How should palliative care services integrate into oncology services?

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  – Insys Therapeutics
  – Teva Pharmaceutical
  – Depomed Inc
Outline

• Introduction
• Primary palliative care
• Specialist palliative care
• Summary
Dimensions of Care

- Physical
  - Pain
  - Fatigue
  - Dyspnea
  - Anorexia-cachexia
  - Nausea
  - Delirium
  - Function

- Emotional
  - Anxiety
  - Depression
  - Coping
  - Denial
  - Adjustment disorder

- Social
  - Family caregivers
  - Relationships
  - Living situation
  - Financial issues

- Spiritual
  - Hope
  - Meaning
  - Dignity
  - Faith & religion

- Informational
  - Prognosis/illness understanding
  - Treatment risks and benefits
  - Advance care plans
  - Home care

Hui et al. CA: Cancer J Clin 2018
Interprofessional Team

1. Situational leadership
2. Unified message
3. Different personality
4. Common goal
5. Shared responsibility

Hui et al. CA: Cancer J Clin 2018
Levels of Palliative Care

Primary PC
- Oncologists and primary care specialists
- Inpatient units, outpatient clinics
- Basic symptom assessment
- Basic symptom interventions
- Basic communication skills
- Complex cancer treatment decisions
- Basic end-of-life care
- Referral to palliative care

Secondary PC
- Specialist palliative care team as consultants
- Inpatient units, outpatient clinics
- Comprehensive symptom assessment and management
- Psychosocial and spiritual care
- Communication and decision making about advance care planning and end-of-life care

Tertiary PC
- Specialist palliative care as attending team
- Palliative care units
- Intensive symptom management
- Comprehensive psychosocial and spiritual care
- Complex communication and decision making about advance care planning and end-of-life care
- Often academic centers that facilitate PC education and research

Increased expertise in palliative care, larger centers

Hui et al. CA: Cancer J Clin 2018
Levels of Palliative Care
Many Variations

Specialist Palliative Care
- Interdisciplinary PC teams
- PC advanced practice providers
- PC advanced practice providers → PC team
- PC Physician specialists
- Primary care physicians with PC specialization
- Others...

Primary Palliative Care
- Oncologists
- Oncology advanced practice providers
- Primary care physicians
Primary Palliative Care
Models of Integration

Patient Care Needs
- Pain
- Delirium
- Bowel obstruction
- End-of-Life
- Dyspnea
- Psychosocial distress
- Cancer assessment & treatment

Solo Practice Model
- Pain
- End of life
- Dyspnea
- Psychosocial distress
- Cancer Assessment & Treatment

Bruera & Hui J Clin Oncol 2010
Primary Palliative Care
Cluster Randomized Trial

146 patients diagnosed with late stage cancer within 100 days

Gyne and lung clinics: 10 week Primary PC intervention

H&N and GI: Enhanced usual care

Primary Palliative Care Intervention
- Oncology APNs, PAs, and MSWs participated in three one-hour, one-on-one training sessions with the study APN coordinator
- Clinic APNs initially contacted patients within 24 hours, and weekly phone and in-person contacts were scheduled (five clinic visits and five telephone calls)
- The clinic APN oversaw the coordination and implementation of the intervention by different members of the team.

Outcomes at baseline, 1 month, 3 months
1. Symptom Distress Scale, Health Distress, PHQ9, Enforced Social Dependency Scale, Self-rated health
2. HADS, Self efficacy, Mishel Uncertainty in Illness Scale, FACT-G

# Primary Palliative Care

## Cluster Randomized Trial

### Table 2. Means and Standard Deviations of Primary Outcomes by Group at Baseline, One Month, and Three Months

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Baseline</th>
<th>One month</th>
<th>Three months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (n=146)</td>
<td>Usual care (n=80)</td>
<td>Intervention (n=66)</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>SDSa</td>
<td>23.82 (7.18)</td>
<td>23.63 (6.99)</td>
<td>24.05 (7.45)</td>
</tr>
<tr>
<td>EDTa</td>
<td>3.97 (2.77)</td>
<td>3.84 (2.74)</td>
<td>4.14 (2.82)</td>
</tr>
<tr>
<td>Health distressa</td>
<td>1.82 (1.27)</td>
<td>1.78 (1.15)</td>
<td>1.87 (1.40)</td>
</tr>
<tr>
<td>PHQ-9a</td>
<td>5.10 (4.33)</td>
<td>4.91 (4.06)</td>
<td>5.33 (4.65)</td>
</tr>
<tr>
<td>ESDDS personala</td>
<td>12.66 (7.56)</td>
<td>13.79 (8.73)</td>
<td>11.30 (5.61)</td>
</tr>
<tr>
<td>ESDDS socialab</td>
<td>7.42 (3.18)</td>
<td>7.69 (3.47)</td>
<td>7.09 (2.77)</td>
</tr>
<tr>
<td>Self-rated healthb</td>
<td>3.58 (1.11)</td>
<td>3.61 (1.12)</td>
<td>3.55 (1.11)</td>
</tr>
</tbody>
</table>

### Table 4. Means and Standard Deviations of Secondary Outcomes at One Month and Three Months

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Three months (n=92)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (n=122)</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>HADS-anxietya</td>
<td>4.29 (3.86)</td>
</tr>
<tr>
<td>Self-efficacyb</td>
<td>7.30 (2.17)</td>
</tr>
<tr>
<td>MUIS-Cc</td>
<td>47.10 (13.89)</td>
</tr>
<tr>
<td>FACT-Gd</td>
<td>80.70 (16.98)</td>
</tr>
<tr>
<td>PWB</td>
<td>20.28 (5.65)</td>
</tr>
<tr>
<td>SWB</td>
<td>23.97 (4.59)</td>
</tr>
<tr>
<td>EWB</td>
<td>19.00 (4.60)</td>
</tr>
<tr>
<td>FWB</td>
<td>17.45 (6.77)</td>
</tr>
</tbody>
</table>


P<0.01 Favoring control group
Primary Palliative Care Randomized Trial

26 patients with diagnosis of metastatic cancer and strong expectation of hospice referral in 12 months

Primary Palliative Care Intervention
- An oncology ARNP who taught patients about hospice, helped fill out the Five Wishes and living will forms, and assessed their psychological, physical, intellectual/cognitive, social, and spiritual needs
- One visit at baseline and then followup 1 month later

Outcomes
1. Time to hospice referral (not assessable)
2. Hospice Knowledge Questionnaire, FACT-G, Linear Analogue Self Assessment Scale, Spiritual needs, sense of abandonment

Powered for 50 patients per group but stopped early

Primary Palliative Care Communication
Cluster Randomized Trial

278 cancer patients with “No” in Surprise Question-12 months

Primary Palliative Care Intervention
• Clinician (MD, NP, PA) training included a 2.5-hour interactive, skills-based training session on the SICG delivered by palliative care experts who offered follow-up coaching
• A patient letter introducing the SICG
• A Family guide after the discussion
• Routine identification of patients at high risk of death, email reminders to initiate conversations and a structured EHR template

Patients partially blinded

Usual care

Primary PC intervention: Serious Illness Conversation Guide

Outcomes
1. Goal concordant care (top 3) and Peacefulness
2. Human Connection Scale, GAD-7, PHQ-9

Powered for 200 evaluable patients per arm, but only 38 and 26 patients analyzed for primary outcome

Bernacki et al. JAMA Intern Med 2019
Primary Palliative Care Communication
Cluster Randomized Trial

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Intervention Arm</th>
<th>Control Arm</th>
<th>Differences (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>Mean (95% CI)</td>
<td>Median (95% CI)</td>
</tr>
<tr>
<td>Goal-concordant care&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of goals met</td>
<td>38</td>
<td>1.4 (1.0 to 1.7)</td>
<td>0.8 (0.6 to 1.1)</td>
</tr>
<tr>
<td>Sensitivity analysis</td>
<td>29</td>
<td>1.3 (1.0 to 1.6)</td>
<td>0.8 (0.5 to 1.1)</td>
</tr>
<tr>
<td>PEAC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PA scale</td>
<td>47</td>
<td>16.9 (16.1 to 17.6)</td>
<td>NA</td>
</tr>
<tr>
<td>SI scale</td>
<td>44</td>
<td>14.0 (12.9 to 15.1)</td>
<td>NA</td>
</tr>
</tbody>
</table>

<sup>a</sup> Adjusted for baseline mean.

<sup>b</sup> At follow-up.

Bernacki et al. *JAMA Intern Med* 2019
Primary Palliative Care

Right Individuals, Right Training, Right Complexity

• Right individuals
  – Difficult to expect all primary care providers
  – Some specialties such as oncology may need more primary care skills
  – Only those who have interest and greater exposure to patients with advanced illness

• Right training
  – Too little (e.g. 3 hours) is inadequate; too much is not realistic
  – Clinical rotation (1-2 months) at centers of excellence
  – Continuing education

• Right expectations
  – Basic skills such as symptom management and communication
  – Know when to refer or consult (e.g. teleconference)
Specialist Palliative Care
Models of Integration

Congress Model

Integrated Care Model

Bruera & Hui J Clin Oncol 2010
Models of Specialist Palliative Care

Diagnosis of advanced cancer

Outpatient PC clinic

Inpatient PC consultation team

Inpatient PCU

Community based PC

Hospice care

Hui & Bruera J Clin Oncol 2019 (in press)
## Quality of EOL Care

### Timing of Palliative Care Referral

<table>
<thead>
<tr>
<th>Within last 30 days of life</th>
<th>Early &gt;3 m N=120 (%)</th>
<th>Late ≤3 m N=246 (%)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any emergency room visit</td>
<td>47 (39)</td>
<td>168 (68)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2 or more emergency room visits</td>
<td>12 (10)</td>
<td>57 (23)</td>
<td>0.003</td>
</tr>
<tr>
<td>Any hospital admission</td>
<td>58 (48)</td>
<td>200 (81)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2 or more hospital admissions</td>
<td>12 (10)</td>
<td>52 (21)</td>
<td>0.01</td>
</tr>
<tr>
<td>More than 14 days of hospitalization</td>
<td>14 (12)</td>
<td>40 (16)</td>
<td>0.28</td>
</tr>
<tr>
<td>Hospital death</td>
<td>20 (17)</td>
<td>77 (31)</td>
<td>0.004</td>
</tr>
<tr>
<td>Any ICU admission</td>
<td>7 (6)</td>
<td>28 (11)</td>
<td>0.13</td>
</tr>
<tr>
<td>ICU death</td>
<td>3 (3)</td>
<td>10 (4)</td>
<td>0.56</td>
</tr>
<tr>
<td>Chemotherapy and targeted agent use</td>
<td>29 (24)</td>
<td>67 (27)</td>
<td>0.61</td>
</tr>
</tbody>
</table>

Hui et al. *Cancer* 2014
# Timely Palliative Care is Preventative Care

<table>
<thead>
<tr>
<th>Components of preventative care</th>
<th>Key Aspects</th>
<th>Example 1</th>
<th>Example 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Insight into Illness</strong></td>
<td>• Natural history • Prognostication</td>
<td>Stage IV pancreatic cancer = symptoms</td>
<td>Stage IV lung cancer = short prognosis</td>
</tr>
<tr>
<td><strong>Foresight for Individual</strong></td>
<td>• Anticipate concerns • Risk factors</td>
<td>Mild pain now can get worse</td>
<td>Patient will deteriorate</td>
</tr>
<tr>
<td><strong>Interventions Available</strong></td>
<td>• Risk reduction • Evidence-based</td>
<td>Opioids can be useful</td>
<td>Serious illness conversations</td>
</tr>
<tr>
<td><strong>Introduce Intervention</strong></td>
<td>• Timely initiation • Longitudinal followup</td>
<td>Start scheduled opioids Educate and monitor</td>
<td>Prognostic discussions Advance care planning</td>
</tr>
<tr>
<td><strong>Crisis Prevention</strong></td>
<td>• Improved outcomes • Preparations in place</td>
<td>Better quality of life Avoid pain crisis</td>
<td>Better quality of EOL Avoid ICU visit</td>
</tr>
</tbody>
</table>

Hui et al. *CA: Cancer J Clin* 2018
Outpatient Models
Primary and Secondary Palliative Care

Interdisciplinary Specialist Palliative Care team
- Oncology Clinic

Physician Only Palliative Care
- Oncology Clinic

Telephone-Based Intervention with Nurse-Led Specialist Palliative Care
- Oncology Clinic

Nurse-Led Specialist Palliative Care
- Oncology Clinic

Advanced Practice Providers Based Enhanced Primary Palliative Care
- Oncology Clinic

Examples
- Temel 2010
- Zimmermann 2015
- Temel 2016
- Groenvold 2017

- Maltoni 2016
- Scarpi 2018

- Bakitas 2009
- Bakitas 2015

- Tattersall 2014
- Vanbutsele 2018

- Dyar 2012
- McCorkle 2015

Hui Curr Treat Options in Oncol 2019
# Outpatient Models

## What Does the Literature Say?

<table>
<thead>
<tr>
<th></th>
<th>Interdisciplinary</th>
<th>MD only</th>
<th>APN-led</th>
<th>RN-led</th>
<th>Primary PC: APN-led</th>
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</thead>
<tbody>
<tr>
<td>Temel 2010</td>
<td>PC &gt; UC for some</td>
<td>PC &gt; UC</td>
<td>No difference</td>
<td>No difference</td>
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<tr>
<td>Zimmermann 2015</td>
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</tr>
<tr>
<td>Temel 2016</td>
<td>PC &gt; UC for some</td>
<td>PC &gt; UC</td>
<td>No difference</td>
<td>No difference</td>
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</tr>
<tr>
<td>Groenvold 2017</td>
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<td>No difference</td>
<td>No difference</td>
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<tr>
<td>Monteiro do Carmo 2018</td>
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<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
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<tr>
<td>Maltoni 2016</td>
<td>PC &gt; UC</td>
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<td>No difference</td>
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<tr>
<td>Scarpi 2018</td>
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<td>No difference</td>
<td>No difference</td>
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<tr>
<td>Bakitas 2009</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
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<tr>
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<td>No difference</td>
<td>No difference</td>
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<tr>
<td>Tattersall 2014</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
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<tr>
<td>Vanhutsele 2018</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
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<td>No difference</td>
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<tr>
<td>Dyar 2012</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
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<td>No difference</td>
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<tr>
<td>McCormke 2015</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
</tr>
</tbody>
</table>

### Quality of life
- PC > UC for some
- PC > UC
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference

### Symptom
- PC > UC for some
- PC > UC
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference

### Depression
- PC > UC
- PC > UC for some
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference

### Patient satisfaction
- PC > UC
- PC > UC for some
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference

### Communication
- PC > UC
- No difference
- PC > UC for some
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference

### End-of-life care
- PC > UC for some
- No difference
- PC > UC for some
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference

### Survival
- PC > UC
- No difference
- No difference
- No difference
- PC > UC at 1 yr
- UC > PC
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference

### Caregiver outcomes
- PC > UC for some
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference
- No difference

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Hui & Bruera *J Clin Oncol* 2019 (in press)
Advantages of Personalized Criteria

A. Selective referral (current practice)
   - Variable degree of palliative care referral
   - Pros: Some patients can benefit
   - Cons: Referral often delayed, Inconsistent care, Missed opportunities to improve care

B. Universal referral (clinical trials)
   - All patients receive early palliative care referral
   - Pros: Improved outcomes for many patients
   - Cons: Overwhelming limited resource, Some patients may not need PC yet

C. Need based referral coupled with systematic screening
   - Patients with greater needs receive timely palliative care referral
   - Pros: Improved outcomes, likely greater benefit because of enriched population, Appropriate matching of resources to care needs

Hui et al. CA: Cancer J Clin 2018

Key
- Patient in severe distress or has unmet supportive care needs
- Patient needs adequately addressed by oncologist
- Patient referred to palliative care

Journal of Clinical Oncology

Research Article

Management of advanced cancer: Clinical decision-making and perspectives of patients and caregivers

Abstract

Purpose:
- To describe the current state of management of advanced cancer and
- To present potential improvements in clinical practice and outcomes

Methods:
- Literature review
- Expert panel discussion

Results:
- Current state of management:
- Limited access to palliative care
- Inadequate communication between caregivers and patients
- Lack of standardized guidelines

Potential improvements:
- Improved access to palliative care
- Enhanced communication and collaboration
- Development of evidence-based guidelines

Conclusion:
- Improved management of advanced cancer
- Enhanced quality of life for patients and caregivers

Keywords:
- Advanced cancer
- Palliative care
- Management

References

1. Hui et al. CA: Cancer J Clin 2018

Figure 1: Flowchart of decision-making process in advanced cancer management

- Patient in severe distress or has unmet supportive care needs
- Patient needs adequately addressed by oncologist
- Patient referred to palliative care

Figure 2: Comparison of current and proposed management strategies

- Selective referral (current practice)
- Universal referral (clinical trials)
- Need based referral coupled with systematic screening

Figure 3: Outcomes of improved management strategies

- Improved outcomes
- Enhanced quality of life

Figure 4: Challenges and barriers to improved management

- Limited access to palliative care
- Inadequate communication
- Lack of standardized guidelines

Figure 5: Potential solutions to address challenges

- Improved access to palliative care
- Enhanced communication
- Development of evidence-based guidelines

Figure 6: Cost-effectiveness analysis

- cost-saving
- improved outcomes

Figure 7: Patient satisfaction and feedback

- Increased satisfaction
- Positive feedback from patients and caregivers
Summary

• Delivery of high quality palliative care is highly complex
  – Expertise/training matters
  – Teamwork matters
  – Timing matters
  – Resources matter

• Primary palliative care
  – Important role to provide front line care and sometimes may be only way to provide palliative care
  – Cannot expect same level of benefit as specialist palliative care
  – Plays a critical role to facilitate targeted palliative care referrals

• Outpatient interdisciplinary palliative care
  – Earlier referral
  – Need to triage because of resource limitation
  – Targeted referral may further improve access for those in need

• More high quality research is needed
Thank You!

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  - Helsinn Therapeutics

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  - Dr. Renata dos Santos (Brazil)
  - Dr. Maria Salete Angelis (Brazil)
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  - Dr. Mary Ann Muckaden (India)
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  - Dr. Stein Kassa (Norway)
  - Dr. Florian Strasser (Swiss)
  - Dr. Egizio Del Fabbro (USA)
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