Palliative Care in HCT: Benefits, Challenges and the Patient Experience

Areej El Jawahri, MD & Alison H. Rhodes, ACNP-BC, ACHPN
Blood and Marrow Transplant Program, Massachusetts General Hospital
Jody Newman – Transplant Recipient
Jessie Newman - Caregiver

Saturday November 10th
The following faculty and planning committee staff have no financial disclosures:

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Areej El-Jawahri, MD</td>
<td>Blood and Marrow Transplant Program Massachusetts General Hospital</td>
</tr>
<tr>
<td>Alison H. Rhodes, ACNP-BC, ACHPN</td>
<td>Blood and Marrow Transplant Program Massachusetts General Hospital</td>
</tr>
<tr>
<td>Jessie Newman</td>
<td>N/A</td>
</tr>
<tr>
<td>Joanne Newman</td>
<td>N/A</td>
</tr>
<tr>
<td>Christa Meyer</td>
<td>National Marrow Donor Program/Be The Match</td>
</tr>
<tr>
<td>Martha Lassiter</td>
<td>TBD</td>
</tr>
<tr>
<td>Katie Schoepner, MSW, LICSW</td>
<td>National Marrow Donor Program/Be The Match</td>
</tr>
</tbody>
</table>
Learning Objectives

- Discover patient and caregiver palliative and supportive care needs from diagnosis through transplant and beyond
- Synthesize the current science regarding the benefits of palliative care integration
- Evaluate current barriers to palliative care integration and
- Assess potential solutions to improve palliative care integration
Palliative Care Integration in HCT

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

• Unmet palliative care needs in patients with hematologic malignancies and those undergoing HCT

• Barriers to palliative care integration

• A model of successful palliative care integration in patients with hematologic malignancies undergoing HCT

• Where do we go from here?
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 EOL care needs
  - Survivors struggle with long-term complications
Unmet Palliative Care Needs

Despite substantial unmet needs, palliative care is rarely utilized for patients with hematologic malignancies

Why?
Illness Specific Barriers

• Hematologic malignancies 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

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
Cultural Barriers

Physician’s perception: “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 9%
- They feel hopeful: Agree 43%, Neutral 45%, Disagree 13%
- They feel secure: Agree 41%, Neutral 41%, Disagree 19%
- They feel reassured: Agree 41%, Neutral 41%, Disagree 19%

El-Jawahri, Cancer 2018
Cultural Barriers

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

- Worry that PC team would talk to them about dying: Agree - 65%, Neutral - 20%, Disagree - 15%
- Think they will lose contact with their current doctor: Agree - 52%, Neutral - 20%, Disagree - 29%
- Think their doctor has given up on them: Agree - 49%, Neutral - 28%, Disagree - 23%
- Think nothing more can be done for their disease: Agree - 65%, Neutral - 20%, Disagree - 15%
- Feel more in control of their situation: Agree - 35%, Neutral - 34%, Disagree - 31%
- Think about the future more positively: Agree - 13%, Neutral - 36%, Disagree - 51%

El-Jawahri, Cancer 2018
Cultural Barriers

Regarding "Palliative Care"

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

El-Jawahri, Cancer 2018
System-Based Barriers

- EOL care delivery models → not developed for hematologic malignancies
- Difficulty managing blood product support at the EOL
- Challenges of addressing infectious complications at the EOL
- How to manage GVHD in hospice?
- Lack of understanding of what death looks like for a heme-malignancy patients
- Lack of preparation for family

El-Jawahri, JOP 2017
Rationale for Palliative Care in HCT Model

- Symptom management needed during HCT
- HCT patients rarely utilizes palliative care services
- Opportunity to build trust: palliative care & hematologic malignancies
- Population-specific palliative care & oncology care model
SHIELD: Conceptual Model

Conceptual Model:
Figure 1

Pre-HCT

Patient
Symptom burden
QOL and mood

Family caregiver
Caregiving burden
QOL and mood

HCT Hospitalization

Palliative Care
- Address symptoms
- Manage expectations
- Enhance effective coping

Patient
Symptom burden
QOL and mood

Family caregiver
Caregiving burden
QOL and mood

Post-HCT

Patient
QOL and mood
Post-traumatic stress

Family caregiver
Caregiving burden
QOL and mood
160 patients with hematologic malignancies within 72 hour of admission for HCT (and their willing family caregivers)

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

El-Jawahri JAMA 316(20) 2016
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%
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%
## 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>

El-Jawahri JAMA 316(20) 2016
## 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>
</tr>
</tbody>
</table>

El-Jawahri JAMA 316(20) 2016
# 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 symptoms</td>
<td>-1.21</td>
<td>-2.26 to -0.16</td>
<td>0.024</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>0.027</td>
</tr>
<tr>
<td>PCL – PTSD Symptoms</td>
<td>-4.02</td>
<td>-7.18 to -0.86</td>
<td>0.013</td>
</tr>
</tbody>
</table>

El-Jawahri, JCO 2017, in press
Psychological Distress Six Months

El-Jawahri, JCO 2017, in press
### Caregiver Outcomes

**• Improvement in two domains of QOL**

- **Coping:** adjusted mean difference = 1.01, \( P = 0.009 \)
- **Administrative/finances:** adjusted mean difference = 0.67, \( P = 0.029 \)

---

<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>

El-Jawahri JAMA 316(20) 2016
This is not one-size-fits all

Patients with hematologic malignancies

Low symptom burden and low mortality
PC when prognosis poor

High symptom burden and mortality
Early longitudinal PC

Moderate symptom burden and mortality
Early intermittent PC

Prolonged periods with low symptom burden
Identify triggers for PC (i.e. hospitalization)
MGH Integrate PC Trial

Lung Cancer

GI Cancer

Temel, JCO 2017
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