td>0.008</td>
</tr>
<tr>
<td>HADS – Anxiety symptoms</td>
<td>-2.26</td>
<td>-3.22 to -1.29</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>PHQ-9 – Depression</td>
<td>-1.28</td>
<td>-2.82 to 0.27</td>
<td>0.104</td>
</tr>
</tbody>
</table>
### SHIELD: Patient 3-Month Outcomes

<table>
<thead>
<tr>
<th>3-Month Outcomes</th>
<th>Adjusted Mean Difference</th>
<th>95% CI</th>
<th>P- Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACT – BMT</td>
<td>5.34</td>
<td>0.04 to 10.65</td>
<td>0.048</td>
</tr>
<tr>
<td>FACT – Fatigue</td>
<td>2.00</td>
<td>-1.08 to 5.09</td>
<td>0.202</td>
</tr>
<tr>
<td>ESAS – Symptom Burden</td>
<td>-2.44</td>
<td>-6.29 to 1.41</td>
<td>0.212</td>
</tr>
<tr>
<td>HADS – Depression symptoms</td>
<td>-1.70</td>
<td>-2.75 to -0.65</td>
<td>0.002</td>
</tr>
<tr>
<td>HADS – Anxiety symptoms</td>
<td>-0.76</td>
<td>-1.73 to 0.23</td>
<td>0.130</td>
</tr>
<tr>
<td>PHQ-9 – Depression</td>
<td>-2.12</td>
<td>-3.42 to -0.81</td>
<td>0.002</td>
</tr>
<tr>
<td>PCL – PTSD Symptoms</td>
<td>-4.35</td>
<td>-7.12 to -1.58</td>
<td>0.002</td>
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</tbody>
</table>
# SHIELD: Patient 6-Month Outcomes

<table>
<thead>
<tr>
<th>6 Month Outcomes</th>
<th>Adjusted Mean Difference</th>
<th>95% CI</th>
<th>P- Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACT – BMT</td>
<td>2.72</td>
<td>-2.96 to 8.39</td>
<td>0.346</td>
</tr>
<tr>
<td>FACT – Fatigue</td>
<td>0.10</td>
<td>-3.38 to 3.58</td>
<td>.957</td>
</tr>
<tr>
<td>HADS – Depression</td>
<td>-1.21</td>
<td>-2.26 to -0.16</td>
<td><strong>0.024</strong></td>
</tr>
<tr>
<td>HADS – Anxiety symptoms</td>
<td>-0.61</td>
<td>-1.69 to 0.47</td>
<td>0.267</td>
</tr>
<tr>
<td>PHQ-9 – Depression</td>
<td>-1.63</td>
<td>-3.08 to -0.19</td>
<td><strong>0.027</strong></td>
</tr>
<tr>
<td>PCL – PTSD Symptoms</td>
<td>-4.02</td>
<td>-7.18 to -0.86</td>
<td><strong>0.013</strong></td>
</tr>
</tbody>
</table>
SHIELD: Psychological Distress at 6-Months

**Depression (HADS)**
- Intervention: 10.1%
- Control: 26.4%
- P = 0.017

**Depression (PHQ-9)**
- Intervention: 14.3%
- Control: 33.3%
- P = 0.010

**PTSD (PCL)**
- Intervention: 7.3%
- Control: 21.1%
- P = 0.029
SHIELD: Caregiver Outcomes

<table>
<thead>
<tr>
<th>2-week Caregiver Outcomes</th>
<th>Adjusted mean difference</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS-Depression</td>
<td>-1.65</td>
<td>-3.01 to -0.29</td>
<td>0.018</td>
</tr>
<tr>
<td>HADS-Anxiety</td>
<td>-0.14</td>
<td>-1.56 to 1.27</td>
<td>0.84</td>
</tr>
<tr>
<td>QOL</td>
<td>3.38</td>
<td>-1.59 to 8.35</td>
<td>0.180</td>
</tr>
</tbody>
</table>

- 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

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

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<th>Healthcare utilization</th>
<th>Survival</th>
<th>Caregiver outcomes</th>
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</thead>
<tbody>
<tr>
<td>Bakitas</td>
<td>Patients with advanced stage solid tumor or hematologic malignancy (n=10, 4.8%) with prognosis 6-24 months</td>
<td>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</td>
<td>n=103 Delayed initiation of PC (3 months after diagnosis)</td>
<td>--</td>
<td>--</td>
<td>One-year survival: yes Overall survival: no</td>
<td>↑</td>
</tr>
<tr>
<td>Grudzen</td>
<td>Patients with advanced stage solid tumor in the emergency department</td>
<td>n=69 PC consultation by inpatient team, refer to outpatient PC clinic if appropriate</td>
<td>n=67 Usual care</td>
<td>↑</td>
<td>↓</td>
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Grudzen 2016
**Palliative Care & Oncology Studies…**

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<th>Control</th>
<th>QOL/mood</th>
<th>Healthcare utilization</th>
<th>Survival</th>
<th>Caregiver outcomes</th>
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<tr>
<td>Temel 2016</td>
<td>Patients with newly diagnosed incurable lung or noncolorectal GI cancer</td>
<td>n=175 Early integrated PC with monthly outpatient PC clinic visits</td>
<td>n=175 Usual care</td>
<td>Lung cancer: ↑</td>
<td>--</td>
<td>--</td>
<td>pending</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>GI cancer: --</td>
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<tr>
<td>El-Jawahri 2016</td>
<td>Caregivers of patients with new diagnosis of incurable lung or non-colorectal GI cancer</td>
<td>n=137 PC visit for patient within 4 weeks of enrollment and at least monthly until death. Caregivers encouraged, but not required to attend.</td>
<td>n= 138 Usual care</td>
<td>↑</td>
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</table>
Integrative Palliative Care Studies in Oncology Citations for Reference


Transplant Physicians’ Perspectives on Palliative Care

Areej El-Jawahri MD
Blood and Marrow Transplant Program
Massachusetts General Hospital
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, 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

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

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

Collaboration with Palliative Care

- Outpatient palliative care:
  - Often: 21%
  - Occasionally: 43%
  - Rarely or Never: 37%

- Inpatient palliative care:
  - Occasionally: 14%
  - Rarely or Never: 43%

Quality of Palliative Care Services

- Outpatient palliative care:
  - Excellent: 25%
  - Good: 37%
  - Fair or Poor: 30%

- Inpatient palliative care:
  - Excellent: 17%
  - Good: 36%
  - Fair or Poor: 45%
Ownership over PC Issues

Transplant Physicians’ Ownership over Palliative Care Issues

- Transplant physician should coordinate the care of patients at all stages of their disease including EOL: 84%
- Transplant physician should be an expert in management of physical symptoms of hematologic diseases: 89%
- Transplant physician should be an expert in management of psychological symptoms of hematologic diseases: 53%

Agree  Neutral  Disagree
Attitudes about PC

Palliative care begins where active therapy ends

- 76% Agree
- 11% Neutral
- 13% Disagree

All patients with advanced hematologic diseases should receive palliative care even if they are receiving active therapy

- 70% Agree
- 19% Neutral
- 11% Disagree

I trust palliative care clinicians to care for my patients

- 76% Agree
- 16% Neutral
- 8% Disagree

Palliative care clinicians do not have enough understanding of hematology/oncology to council patients regarding active treatment options

- 39% Agree
- 21% Neutral
- 40% Disagree

Palliative care begins where active therapy ends
Attitudes about PC

Physicians’ perceptions: “When patients hear the term palliative care”

- They feel scared: Agree 82%, Neutral 14%, Disagree 4%
- They feel stressed: Agree 72%, Neutral 18%, Disagree 10%
- They feel depressed: Agree 58%, Neutral 30%, Disagree 12%
- They feel anxious: Agree 75%, Neutral 16%, Disagree 8%
- They feel hopeful: Agree 24%, Neutral 67%, Disagree 9%
- They feel secure: Agree 45%, Neutral 13%, Disagree 43%
- They feel reassured: Agree 19%, Neutral 41%, Disagree 41%

MGH 1811

CORê
### Attitudes about PC

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

<table>
<thead>
<tr>
<th>Attitude</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worry that PC team would talk to them about dying</td>
<td>65%</td>
<td>20%</td>
<td>15%</td>
</tr>
<tr>
<td>Think they will lose contact with their current doctor</td>
<td>52%</td>
<td>20%</td>
<td>29%</td>
</tr>
<tr>
<td>Think their doctor has given up on them</td>
<td>49%</td>
<td>28%</td>
<td>23%</td>
</tr>
<tr>
<td>Think nothing more can be done for their disease</td>
<td>65%</td>
<td>20%</td>
<td>15%</td>
</tr>
<tr>
<td>Feel more in control of their situation</td>
<td>35%</td>
<td>34%</td>
<td>31%</td>
</tr>
<tr>
<td>Think about the future more positively</td>
<td>13%</td>
<td>36%</td>
<td>51%</td>
</tr>
</tbody>
</table>
Barriers to PC Utilization

Regarding "Palliative Care"

- Service name is barrier for me to refer patients: Agree 35%, Neutral 19%, Disagree 46%
- Service name is synonymous with hospice and EOL care: Agree 33%, Neutral 15%, Disagree 51%
- Service name can decrease hope in patients & families: Agree 15%, Neutral 18%, Disagree 67%
- Service name is associated with management of treatment-related side effects: Agree 25%, Neutral 22%, Disagree 53%

Legend: Agree, Neutral, Disagree
Barriers to PC Utilization

Perceived Barriers to Palliative Care Utilization

- Cultural factors influencing EOL care: 16% Not a barrier, 60% Somewhat a barrier, 24% Substantial barrier
- Family's discomfort with discussing EOL care: 17% Not a barrier, 61% Somewhat a barrier, 21% Substantial barrier
- Patient's discomfort with discussing EOL care: 20% Not a barrier, 65% Somewhat a barrier, 15% Substantial barrier
- Health care professionals discomfort with death: 39% Not a barrier, 47% Somewhat a barrier, 13% Substantial barrier
- Lack of clinical PC knowledge by health care professionals: 40% Not a barrier, 47% Somewhat a barrier, 13% Substantial barrier
## Perceived Unmet Palliative Care Needs

<table>
<thead>
<tr>
<th>Category</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supporting family &amp; friends</td>
<td>70%</td>
<td>10%</td>
<td>20%</td>
</tr>
<tr>
<td>discussing death and dying</td>
<td>58%</td>
<td>13%</td>
<td>29%</td>
</tr>
<tr>
<td>Preparing for the future</td>
<td>65%</td>
<td>13%</td>
<td>21%</td>
</tr>
<tr>
<td>Spiritual needs</td>
<td>64%</td>
<td>16%</td>
<td>20%</td>
</tr>
<tr>
<td>Emotional &amp; Psychological needs</td>
<td>71%</td>
<td>9%</td>
<td>20%</td>
</tr>
<tr>
<td>Pain</td>
<td>58%</td>
<td>15%</td>
<td>26%</td>
</tr>
<tr>
<td>GVHD symptoms</td>
<td>51%</td>
<td>14%</td>
<td>34%</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>55%</td>
<td>16%</td>
<td>29%</td>
</tr>
</tbody>
</table>

Legend: 
- **Agree**
- **Neutral**
- **Disagree**
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!