Overview of main palliative care interventions delivered by oncologists and by specialists in palliative care

Florian Strasser, MD
Supportive & Palliative Oncology
Clinic Oncology/Hematology
Dept. Internal Medicine & Palliative Center
Cantonal Hospital St. Gallen, Switzerland

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What is Palliative Care?
What is a Palliative Care Intervention?
What is the Evidence?
Who should deliver Palliative Care?
What is the role of the Oncologist?
When to involve a specialist PC Team?
What shall I do tomorrow in my clinic?
Palliative Care

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological & spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
Palliative Care Interventions (PCIs)

Definable interventions as part of the specialist Palliative Care «package»

From the US Mass General RCT: documented PCIs

Temel J et al. JCO 2016; Dec 28
Incurable Lung Cancer (NSCLC, SCLC, Mesoth)

Incurable non-CRC GI Cancer (pancreatic, esophageal, gastric, hepatobiliary)

Effects of specialized Palliative Care are different in incurable Lung and non-CRC GI Cancer Patients

«Dose» of specialized PC in 24 weeks: 6.54 (mean, range 0-14)

→ Once a month: recommended dose*

Temel J et al. JCO 2016; Dec 28
Ferrrel BL et al. JCO 2017;35:96-112
Palliative Care Interventions

<table>
<thead>
<tr>
<th>Pharmacological</th>
<th>(e.g. pleural pct)</th>
</tr>
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<tbody>
<tr>
<td>Procedural</td>
<td>(e.g. prognosis)</td>
</tr>
<tr>
<td>Educational</td>
<td>(e.g. decisions)</td>
</tr>
<tr>
<td>Counselling</td>
<td>(e.g. prompt list)</td>
</tr>
<tr>
<td>Coaching, Empower</td>
<td>(e.g. behavioural)</td>
</tr>
<tr>
<td>Psychological</td>
<td>(e.g. HCP network)</td>
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... Complex: relevant interactions between interventions

**Simplified PCIs**

- **Illness understanding**
  (prognosis, mechanism, trajectory)
- **Symptom control**
  (bio-psycho-social-spiritual)
- **Decision processes**
  (cancer-specific Tx, nutrition, ...)
- **Continuity of care Network**
  (various HCP, home-out- inpat)
- **Care of family members**
  (incl. premortal grief, coaching)
- **End of life preparation & care**
  (family; double way, legacy, dying)
- **Spirituality**
  (meaning, transcendence, ..)

Illness & Prognosis Understanding Intervention

In daily practice: HCP learn and apply, empower patients

- Ask proactive patients about their illness understanding
  “In your own words, what do you tell proxies what you have?”

- Truth telling about prognosis, expected trajectory
  worst (5%) & best case (95%) scenarios: weeks, months, years

- Fair information to make decisions, use time left well
  → normalization approach: “many patients want to know...”

Question prompt list: patients can ask clinicians

Communication skills training for oncologists important

Many HCPs believe patients and caregivers should be told the truth about the prognosis → but in practice avoid discussion / withhold info

- no time (?)
- fear of a negative impact on patient
- uncertain prognosis
- family requests
- feel inadequate/ hopelessness

2: Epstein RM et al. JAMA Oncol 2016 Sep 9  
<table>
<thead>
<tr>
<th>Measure</th>
<th>Usual Care</th>
<th>Early PC</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary goal of cancer treatment is cure</td>
<td>34.5%</td>
<td>28.7%</td>
<td>0.29</td>
</tr>
<tr>
<td>Prefer to extend life as long as possible, even if meant more pain and discomfort</td>
<td>34.5%</td>
<td>33.6%</td>
<td>0.99</td>
</tr>
<tr>
<td>Knowing about prognosis is very/extremely helpful for:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making decision about treatment</td>
<td>89.8%</td>
<td>96.5%</td>
<td>0.043</td>
</tr>
<tr>
<td>Coping with the disease</td>
<td>83.6%</td>
<td>97.3%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Discussed wishes about care if dying</td>
<td>14.5%</td>
<td>30.2%</td>
<td>0.004</td>
</tr>
</tbody>
</table>
Many symptoms are still poorly controlled
. insufficient access to drugs (e.g., opioids)¹
. no proactive screening
. non-specialized setting²
. silent symptoms (fatigue, depression) neglected

Monitoring incl. coaching³ or symptom mgmt drugs⁴ or email alerts to HCPs⁵ improve outcomes

1: Cherny N Ann Oncol 2013;S11:xi7-13
2: Greco MT JCO 2014;32:4149-54
3: Berry DL JCO 2014;32:199-205
5: Basch E JCO 2016;34:557-65

Symptom Control Intervention(s)

Manage symptoms & syndromes multidimensional
- physical, emotional, intellectual, social, spiritual

Define Syndrome and risk factors
- Pain: incident, neuropathic, cognitive, emotional⁶
- Cachexia: concurrent malnutrition, constipation⁷
- Depression: concurrent delirium, dementia

Management by drugs, education, counseling, etc.⁸
- always consider mechanism, ev. location
- always ask for impact of symptom on quality of life
- pharmacological management: Guidelines⁸

7: Aapro M Ann Oncol 2014;25:1492-9
8: Sheinfeld Gorin S et al. JCO 2012; 30:539-547
Edmonton Symptom Assessment System Revised (ESAS-R)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Range</th>
<th>Worst Possible</th>
</tr>
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<tbody>
<tr>
<td>No Pain</td>
<td>0-10</td>
<td>Pain</td>
</tr>
<tr>
<td>No Tiredness</td>
<td>0-10</td>
<td>Tiredness</td>
</tr>
<tr>
<td>No Drowsiness</td>
<td>0-10</td>
<td>Drowsiness</td>
</tr>
<tr>
<td>No Nausea</td>
<td>0-10</td>
<td>Nausea</td>
</tr>
<tr>
<td>No Lack of Appetite</td>
<td>0-10</td>
<td>Lack of Appetite</td>
</tr>
<tr>
<td>No Shortness of Breath</td>
<td>0-10</td>
<td>Shortness of Breath</td>
</tr>
<tr>
<td>No Depression</td>
<td>0-10</td>
<td>Depression</td>
</tr>
<tr>
<td>No Anxiety</td>
<td>0-10</td>
<td>Anxiety</td>
</tr>
<tr>
<td>Best Wellbeing</td>
<td>0-10</td>
<td>Wellbeing</td>
</tr>
<tr>
<td>Other Problem</td>
<td>0-10</td>
<td>Other Problem</td>
</tr>
</tbody>
</table>

Can be completed by proxies, HCP

- as paper or by computer
- verbally

Completed in daily routine care

Watanabe SM JPSM 2011;41:456-68

www.palliative.org/NewPC/professionals/tools/esas
3728 pts & caregiver rated **26 concerning issues** of support related to their cancer¹
. 91% „**making decisions** about about care“ in top categories important & very important
. lung cancer rank **3/26**, breast cancer **4/26**

Syst Lit Rev 5 databases decision making²
37 articles (original research, western, adult)
Majority pts **want participate** in DM process
Most not achieve level of involvement:
. Decisions are delayed
. Alternative treatment options not discussed

Anticancer treatment close to end-of-life «aggressive», if no spec. Pall Care unit³

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**Decision support Intervention**

**Preparing the decisional encounter⁴**
. Consider emotional burden of patient
. Assess illness & prognosis understanding
. Check individual meaning of hope
. Relate symptoms to cancer disease
. Adress family emotional / logistic burden
. Discuss preparation for End-of-Life
. Ask for preferred decisional involvment

**Decision⁴**
. Define specific goal, when & how measure
. Inform about non-abandement if no Tx
. Prepare worst & best case scenarios
. Empower pts to cope with & report toxicity

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¹ Gralla RJ Supp Care Cancer 2011;19(S2);S160
² Bélanger E Palliat Med 2011;242-61
⁴ Ribi K […] Strasser F; submitted
Continuity of care Network Intervention

Prepare with the multiprofessional team a **concrete care plan** for community-based patients
- what symptoms are expected, what drugs needed
- who will assess patient, who gives drugs, how?
- who cares for the patients‘ care needs?
- which phone numbers 1\textsuperscript{st} – 2\textsuperscript{nd} -3\textsuperscript{rd} to call? 24/7

Care of family members Intervention

Discuss & acknowledge family members double role
- carer, advocate, „nurse“, coordinator,..
- own burden, grief work, prepare role after death
Preparing for End-of-life Intervention

Communication About Serious Illness Care Goals
A Review and Synthesis of Best Practices

Rachelle E. Bernacki, MD, MS; Susan D. Block, MD; for the American College of Physicians High Value Care Task Force

Evidence That Early Communication About Goals of Care and End-of-Life Preferences Improves Care

End-of-life conversations are associated with better quality of life, reduced use of life-sustaining treatments near death, earlier hospice referrals, and care that is more consistent with patient preferences.

Patients who received early palliative care showed significant improvements in quality of life and mood, and survived 25% longer.\(^b\)

Patients who engaged in advance care planning were more likely to have their wishes known and followed.

Preparation for the end of life is associated with improved bereavement outcomes for family.

Intervention is (cost-) effective\(^1\)

Discuss living will, DNR, value-based diagnostic / therapeutic interventions

Solve legal and financial issues

Support concrete legacy work (dignity therapy\(^2\), narratives, books)

Use of remaining life time & finish business: dreams, duties, people, etc.

Support pre-mortal grief work

Preferred place of death, funeral

Care in dying phase (awakensness, skin care, pastoral care, catheter, etc.)

Prepare family for after death roles

1: Zhang B Arch Int Med 2009;169:480-8
2: Chochinov HM Lancet Oncol 2011;12:753-6
Martinez M Palliat Med 2016 Aug 26
Evidence of Palliative Care: specialized teams

- US Lung Cancer (Temel, NEJM 2010): QoL, Depression, Survival
- US Lung & non-crc GI (Temel, JCO 2016): QOL Lung wk 12/24, GI wk24 Prognostic awareness
- US Hemonc trspl. (El-jawahri JCO 2016): QoL wk 2
- Canadian (Zimmermann, Lancet 2014): QoL, EOL burden
- ENABLE I, II, III (Bakitas, JCO 2015): QoL Pat & Caregiver, Survival
- Japan (Nakajima JPSM 2014): Communikation, QOL
- Denmark (Groenvold, DanPact EAPC 2015): negativ (Intensity PC too low)
- Italy (Franciosi ESMO 2016): negative (contamination?)
- US (Ferrel, JPSM 2015): Family QoL, Survival
- Japan (Murakami BMC Pall 2015): Survival
- England (Higginson Lancet Resp 2015): QoL, Survival
“Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.”

Patients with advanced cancer: **Evidenced-based** *(Evidence Quality, Recommendation level)*
- referred to interdisciplinary palliative care teams
  - intermediate strong
- consultation available both inpatient and outpatient care
  - intermediate strong
- early in the course of disease, alongside active treatment
  - intermediate moderate

Newly diagnosed pts, referral < 8 weeks: **In-formal consensus**
- intermediate moderate

Cancer patients with high symptom burden: **Evidence-based**
- intermediate moderate

and/or unmet physical or psychosocial needs outpatient cancer care programs shall use dedicated resources

For family caregivers in outpatient setting: **Evidence-based**
- low weak

nurses, social workers, et al. caregiver-tailored PC support
## Recommendation Type and Strength

<table>
<thead>
<tr>
<th>Type of Recommendation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Evidence based</td>
<td>There was sufficient evidence from published studies to inform a recommendation to guide clinical practice.</td>
</tr>
<tr>
<td>Formal consensus</td>
<td>The available evidence was deemed insufficient to inform a recommendation to guide clinical practice. Therefore, the Expert Panel used a formal consensus process to reach this recommendation, which is considered the best current guidance for practice. The Expert Panel may choose to provide a rating for the strength of the recommendation (ie, “strong,” “moderate,” or “weak”). The results of the formal consensus process are summarized in the guideline and reported in the Data Supplement.</td>
</tr>
<tr>
<td>Informal consensus</td>
<td>The available evidence was deemed insufficient to inform a recommendation to guide clinical practice. The recommendation is considered the best current guidance for practice, based on informal consensus of the Expert Panel. The Expert Panel agreed that a formal consensus process was not necessary for reasons described in the literature review and discussion. The Expert Panel may choose to provide a rating for the strength of the recommendation (ie, “strong,” “moderate,” or “weak”).</td>
</tr>
<tr>
<td>No recommendation</td>
<td>There is insufficient evidence, confidence, or agreement to provide a recommendation to guide clinical practice at this time. The Expert Panel deemed the available evidence as insufficient and concluded it was unlikely that a formal consensus process would achieve the level of agreement needed for a recommendation.</td>
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<thead>
<tr>
<th>Rating for Strength of Recommendation</th>
<th>Definition</th>
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<tr>
<td>Strong</td>
<td>There is high confidence that the recommendation reflects best practice. This is based on (1) strong evidence for a true net effect (eg, benefits exceed harms); (2) consistent results, with no or minor exceptions; (3) minor or no concerns about study quality; and/or (4) the extent of Expert Panelists’ agreement. Other compelling considerations (discussed in the guideline’s literature review and analyses) may also warrant a strong recommendation.</td>
</tr>
<tr>
<td>Moderate</td>
<td>There is moderate confidence that the recommendation reflects best practice. This is based on (1) good evidence for a true net effect (eg, benefits exceed harms); (2) consistent results, with minor and/or few exceptions; (3) minor and/or few concerns about study quality; and/or (4) the extent of Expert Panelists’ agreement. Other compelling considerations (discussed in the guideline’s literature review and analyses) may also warrant a moderate recommendation.</td>
</tr>
<tr>
<td>Weak</td>
<td>There is some confidence that the recommendation offers the best current guidance for practice. This is based on (1) limited evidence for a true net effect (eg, benefits exceed harms); (2) consistent results, but with important exceptions; (3) concerns about study quality; and/or (4) the extent of Expert Panelists’ agreement. Other considerations (discussed in the guideline’s literature review and analyses) may also warrant a weak recommendation.</td>
</tr>
</tbody>
</table>
Patients with advanced cancer should receive palliative care services, which may include referral to a palliative care provider.

**Essential components of palliative care** may include:

- Rapport and relationship building with patients and family caregivers
- **Symptom**, distress, and functional status management (e.g., pain, dyspnea, fatigue, sleep disturbance, mood, nausea, or constipation)
- Exploration of understanding & education about **illness** and **prognosis**
- Clarification of [anticancer] treatment **goals**
- Assessment and support of coping needs (e.g., dignity therapy)
- Assistance with medical **decision** making
- Coordination with other care providers
- Provision of referrals to other care providers as indicated

→ interestingly, explicit end-of-life preparation not mentioned (US setting)
Who should deliver Palliative Care Interventions?  
Role of Medical Oncologist

Evidence for specialized PC teams → but Medical Oncology Curriculum includes many topics

Palliative care and oncology have roles that are distinct and overlapping

A medical oncologist may need to train 3 months in a specialized palliative care unit during the 3 year Curriculum

Figure 2. Elements of palliative care (PC) vs oncologic care visits at clinical turning points. EOL indicates end of life.
966 PC service items as candidate elements of primary PC for pts with advanced cancer or high symptom burden. Modified Delphi by 31 experts: importance, feasibility, scope within medical oncology practice.

Bickel KE et al. JOP 2016;12:e828-38
Referral criteria for outpatient Palliative Care

Which Patients?
When?

The 11 major criteria

Methods: 60 intl Cancer PC experts (26 North America, 19 Australia/Asia, 11 Europe) rated 39 needs-based & 22 time-based criteria, 3 iterative rounds

Hui D Lancet Oncol 2016;17:e552-e559
Referral criteria for outpatient Palliative Care

When?

Hui D. Lancet Oncol 2016;17:e552-e559
Hui D. Oncologist 2016;21:895-901
Practice change in my clinic fostering Palliative Care Interventions

- Implement routine screening for main symptoms (e.g. ESAS)
- Deliver and document in flow charts main Palliative Interventions
- Collaborate with other health care professionals\(^1\)
- Rotate three months in a specialized Palliative Care Service, OR become a double boarded Palliative Oncologist\(^2\)

2: Hui D JCO 2015;33:2314-7