Palliative and End-of-Life Care: Challenges and Opportunities for Applied Cancer Research

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Palliative and End-of-Life Care: Challenges and Opportunities for Applied Cancer Research

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Making the case for palliative care, including hospice

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2. I have grant or research funding to Johns Hopkins University Sidney Kimmel Comprehensive Cancer Center from
   - National Cancer Institute RO1 Randomized Trial of PC for Phase I new drug patients; NINR RO1 PC for HIV/AIDS Caregivers; SKCCC Core Grant
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   - Ho-Chiang Foundation (pancreas cancer)
   - Lerner Foundation (fellowship in palliative medicine); Hearst Foundation for geri-pall fellowship
   - Axitinib for VEGF driven ascites trial, no financial support
   - Open Society Institute for work in developing countries
   - California Healthcare Foundation to establish web-based decision aids for solid tumors
Objectives

1. Making the clinical and economic case for palliative care.
2. Palliative care offers practical ways to improve health, quality of care, and value
   - Better patient and family quality of life
   - Better quality of care, especially reduced hospital use
   - Equal or improved survival with both hospice and palliative care.
   - At a cost we can afford.
3. Why we need research
   - Symptoms
   - Care models
   - Finance
Cancer patient symptoms are improved by PC consultation or transfer, with no change in mortality.

Memorial Symptom Assessment Scale, Condensed
30 pts with at least 2 consult days and symptoms > 0
Khatcheressian J, Coyne P, Smith T. Oncology September 2005
Next, we showed that palliative care programs save money for hospitals and health systems...

A High-Volume Specialist Palliative Care Unit and Team May Reduce In-Hospital End-of-Life Care Costs

THOMAS J. SMITH, M.D., PATRICK COYNE, R.N., M.S.N., BRIAN CASSEL, Ph.D., LYNNE PENBERTHY, M.D., ALISON HOPSON, R.N., M.S.N., and MARY ANN HAGER, R.N., M.S.N.

ABSTRACT

Background: Current end-of-life hospital care can be of poor quality and high cost. High-volume and/or specialist care, and standardized care with clinical practice guidelines, has improved outcomes and costs in other areas of cancer care.

Methods: The objective of this study was to measure the impact of the palliative care unit (PCU) on the cost of care. The PCU is a dedicated 11-bed inpatient (PCU) staffed by a high-volume specialist team using standardized care. We compared daily charges and costs of the days prior to PCU transfer to the stay in the PCU, for patients who died in the first 6 months after the PCU opened May 2000. We performed a case-control study by matching 38 PCU patients by diagnosis and age to contemporary patients who died outside the PCU cared for by other medical or surgical teams, to adjust for potential differences in the patients or goals of care.

Results: The unit admitted 237 patients from May to December 2000. Fifty-two percent had cancer followed by vascular events, immunodeficiency, or organ failure. For the 123 patients with both non-PCU and PCU days, daily charges and costs were reduced by 66% overall and 74% in “other” (medications, diagnostics, etc.) after transfer to the PCU ($2,358 \rightarrow $1,095, \text{P}=0.009).

Comparing the 38 contemporary control patients who died outside the PCU to similar patients who died in the PCU, daily charges were 59% lower ($5,304 \pm 5,850$ to $2,172 \pm 2,250$, \text{P}=0.005), direct costs 56% lower ($1,441 \pm 1,438$ to $632 \pm 690$, \text{P}=0.004), and total costs 57% lower ($2,538 \pm 2,918$ to $1,095 \pm 1,153$, \text{P}=0.009).

Conclusions: Appropriate standardized care of medically complex terminally ill patients in a high-volume, specialized unit may significantly lower cost. These results should be confirmed in a randomized study but such studies are difficult to perform.
Next, we hit the mainstream...

"I want to send a team down to learn how to do this palliative care...."

**Final Days**

Unlikely Way to Cut Hospital Costs: Comfort the Dying

$7000 less in last 5 days of life if PC involved.
With equal survival.
And better symptom control.
Kaiser Permanente System *randomized* clinical trials of IDPCTs
- equal survival
- better communication and quality of care
- **Net savings of $5-7000/person, now standard in all KP markets.**

![Bar chart showing cost comparisons between Usual Care and IDPCT]

Care – not just cancer care - is becoming more expensive

U S National health expenditures per capita (adjusted for inflation).

Mehta A J, and Macklis R M JOP 2013;9:216-221
Cancer care costs are rising exponentially
- $173 billion at 2% growth rate

Smith TJ, Hillner BE. Bending the cancer care cost curve. NEJM 2011.
Traditionally, there has been a “U-shaped” cost curve for cancer patients – high at the beginning and end of life.

With new drugs and procedures, the U has flattened and total costs can be much higher.

Medicare spends a substantial amount on care near the end of life – not optimally spent

- About 25% of all Medicare dollars are spent in the last year of life.
- About 40% of that, or 10% of the total (~$60 billion), is spent in the last MONTH of life.
- And care is getting MORE aggressive and expensive at EOL.

Riley GF, Lubitz JD. Long-term trends in Medicare payments in the last year of life. Health Serv Res. 2010 Apr;45(2):565-76.
Resource use and costs of end-of-Life/palliative care in **Ontario** adult cancer patients is similar.

- Direct medical cost of end-of-life and palliative (EOL/PAL) care for cancer patients during the last six months of their lives
- **average per patient cost of about $25,000 in 2002-2003.**
- Add out-of-pocket costs of approximately $3,500 (or 14 percent) to EOL/PAL costs
- Our results suggest that **acute care consumes 75 percent of EOL/PAL funding** and that **only a small proportion of health care services used by EOL/PAL care cancer patients is likely to be formal palliative care.**
Switch to palliative care often comes late, Ontario study finds

Timing a move from life-saving care to full palliative care can be complex, and nursing home residents in Ontario often do not make the full transition until they are near death, which can create a crisis-like situation, researchers reported in the Open Journal of Nursing. The study, which included data from three long-term care facilities, found even when advance directives were available, family often asked for additional interventions and nurses admitted to being somewhat resistant to switching to palliative care. McKnight's Long-Term Care News (4/24)
Chemo use in the last month of life similar worldwide, has associated CAT, PET scan use, hospitalizations

<table>
<thead>
<tr>
<th>Country</th>
<th>% getting chemo in last month of life</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sweden</td>
<td>23%</td>
<td>Nappa, 2011</td>
</tr>
<tr>
<td>US Medicare</td>
<td>15%</td>
<td>Earle, 2004</td>
</tr>
<tr>
<td>Italy</td>
<td>23% 14%</td>
<td>Andreis, 2011 Magarotto 2011</td>
</tr>
<tr>
<td>Portugal</td>
<td>37% 13%</td>
<td>Braga, 2007 Goncalves, 2011</td>
</tr>
<tr>
<td>Korea</td>
<td>30%</td>
<td>Keam, 2008</td>
</tr>
<tr>
<td>Australia</td>
<td>18%</td>
<td>Kao, 2009</td>
</tr>
<tr>
<td>US Private practice</td>
<td>43% lung ca 20% last 2 weeks</td>
<td>Murillo, 2006</td>
</tr>
<tr>
<td>US Veterans</td>
<td>18% (↑ since 2002)</td>
<td>Gonsalves, 2011</td>
</tr>
<tr>
<td>US Medicare national</td>
<td>5-20%</td>
<td>Morden, 2011</td>
</tr>
<tr>
<td>ASCO QOPI target</td>
<td>5%</td>
<td></td>
</tr>
</tbody>
</table>

Kelly R, Smith TJ. Lancet Oncology, 2014
We are still very hospital-oriented, and not hospice-oriented, in the last month of life.

<table>
<thead>
<tr>
<th>Measure</th>
<th>All Hospitals, academic or not</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death in hospital (%)</td>
<td>30.2</td>
</tr>
<tr>
<td>- ideally, &lt; 10% of deaths in hospital</td>
<td></td>
</tr>
<tr>
<td>Hospice use, last month of life (%)</td>
<td>53.8</td>
</tr>
<tr>
<td>Days in hospice, last month of life (per decedent)</td>
<td>8.4</td>
</tr>
<tr>
<td>- ideally, in hospice for 30 days</td>
<td></td>
</tr>
<tr>
<td>Hospitalized, last month of life (%)</td>
<td>64.9</td>
</tr>
<tr>
<td>Days in hospital, last month of life (per decedent)</td>
<td>5.3</td>
</tr>
<tr>
<td>ICU use, last month of life (%)</td>
<td>24.7</td>
</tr>
</tbody>
</table>

Medicare Patients, Unadjusted Cancer Care Measures, By Hospital Characteristics, Morden N, Health Affairs, 2011
Cancer patient hospital admissions increase in final month of life

Cancer more than any other disease at a large US hospital

Cassel, Kerr, Del Fabbro. Virginia Commonwealth University. Presented at Center to Advance Palliative Care National Seminar, 2013.
Chief reasons for admission to the inpatient oncology service – 66% were SYMPTOMS.
Solutions....

1. Evidence-based pathways such as those used by U. S. Oncology;
2. Elicitation of advance directives with better planning for the last months of life, including death, to avoid the hospital;
3. Cost control by limitation of prices (NICE; Veterans Administration Medical Centers; pharmacy benefit managers);
4. Integration of palliative care earlier, with transition to hospice when appropriate;
5. Regionalization and specialization of services, such as specialty pharmacies for expensive oral drugs;
6. Better communication about medically appropriate treatments with decision aids;
7. Better communication in the community including traditional (Gunderson, Wisconsin) and “cloud” solutions (NHS Coordinate my Care); and
8. Better information about actual patterns of care with real-time feedback to practitioners.

Kelly R, Smith TJ. Lancet Oncology, 2014
1. U S Oncology pathways reduce chemo amount and variation, preserve survival, increase choice about EOL care, and reduce cost by 35% in lung and colon cancer.

1. Evidence based pathways of U S Oncology incorporates Advance Care Planning

- Insist on hospice referral with 3-6 months to live (not 2 weeks)
- Audit hospice referrals and give feedback to physician
Solutions....

3. Cost control by changing SERVICES can improve care
Medical homes give better and less expensive care.

– Consultants in Hematology and Oncology, a 9 doctor practice
– Better information technology, RN calls to patients the day after chemoRx, pathways, more Advance Directive discussion
– 68% reduction in emergency department visits,
– 51% reduction in hospital admissions per patient with a
  21% reduced length of stay, a
– 22% reduction in outpatient visits per patient per year, and
– $1 million in savings per physician per year.

Solutions....

1. Evidence-based pathways such as those used by U. S. Oncology;
2. Elicitation of advance directives with better planning for the last months of life, including death, to avoid the hospital;
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8. Better information about actual patterns of care with real-time feedback to practitioners.
4. Integration of Hospice and palliative care


• 75% died in hospice care vs. 13% before
  – median length of stay in hospice of 36 d after vs. 10 d before

• Hospice relieves symptoms, prevents caregiver distress, and saves payers $2500-5000/person. (Kelley S, et al. Health Affairs 2013)
People with lung cancer who use hospice live longer than those who do not.

People who use hospice for even one day live longer.

Matched cohort study: hospice use or not. 4493 Medicare patients, 2095 (47%) received hospice care for at least one day, 1999

<table>
<thead>
<tr>
<th>Disease</th>
<th>Added survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHF</td>
<td>+ 81 days, P = 0.0540</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>+ 39 days, P &lt; 0.0001</td>
</tr>
<tr>
<td>Pancreatic cancer</td>
<td>+ 21 days, P = 0.0102</td>
</tr>
<tr>
<td>Colon cancer</td>
<td>+ 33 days, P = 0.0792</td>
</tr>
<tr>
<td>Breast</td>
<td>+ 12 days, P = 0.6136</td>
</tr>
<tr>
<td>Prostate</td>
<td>+ 4 days, P = 0.8266</td>
</tr>
</tbody>
</table>

Definition of palliative care

“Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support.

Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.”

— Diane Meier, MD, Director, Center to Advance Palliative Care, July 1, 2011
The American Society of Clinical Oncology now recommends concurrent palliative care “should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden"
5 (or, really, 7) RCTS now show...

- No harm in any trial
- Better satisfaction
- Usually better Quality of life
- Sometimes better symptom control
- LESS depression and anxiety
- 2 show better survival, one significant 2.7 months in NSCLC

- No increased cost in any trial
- Usually markedly lower costs per day – at least $300/day
- 10-fold increase in hospice referrals

* ED denotes emergency department, ICU intensive care unit, and PC palliative care.
Early Specialty Palliative Care — Translating Data

Traditional Palliative Care

Life-prolonging or curative treatment

Early Palliative Care

Life-prolonging or curative treatment

Palliative care to manage symptoms and improve quality of life

Diagnosis

Death

Hospice INFO visit

Mention Hospice as part of care

Hospice Activation
4. We can recognize hospice-eligible patients, prevent readmissions, honor choices, and save money.

U of Iowa Hospitals. 688 in-hospital deaths. 209 decedents had preceding admission.
- 60% eligible for hospice on the NEXT to LAST TERMINAL admission
- Only 14% had any discussion of hospice, despite being eligible; 14 of 17 enrolled in hospice, all from ONE service

Table 1. Comparison of Cost and Length of Stay Between Patients Enrolled and Not Enrolled in Hospice During a Terminal Hospital Admission

<table>
<thead>
<tr>
<th>Who got re-admitted?</th>
<th>Enrolled in hospice before last admission n = 7/14</th>
<th>Not enrolled in hospice n = 202/209</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost (Mean)</td>
<td>$4963</td>
<td>$52,219</td>
</tr>
</tbody>
</table>

4. Integration of Hospice and Palliative Care.


Allowed concurrent use of hospice/PC and chemo or radiation
Hospice use increased
- Enrollees doubled from 31% to 72% , p<0.0001
- Hospice days increased 15.9 to 28.6 , p<.0001

IP days reduced
- Medicare 15,217 down to 2309 per thousand members
- …@ $2500/day

- ICU days reduced
- Medicare CM Group; 9840 down to 1189 per thousand members
- …@ $3500/day

- Overall, at least 22% savings in last 40 days of life.
By R. Sean Morrison, Jessica Dietrich, Susan Ladwig, Timothy Quill, Joseph Sacco, John Tangeman, and Diane E. Meier

Palliative Care Consultation Teams Cut Hospital Costs For Medicaid Beneficiaries

ABSTRACT Patients facing serious or life-threatening illnesses account for a disproportionately large share of Medicaid spending. We examined 2004–07 data to determine the effect on hospital costs of palliative care team consultations for patients enrolled in Medicaid at four New York State hospitals. On average, patients who received palliative care incurred $6,900 less in hospital costs during a given admission than a matched group of patients who received usual care. These reductions included $4,098 in hospital costs per admission for patients discharged alive, and $7,563 for patients who died in the hospital. Consistent with the goals of a majority of patients and their families, palliative care recipients spent less time in intensive care, were less likely to die in intensive care units, and were more likely to receive hospice referrals than the matched usual care patients. We estimate that the reductions in Medicaid hospital spending in New York State could eventually range from $84 million to $252 million annually (assuming that 2 percent and 6 percent of Medicaid patients discharged from the hospital received palliative care, respectively), if every hospital with 150 or more beds had a fully operational palliative care consultation team.
Solutions....

1. Evidence-based pathways such as those used by U. S. Oncology;
2. Elicitation of advance directives with better planning for the last months of life, including death, to avoid the hospital;
3. Cost control by limitation of prices (NICE; Veterans Administration Medical Centers);
4. Integration of palliative care earlier, with transition to hospice when appropriate;
5. Regionalization and specialization of services, such as specialty pharmacies for expensive oral drugs;
6. Better communication about medically appropriate treatments with decision aids;
7. Better communication in the community including traditional (Gunderson, Wisconsin) and “cloud” solutions (NHS Coordinate my Care); and
8. Better information about actual patterns of care with real-time feedback to practitioners.
Help us learn to Assess Hospice Eligibility routinely

• This is a great tool for iPads and iPhones. And now Androids.

• It gives us the WORDS to say…. “A service offered to patients when cure is no longer possible or sought, and the prognosis is 6 months or less....”

• Give it with the Salpeter JPM article! That documents the 6 month or less....

Our ER project to identify hospice eligible patients in the ED and get PC involved has been successful.

EPs identified 88 hospice-eligible patients with 91% accuracy, in 6 mos. 6 patients were discharged from the ED preventing admission or re-admission.

We decreased time to PC consult to < 24 hours, and if PC consulted, more went home with hospice, 57% vs. 27%, p<0.003.

In 24 months admissions to hospice have increased, putting us in the upper part of academic centers.

Referrals to Gilchrist shown; others similar.
Always do a religious/spiritual assessment – and get some help.

For cancer patients, 87% want US to know about and help with their spiritual needs. About 6% of us ever ask.

Is religion important to you? Would you like to see a chaplain?

Clicking the radio button automatically generates referral to Pastoral Care

If pastoral care (hospital chaplains) are involved, and people’s spiritual needs are met, care becomes LESS aggressive at EOL, and slightly less expensive. And vice versa. Balboni T. Support of cancer patients' spiritual needs and associations with medical care costs at the end of life. Cancer. 2011 Dec 1;117(23):5383-91
The Johns Hopkins Checklist: Are there other issues that I should address at this time?

Since ____________(LVAD, TAVR, pancreas ca) is such a serious illness, and nearly all people die within 2 years, we are asking that you consider Advance Care Planning.

- Do you have a Will?
- Do you have a living will? For instance, if you could not speak for yourself, who would you want to make decisions about your care? If your heart stopped beating, or you stopped breathing, due to the cancer worsening, would you want to have resuscitation (CPR), or be allowed to die naturally without resuscitation?
- Do you have someone who will speak for you, if you can’t speak for yourself about medical issues, like CPR?
- Any family issues to address?
- Any spiritual issues to address?
- Some people use this time to discuss with their loved ones how they would like to spend the rest of their life. For instance, how and where do you want to spend your last days? Do you want to have hospice involved?
- Some people use this time to address a life review. That would include what they have learned during life that they want to share with their families, and planning for events in the future like birthdays or weddings.

Under development with Dr. Peter Pronovost and Rita Moldovan RN, DNP for the JH website and part of all our Advanced Illness programs.
Conclusions

1. It is easy to make the clinical, economic, and ethical case for expanding palliative and hospice care.
2. It is harder to garner the resources to switch.
3. Palliative care and hospice care are better care at a cost we can afford.
4. There is still a lot of research to be done.
   • Who should be doing this?
   • What are the needed elements?
   • What are the best triggers?
   • What is the best patient centered approach?
Thanks to the growing Hopkins Program in Palliative Care
Dr. Jennifer Temel, MD
Associate Professor of Medicine at Harvard Medical School and Clinical Director of Thoracic Oncology at Massachusetts General Hospital
What’s the data supporting an integrated palliative and oncology care model in patients with advanced cancer?

Jennifer Temel, MD
May 12, 2014
The Good News

- There are now three randomized studies conducted exclusively in patients with advanced cancers using integrated ambulatory care models that demonstrate improvements in both patient-reported outcomes and health care utilization.
The BEST News

- One of them is Canadian
- The studies’ similarities and differences can help us figure out the best way to conduct palliative care studies in the future and identify key research questions.
Project ENABLE

322 patients within 8-12 weeks of a new diagnosis of GI, lung, GU or breast cancer with a prognosis of approximately one year

ENABLE intervention

Usual Care

Outcome Measures

Patient-reported Outcomes
1. FACIT Palliative Care
2. ESAS (symptom intensity)
3. CES-D (depression)

Health Service Utilization
1. Number of days in hospital, intensive care unit and emergency department
2. Use of advanced directives
3. Referral to palliative care or hospice

Bakitas JAMA 302 (7) 2009
Nature of the Intervention

- Case management, educational approach to encourage patient activation, self-management and empowerment.
- Delivered in a manualized, telephone-based format (to administer to a rural population).
- Administered by advanced practice nurses with palliative care training.
- Included 4 initial structured educational and problem-solving sessions and at least monthly telephone follow up.
Figure 2. Quality of Life, Symptom Intensity, and Mood Scores for All Patients

- Functional Assessment of Chronic Illness Therapy for Palliative Care
- Edmonton Symptom Assessment Scale
- Center for Epidemiological Studies Depression Scale

Patients, No.
Usual care: 130, 97, 74, 54, 44, 31

Scores over time (Baseline 1 to 13 months)
Randomized Trial in Patients with Lung Cancer

150 patients within 8 weeks of diagnosis of metastatic NSCLC with an ECOG PS 0-2

Integrated care

Standard care

Outcome Measures

Patient-reported Outcomes
1. FACT Lung
2. HADS (mood)
3. PHQ-9 (depression)
4. Prognostic awareness

Health Service Utilization
1. Hospice referrals
2. Chemotherapy administration
3. Documentation of resuscitation preferences

Temel NEJM 363 (8) 2010
Nature of the Intervention

- Palliative care visits within 3 weeks of enrollment and at least monthly.
- Visits performed by physicians or advanced practice nurses within the Cancer Center (medical oncology or chemotherapy visits).
- Palliative care visits were not scripted or manualized but followed general guidelines as per the national consensus project.
- If patients were admitted to the hospital, they were also followed by the palliative care team.
# Palliative Care Visits by 12 Weeks

<table>
<thead>
<tr>
<th>Palliative Care Visits</th>
<th>Standard Care N (%)</th>
<th>Early Palliative Care N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>64 (87)</td>
<td>1 (1)*</td>
</tr>
<tr>
<td>1</td>
<td>7 (9)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>3 (4)</td>
<td>8 (10)</td>
</tr>
<tr>
<td>3</td>
<td>0</td>
<td>18 (23)</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
<td>26 (34)</td>
</tr>
<tr>
<td>≥ 5</td>
<td>0</td>
<td>24 (31)</td>
</tr>
</tbody>
</table>

* Died within 2 weeks of enrollment
## Impact of Palliative Care on QOL

**Table 2. Bivariate Analyses of Quality-of-Life Outcomes at 12 Weeks.**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standard Care (N=47)</th>
<th>Early Palliative Care (N=60)</th>
<th>Difference between Early Care and Standard Care (95% CI)</th>
<th>P Value†</th>
<th>Effect Size‡</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACT-L score</td>
<td>91.5±15.8</td>
<td>98.0±15.1</td>
<td>6.5 (0.5–12.4)</td>
<td>0.03</td>
<td>0.42</td>
</tr>
<tr>
<td>LCS score</td>
<td>19.3±4.2</td>
<td>21.0±3.9</td>
<td>1.7 (0.1–3.2)</td>
<td>0.04</td>
<td>0.41</td>
</tr>
<tr>
<td>TOI score</td>
<td>53.0±11.5</td>
<td>59.0±11.6</td>
<td>6.0 (1.5–10.4)</td>
<td>0.009</td>
<td>0.52</td>
</tr>
</tbody>
</table>

*MGH 1811  CANCER CENTER  HARVARD MEDICAL SCHOOL*
Impact of Palliative Care on Mood

38 v 16%. $p=0.01$

17 v 4%. $p=0.04$
Improvement in Prognostic Awareness

My cancer is curable: Yes or No

Palliative care v Standard care
82.5% v 59.6%, p=0.02
## End of Life Care Measures

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standard Care N (%) or Median</th>
<th>Early Palliative Care N (%) or Median</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documented Resuscitation Preference</td>
<td>11 (28)</td>
<td>18 (53)</td>
<td>0.05</td>
</tr>
<tr>
<td>Hospice Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received hospice care</td>
<td>44/67 (66)</td>
<td>44/62 (71)</td>
<td>0.57</td>
</tr>
<tr>
<td>Hospice care &gt; 7 days before death</td>
<td>21/63 (33)</td>
<td>36/60 (60)</td>
<td>0.004</td>
</tr>
<tr>
<td>Median days on hospice</td>
<td>9.5 (1-268)</td>
<td>24 (2-116)</td>
<td>0.02</td>
</tr>
<tr>
<td>Location of Death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>36/66 (55)</td>
<td>40/61 (66)</td>
<td>0.28</td>
</tr>
<tr>
<td>Inpatient hospice</td>
<td>13/66 (20)</td>
<td>9/61 (15)</td>
<td>0.49</td>
</tr>
<tr>
<td>Hospital/nursing home/rehab facility</td>
<td>17/66 (26)</td>
<td>12/61 (20)</td>
<td>0.53</td>
</tr>
</tbody>
</table>
Final Chemotherapy at the EOL

IV Chemotherapy

Oral Chemotherapy

IV chemo within 60 DOD
46% v 24% p=0.01

Greer JCO 30 (4) 2012
Canadian Study

461 patients with stage IV cancer (breast and prostate hormone refractory) or stage III with poor prognosis and ECOG PS 0-2 with a clinical prognosis of 6-24 months

Early Palliative Care Intervention

Usual Care

Outcome Measures

Patient-reported Outcomes
1. FACIT Spiritual Well Being
2. ESAS (symptom severity)
3. Quality of Life at EOL
4. FAMCARE (satisfaction)
5. CARES-MIS (problems with medical interactions)

Zimmermann Lancet 6736 (13) 2014
Nature of the Intervention

- Consultation (within one month) and at least monthly follow up in the oncology palliative care clinic by a physician and nurse.
- Routine telephone contact from nurse one week after consult and as needed.
- Intervention included routine, structured assessments of symptoms and psychosocial needs and discussion about home care needs.
- If patients were admitted to the hospital, they were admitted to palliative care unit.
## Palliative Care Visits

<table>
<thead>
<tr>
<th></th>
<th>Intervention group (n=228)</th>
<th>Control group (n=233)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Palliative care clinic visits</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>0</td>
<td>213 (91.4%)</td>
</tr>
<tr>
<td>1</td>
<td>23 (10.1%)</td>
<td>9 (3.9%)</td>
</tr>
<tr>
<td>2</td>
<td>30 (13.2%)</td>
<td>5 (2.1%)</td>
</tr>
<tr>
<td>3</td>
<td>28 (12.3%)</td>
<td>3 (1.3%)</td>
</tr>
<tr>
<td>4</td>
<td>68 (29.8%)</td>
<td>0</td>
</tr>
<tr>
<td>≥5</td>
<td>79 (34.6%)</td>
<td>3 (1.3%)</td>
</tr>
<tr>
<td><strong>Palliative care unit admissions</strong></td>
<td>17 (7.5%)</td>
<td>0</td>
</tr>
<tr>
<td><strong>Inpatient palliative care consultations</strong></td>
<td>18 (7.9%)</td>
<td>2 (0.9%)</td>
</tr>
<tr>
<td><strong>Palliative home nursing referrals</strong></td>
<td>39 (17.1%)</td>
<td>7 (3.0%)</td>
</tr>
<tr>
<td><strong>Home palliative care physician referrals</strong></td>
<td>18 (7.9%)</td>
<td>7 (3.0%)</td>
</tr>
</tbody>
</table>

Data are n (%). *Numbers for admissions, consultations, and referrals are not exclusive (i.e., one patient might have a consultation and a palliative care unit admission).

*Table 3: Palliative care intensity for intervention and control groups*
### Impact of Early Palliative Care on Patient Outcomes

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Control</th>
<th>Available cases analysis*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean observed change from baseline (SD)</td>
</tr>
<tr>
<td>FACIT-Sp</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 month</td>
<td>154</td>
<td>1.86 (11.99)</td>
</tr>
<tr>
<td>2 months</td>
<td>138</td>
<td>0.58 (13.09)</td>
</tr>
<tr>
<td>3 months</td>
<td>140</td>
<td>1.60 (14.46)</td>
</tr>
<tr>
<td>4 months</td>
<td>122</td>
<td>2.46 (15.47)</td>
</tr>
<tr>
<td>QUAL-E</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 month</td>
<td>154</td>
<td>1.09 (6.79)</td>
</tr>
<tr>
<td>2 months</td>
<td>137</td>
<td>1.38 (7.49)</td>
</tr>
<tr>
<td>3 months</td>
<td>139</td>
<td>2.33 (8.27)</td>
</tr>
<tr>
<td>4 months</td>
<td>121</td>
<td>3.04 (8.33)</td>
</tr>
<tr>
<td>ESAS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 month</td>
<td>180</td>
<td>-0.72 (13.01)</td>
</tr>
<tr>
<td>2 months</td>
<td>158</td>
<td>0.89 (14.83)</td>
</tr>
<tr>
<td>3 months</td>
<td>151</td>
<td>0.14 (16.93)</td>
</tr>
<tr>
<td>4 months</td>
<td>131</td>
<td>-1.34 (15.98)</td>
</tr>
<tr>
<td>FAMCARE-P16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 month</td>
<td>160</td>
<td>1.77 (8.14)</td>
</tr>
<tr>
<td>2 months</td>
<td>140</td>
<td>1.95 (9.12)</td>
</tr>
<tr>
<td>3 months</td>
<td>142</td>
<td>2.33 (9.10)</td>
</tr>
<tr>
<td>4 months</td>
<td>121</td>
<td>3.70 (8.58)</td>
</tr>
</tbody>
</table>
What do these studies tell us?

<table>
<thead>
<tr>
<th></th>
<th>Bakitas</th>
<th>Temel</th>
<th>Zimmermann</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enrollment</td>
<td>322/892 (36%)</td>
<td>151/270 (56%)</td>
<td>461/992 (47%)</td>
</tr>
<tr>
<td>Refused</td>
<td>359 (40%)</td>
<td>59 (22%)</td>
<td>350 (35%)</td>
</tr>
<tr>
<td>Non-offered/referred</td>
<td>224 (25%)</td>
<td>60 (22%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Did not complete baseline</td>
<td>32 (3%)*</td>
<td>N/A</td>
<td>181 (18%)</td>
</tr>
<tr>
<td>Palliative care visits</td>
<td>N/A</td>
<td>99% at least one</td>
<td>100% at least one</td>
</tr>
<tr>
<td></td>
<td></td>
<td>88% ≥ 3 by 12w</td>
<td>77% ≥ 3 by 16w</td>
</tr>
<tr>
<td>Completion of PROs</td>
<td>47 died before 1st assessment</td>
<td>28 died before 1st assessment</td>
<td>32 died before 1st assessment</td>
</tr>
</tbody>
</table>

1. Streamline recruitment measures.
2. Once patients are enrolled, they are compliant with palliative care visits.
3. Completion of PROs is challenging in this patient population.
What do these studies tell us?

- Palliative care improves patients’ QOL, mood and other aspects of care including prognostic awareness, satisfaction and quality of EOL care.
- Many palliative care delivery models work.
- A more “intensive” palliative care model may be needed to impact EOL care measures.
What about survival?

Figure 4. Kaplan-Meier Estimates of Survival According to Treatment Group

No. at risk
- Intervention: 161, 83, 35, 16
- Usual care: 161, 62, 33, 16

Log-rank $P = .14$

Proportion Surviving
- Intervention
- Usual care

Time, mo
0 12 24 36

Patients Surviving (%)
- Early palliative care
- Standard care

Fig. 3. Survival curve for patients with lung cancer.
Unanswered Questions

1. Does everyone need early/integrated palliative care?
2. Probably not. But even if they do – we cannot provide it, so can oncologists provide integrated care?
3. Even if we figure out who needs it – what is the appropriate dose and cost effective delivery model?
Can oncologists do it all??

Figure 2. Elements of palliative care (PC) vs oncologic care visits at clinical turning points. EOL indicates end of life.
Summary

- Many different delivery models of palliative care are effective at improving patients’ experience and QOL.
- We still need to do a better job with EOL care. Maybe focusing on palliative care is not sufficient….
- We must now determine who needs what and by whom.
Dr. Harvey Max Chochinov, MD, PhD, FRCPC

Distinguished Professor of Psychiatry at the University of Manitoba, Director of the Manitoba Palliative Care Research Unit for CancerCare Manitoba
Dignity, Distress and Personhood in Palliative Care

Harvey Max Chochinov OM MD PhD FRSC
Canada Research Chair in Palliative Care
Director, Manitoba Palliative Care Research Unit
Professor, Department of Psychiatry, Family Medicine and Community Health Sciences
University of Manitoba, CancerCare Manitoba
Stability of Will to Live with Pain in an 80 Year-old Patient with Colorectal Cancer

Stability of Will to Live with Pain in an 80 Year-old Patient with Colorectal Cancer

### Distribution of Sense of Dignity Responses

<table>
<thead>
<tr>
<th>Responses</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>0 No sense</strong> of lost dignity</td>
<td>114 (53%)</td>
</tr>
<tr>
<td><strong>1 Minimal</strong> sense of lost dignity</td>
<td>64 (30%)</td>
</tr>
<tr>
<td><strong>2 Mild</strong>; sense of lost dignity occasionally; regarded as minor problem</td>
<td>19 (9%)</td>
</tr>
<tr>
<td><strong>3 Moderate</strong> sense of lost dignity; regards as significant problem</td>
<td>11 (5%)</td>
</tr>
<tr>
<td><strong>4 Strong</strong>; feels clear sense of lost dignity most of time</td>
<td>5 (2%)</td>
</tr>
<tr>
<td><strong>5 Severe</strong>; clear sense of lost dignity almost always present</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>6 Extreme</strong>; sense of lost dignity virtually constant</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

• Desire for death \( (p < 0.0014) \)
• Loss of will to live \( (p < 0.013) \)
• Depression \( (p < 0.0084) \)
• Hopelessness \( (p < 0.020) \)
• Anxiety \( (p < 0.003) \)

• Pain \( (p < 0.048) \)
• Difficulty with bowel functioning \( (p < 0.026) \)
• Physical appearance \( (p < 0.002) \)

• **Bathing** (OR = 8.45 [1.50 to 47.70]; p < 0.016)

• **Dressing** (OR = 2.79 [0.95 - 8.15]; p < 0.061)

• **Incontinence** (OR = 3.47 [1.27 - 9.51]; p < 0.016)

Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care

Kindness, humanity, and respect—the core values of medical professionalism—are too often being overlooked in the time pressured culture of modern health care, says Harvey Chochinov, and the A, B, C, and D of dignity conserving care can reinstate them.

The late Anisele Boyard, essayist and former editor of the New York Times Book Review, wrote eloquently about the psychological and spiritual challenges of facing metastatic prostate cancer. "To the typical physician," he wrote, "my illness is a routine incident in his rounds while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity...I just wish he would...give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way."

Boyard's words underscore the costs and hazards of becoming a patient. The word "patient" comes from the Latin patiens, meaning to endure, bear, or suffer, and refers to an acquired vulnerability and dependency imposed by changing health circumstances. Relinquishing autonomy is no small matter and can exact considerable costs. These costs are sometimes relatively minor—for example, accepting clinic schedules or hospital routines. At other times, the costs seem incompatible with life itself. When patients experience a medical unsettling of their conventional sense of self and a disintegration of personhood, suffering knows few bounds. To feel sick is one thing, but to feel that who we are is being threatened or undermined—that we are no longer the person we once were—can cause despair affecting body, mind, and soul. How do healthcare providers influence the experience of personhood, and what happens when this frame of reference dominates how they view people seeking their care?

Dignity and personhood

Answering these questions begins with an examination of the relationship between personhood and notions of dignity. Although the literature on dignity is sparse, it shows that "how patients perceive themselves to be seen" is a powerful mediator of their dignity. In a study of patients with end stage cancer, perceptions of dignity were most strongly associated with "feeling a burden to others" and "sense of being treated with respect." As such, the more that healthcare providers are able to affirm the patient's value—that is, seeing the person they are or were, rather than just the illness they have—the more likely that the patient's sense of dignity will be upheld. This finding, and the intimate connection between care provider's affirmation and patient's self perception, underscores the basis of dignity conserving care.

Yet, many healthcare providers are reticent to claim this particular aspect of care, which is variously referred to as spiritual care, whole person care, psychosocial care, or dignity conserving care. This reluctance is often framed in terms of lack of expertise or concern about how much time this might consume. Yet, when personhood is not affirmed, patients are more likely to feel they are not being treated with dignity and respect. Not being treated with dignity and respect can undermine a sense of value or worth. Patients who feel their life no longer has worth, meaning, or purpose are more likely to feel they have become a burden to others, and patients...
# Data Table

<table>
<thead>
<tr>
<th>#</th>
<th>Variable</th>
<th>% Agree or strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>thinking how life might end</td>
<td>41.7%</td>
</tr>
<tr>
<td>2</td>
<td>distressing symptoms</td>
<td>53.1%</td>
</tr>
<tr>
<td>3</td>
<td>uncertainly regarding illness</td>
<td>59.2%</td>
</tr>
<tr>
<td>4</td>
<td>feeling depressed or anxious</td>
<td>59.7%</td>
</tr>
<tr>
<td>5</td>
<td>feeling your privacy has been reduced</td>
<td>65.9%</td>
</tr>
<tr>
<td>6</td>
<td>changes in physical appearance</td>
<td>66.4%</td>
</tr>
<tr>
<td>7</td>
<td>not being able to accept things the way they are</td>
<td>71.6%</td>
</tr>
</tbody>
</table>

**Dignity Model Questions**

N=211

| 8   | not having a meaning spiritual life                      | 73.7% |
| 9   | no longer feeling who you were                           | 74.4% |
| 10  | not being able to mentally fight                         | 74.5% |
| 11  | not being able to continue with usual routines           | 74.9% |
| 12  | feeling life no longer has meaning or purpose           | 75.1% |
| 13  | not being able to think clearly                         | 77.3% |
| 14  | not being able to carry out important roles             | 78.5% |
| 15  | tasks of daily living                                    | 79.6% |
## Dignity Model Questions

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
<td>not feeling worthwhile or valued</td>
<td>81.4%</td>
</tr>
<tr>
<td>18</td>
<td>bodily functions</td>
<td>82.9%</td>
</tr>
<tr>
<td>19</td>
<td>not feeling you made a meaning or lasting contribution</td>
<td>83.3%</td>
</tr>
<tr>
<td>20</td>
<td>feeling you don't have control over your life</td>
<td>83.7%</td>
</tr>
<tr>
<td>21</td>
<td>feeling a burden to others</td>
<td>87.1%</td>
</tr>
<tr>
<td>22</td>
<td>not being treated with respect or understanding</td>
<td>87.1%</td>
</tr>
</tbody>
</table>
Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life
Harvey Max Chochinov, Thomas Hock, Thomas Howard, Linda J. Kristjanson, Susan McClement, and Mike Harles

ABSTRACT

Purpose
This study examined a novel intervention, dignity therapy, designed to address psychosocial and existential distress among terminally ill patients. Dignity therapy invites patients to discuss issues that matter most or that they would most want remembered. Sessions are transcribed and edited, with a revised final version that they can bequeath to a friend or family member. The objective of the study was to establish the feasibility of dignity therapy and determine its impact on various measures of psychosocial and existential distress.

Patients and Methods
Terminal illness patients and those receiving home-based palliative care services in Winnipeg, Canada, and Perth, Australia, were asked to complete pre- and postintervention measures of sense of dignity, depression, suffering, and hopelessness, sense of purpose, sense of meaning, desire for death, will to live, and suicidality, and a postintervention satisfaction survey.

Results
Ninety-one percent of participants reported being satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 61% reported that it had been or would be of help to their family. Postintervention measures of suffering showed significant improvement (P < 0.02) and reduced depressive symptomatology (P < 0.05). Finding dignity therapy helpful to their family correlated with life feeling more meaningful (P = 0.486; P = 0.001) and having a sense of purpose (P = 0.962; P = 0.001), accompanied by a lessened sense of suffering (P = 0.327; P = 0.001) and increased will to live (P = 0.387; P = 0.001).

Conclusions
Dignity therapy shows promise as a novel therapeutic intervention for suffering and distress at the end of life.

J Clin Oncol 23:5620-5626. © 2005 by American Society of Clinical Oncology

INTRODUCTION

One of the most confounding challenges faced by end-of-life care providers is helping patients achieve or maintain a sense of dignity. Our prior studies of dignity and end-of-life care have shown a strong association between an undermining of dignity and depression, anxiety, desire for death, hopelessness, feeling of being a burden on others, and overall poorer quality of life. Yet, dying with dignity is usually only vaguely understood; hence, although the pursuit of dignity frequently underlies various approaches to end-of-life care, its therapeutic implications are frequently uncertain. There is mounting evidence that suffering and distress are major issues facing dying patients. Some studies suggest that psychosocial and existential issues may be of even greater concern to patients than pain and physical symptoms. The Institute of Medicine has identified overall quality of life and achieving a sense of spiritual peace and...
The Landscape of Distress in the Terminally Ill

Harvey Max Chochinov, MD, PhD, Thomas Hassard, PhD, Susan McLemore, PhD, Thomas Hard, PhD, C.Psych, Linda J. Kristjanson, PhD, Mike Harlos, MD, Shane Sinclair, BA, MDiv, PhD (C), and Alison Murray, MD, CCPP, MPH

Manitoba Palliative Care Research Unit (H.M.C.), Community Health Sciences (H.M.C., T.H.C.), and Faculty of Nursing (S.M., T.H.C.) University of Manitoba; Winnipeg; Manitoba Palliative Care Research Unit (H.M.C., S.M.), and Patient and Family Support Service (H.M.C., T.H.C.) CancerCare Manitoba, Winnipeg, Manitoba, Canada; Western Australian Centre for Cancer & Palliative Care (H.M.C., L.J.K.), Curtin University of Technology, Perth, Australia; St. Boniface General Hospital (M.H.), Winnipeg, Manitoba; Tim Baker Cancer Centre (S.S.), Calgary, Department of Oncology (S.S.), Faculty of Medicine, University of Calgary, Calgary, and Calgary Health Region (A.M.), Calgary, Alberta, Canada

Abstract

Understanding the complexities of distress and knowing who is most vulnerable is fundamental to the provision of quality, palliative mid-life care. Although prior studies have examined the prevalence of symptom distress among patients nearing death, these studies have tended to largely focus on physical and a lesser extent, psychological challenges. The aim of this study was to use the Patient Dignity Inventory (PDI), a novel, reliable, and validated measure of end-of-life distress, to describe a broad landscape of distress in patients who are terminally ill. The PDI, a 25-item self-report, was administered to 253 patients caring for palliative care. Each PDI item is rated by patients to indicate the degree to which they experience various kinds of end-of-life distress. Palliative care patients reported an average of 5.74 problems (standard deviation, 5.49; range, 0–24), including physical, psychological, existential, and spiritual challenges. Being an inpatient, being educated, and having a partner were associated with certain kinds of end-of-life problems, particularly existential distress. Spirituality, especially its existential or "sense of meaning and purpose" dimension was associated with less distress for terminally ill patients. A better appreciation for the nature of distress is a critical step toward a fuller understanding of the challenges facing the terminally ill. A clear articulation of the landscape of distress, including insight regarding those who are most at risk, should pave the way toward more effective, dignity-preserving end-of-life care. J Pain Symptom Manage 2009;37(3):443–454. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

The work was supported by a grant from the National Cancer Institute of Canada, with funding from the Canadian Institute for Health Research. The authors declare no conflicts of interest. Address correspondence to Harvey Max Chochinov, MD, PhD, Manitoba Palliative Care Research Unit, University of Manitoba, CancerCare Manitoba, 501B, 675 McPherson Avenue, Winnipeg, Manitoba R3E 0W9, Canada. Email: harvey.chochinov@cancercare.mb.ca

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The Patient Dignity Inventory: Applications in the Oncology Setting

Harvey Max Chochinov, M.D., Ph.D.,1,2,4 Susan E. McClement, R.N., Ph.D.,2,3 Thomas F. Hack, Ph.D., Psych3,4 Nancy A. McKeen, R.N., Ph.D.,1,2 Amanda M. Rach, B.A.,2 Pierre Gagnon, M.D.,5 Shane Sinclair, B.A., MDiv, Ph.D.,6 and Jill Taylor-Brown, M.S.W., R.S.W.4

Abstract

**Background:** The Patient Dignity Inventory (PDI) is a novel 25-item psychometric instrument, designed to identify multiple sources of distress (physical, functional, psychosocial, existential, and spiritual) commonly seen in patients who are terminally ill. It was also designed to help guide psychosocial clinicians in their work with patients. While its validity and reliability have been studied within the context of palliative care, its utility in clinical settings has not as yet been examined.

**Purpose:** The purpose of this study was to determine how psychosocial oncology professionals would use the PDI within their practice and what utility it might have across the broad spectrum of cancer.

**Methods:** Between October 2008 and January 2009, psychosocial oncology clinicians from across Canada were invited to use the PDI to determine their impressions of this approach in identifying distress and informing their practice.

**Results:** Ninety participants used the PDI and submitted a total of 429 feedback questionnaires detailing their experience with individual patients. In 76% of instances, the PDI revealed one or more previously unreported concerns; in 81% of instances, clinicians reported that the PDI facilitated their work. While it was used in a wide range of circumstances, clinicians were more inclined to apply the PDI to patients engaged in active treatment or palliation, rather than those in remission, having recently relapsed, or newly diagnosed. Besides its utility in identifying distress, the PDI enabled clinicians to provide more targeted therapeutic responses to areas of patient concern.

**Conclusions:** While this study suggests various clinical applications of the PDI, it also provides an ideal forerunner for research that will directly engage patients living with cancer.
Personhood on the Clinical Radar

“What should I know about you as a person to help me take the best care of you that I can?”
Mrs. F. says that because of the residential school, she always had a hard time trusting people. She in fact moved 82 times so as not to let anyone get too close to her. While this has gotten better over time, she still struggles with being able to trust people. She wants to, but it is hard for her. She sometimes worries that she won’t be told the whole truth, or that people will see her as not being deserving of the whole truth. She appreciates people being friendly towards her, but is frightened of authority figures. ‘Authority scares me, but I’m not as bad as I used to be’. 
# PDQ Study Patient and Family Characteristics

## Patient completed interview

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient completed interview</td>
<td>66</td>
<td>52%</td>
</tr>
<tr>
<td>Family completed interview</td>
<td>61</td>
<td>48%</td>
</tr>
</tbody>
</table>

## Variable

<table>
<thead>
<tr>
<th>Variable</th>
<th>Years</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Age</td>
<td>73.5</td>
<td>12.6</td>
</tr>
<tr>
<td>Family Age</td>
<td>59.4</td>
<td>14.1</td>
</tr>
<tr>
<td>How long know patient</td>
<td>49.3</td>
<td>13.7</td>
</tr>
</tbody>
</table>

## Relationship to Patient

<table>
<thead>
<tr>
<th>Relationship to Patient</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse of partner</td>
<td>27</td>
<td>44%</td>
</tr>
<tr>
<td>Sibling</td>
<td>5</td>
<td>8%</td>
</tr>
<tr>
<td>Adult child</td>
<td>27</td>
<td>44%</td>
</tr>
<tr>
<td>Other relative</td>
<td>2</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2%</td>
</tr>
</tbody>
</table>
## Patient and Family Response to PDQ

<table>
<thead>
<tr>
<th>Patient/Family Perception</th>
<th>Number of PDQs</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The PDQ accurate</td>
<td>121</td>
<td>99%</td>
</tr>
<tr>
<td>Permission to place on chart</td>
<td>124</td>
<td>97%</td>
</tr>
<tr>
<td>Wanted a copy</td>
<td>95</td>
<td>76%</td>
</tr>
<tr>
<td>Information Important for HCP</td>
<td>107</td>
<td>93%</td>
</tr>
<tr>
<td>Could affect my care</td>
<td>78</td>
<td>81%</td>
</tr>
<tr>
<td>Would recommend it for others</td>
<td>117</td>
<td>99%</td>
</tr>
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</table>
### Effect of PDQ on Health Care Provider

<table>
<thead>
<tr>
<th>Effect of PDQ on Health Care Provider</th>
<th>Not Influenced</th>
<th>Neutral</th>
<th>Influenced</th>
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</thead>
<tbody>
<tr>
<td>Learn something new from PDQ</td>
<td>24 (8.3%)</td>
<td>4 (1.4%)</td>
<td>262 (90%)</td>
</tr>
<tr>
<td>Was emotionally affected by PDQ</td>
<td>40 (13.7%)</td>
<td>66 (23.0%)</td>
<td>187 (63.8%)</td>
</tr>
<tr>
<td>PDQ influenced attitude</td>
<td>56 (19.3%)</td>
<td>73 (25.2%)</td>
<td>161 (55.5%)</td>
</tr>
<tr>
<td>PDQ influenced care</td>
<td>75 (26.6%)</td>
<td>82 (29.1%)</td>
<td>125 (44.3%)</td>
</tr>
<tr>
<td>PDQ influence respect</td>
<td>52 (18.3%)</td>
<td>96 (33.8%)</td>
<td>136 (47.9%)</td>
</tr>
<tr>
<td>PDQ influenced empathy</td>
<td>37 (13.2%)</td>
<td>78 (27.9%)</td>
<td>165 (58.9%)</td>
</tr>
<tr>
<td>PDQ affected connectedness</td>
<td>29 (10.4%)</td>
<td>74 (26.5%)</td>
<td>176 (63.1%)</td>
</tr>
<tr>
<td>Variable</td>
<td>p value</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender (Female &gt; Male)</td>
<td>0.0004</td>
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<td></td>
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<tr>
<td>Professional affiliation (Students &gt; Social workers, chaplains, healthcare aids, nurses &gt; physician residents &gt; physicians)</td>
<td>0.0058</td>
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<tr>
<td>Year Professional Experience (&gt;15 years, none, 0-5 years, 5-15 years)</td>
<td>0.004</td>
<td></td>
<td></td>
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<tr>
<td>Association with Empathy</td>
<td>0.010</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Association with Job satisfaction</td>
<td>0.003</td>
<td></td>
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</tr>
<tr>
<td>Association with meaningfulness in life</td>
<td>0.046</td>
<td></td>
<td></td>
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<tr>
<td>Association with perceived social support</td>
<td>0.040</td>
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</tbody>
</table>
Palliative and End-of-Life Care: Challenges and Opportunities for Applied Cancer Research

Dr. Denise Marshall, MD, CCFP, FCFP
Associate Professor, Division of Palliative Care McMaster University
Palliative Care Provincial Lead, Cancer Care Ontario;
Ontario LHIN Collaborative Provincial Lead
What is Hospice Palliative care?

Hospice Palliative Care aims to relieve suffering and improve the quality of living and dying. It strives to help families:

• Address physical, psychological, social, spiritual and practical issues, and their associated needs, hopes and fears

• Prepare for and manage end-of-life choices and the dying process

• Cope with loss and grief

• Treat all active issues

• Prevent new issues from occurring

• Promote opportunities for meaningful and valuable experiences, and personal and spiritual growth
Hospice Palliative care

- Is appropriate for any individual and/or family living with, or at risk of developing a life-threatening illness, at any time they are prepared to accept this type of care and support
- Our Canadian definition from CHPCA (2002)
- Is a philosophy of care
- Implies a social care interface with healthcare (95-5)
- Is about social transformation in which the biomedical is nested
- Is not reductionist
- Is about a good death, not a managed death
What do we have?

- Inequity around Death, Dying, Loss and Bereavement (DDLB)
- “healthy living’ has become “health services”
- “good death” has become “managed death”
- We react and support, when there is a problem, not from a place of normalcy
- Psychosocial reduced to ‘psychological’
- “social’ in general, is missing
- Reductionist thinking from DDLB to “palliative care services”
- Palliative Care has a public relations problem
Dying “in the past”

• Normal and routine
• Built on community relationships
• Whole person care - ie. whole “citizen “ care, not just service-based
• End of life care is more than medical care
• Death and loss are inevitable and universal
“Health Promoting Palliative Care”
HPPC

- is public health guiding end of life care services
- Built on idea that healthcare is participatory
- Applies the Ottawa Charter of Public Health to palliative care
- Not what we do to other but with others and is essentially social
- PC partners with municipalities, schools, workplaces
- Re-orienters volunteers to community development activities rather than bedside..
Applies our own Ottawa Charter for Public Health, to end of life care

- building healthy public policy
- creating supportive environments
- Strengthening community action
- Developing personal skills
- Re-orienting health services
Expanding the responsibility for palliative care and end of life care

- Goes beyond illness - involves the well, and wellness

- Including schools, workplaces, businesses, unions, places of worship, media, leisure groups, clubs etc

- Recognizing the limits to service provision - 'beyond mere services'

- Restores end of life care to the wider public health sphere of policy, practice, and language - involves the state

- Understanding and facilitating the principle that palliative care and end of life care is everyone’s responsibility
This delivery model is fluid and integrates chronic disease management and palliative care from diagnosis until death and through to bereavement.

Generally Intensity Diminishes in Time based on the Individual and their Family's Needs and Goals

Primary Care Investigations Specialists

At Risk

Established Disease

Interdisciplinary primary team

Pain & Symptom Management

Advanced Chronic Disease

Health Complications

End-of-Life Care

Death

Extended inter-professional team and common care plan

Advance Care/Life Planning Options

Psychosocial-Spiritual Support

Self Management Stabilized Treatment

Specialized HPC Team-based therapy to relieve suffering and/or improve quality of life

Last Year of Life

Last Days and Hours of Life

Child and adult palliative care
Community Capacity Development Model

Sequential phases of the capacity development model:

4. Growing the PC program
3. Creating the PC team
2. Community Catalyst
1. Antecedent community conditions

Developing Rural Palliative Care Model (ML Kelley)
Barriers?

- Inability, reluctance or refusal to grasp these concepts
- Health promotion is NOT health education
- Perception of threats to job or organization viability
- Seen as an “add-on” to current care
- Lack of critical mass of champions
International examples from UK, Ireland, Australia

- Hospice friendly hospitals (HfH)
- Frailty index - evidence based, longstanding
- Compassionate Watch ie. neighbourhood Watch
- Death education elementary schools/hospice partnerships
- Spiritual companions
- Integration of formal and informal care networks
- LTC pubs/beer coasters
- Carers’ day
WHO Catalon Spain, 20 year experience

• *Most important learning*
  – Extending care into more general chronic conditions
  – Promoting early interventions in the clinical evolution of the disease
  – Applying palliative care measures in all settings of the health care system
  – Identifying complexity vs prognosis as a criteria for specialist intervention ie Prognostic Indicator guide (PIG) of GSF
Driving policy and quality

• Belgium
  – Definition of care now includes “organized efforts of society”
  – Is a public health priority because of the myriad of social transitions involved
  – Council of Europe 2013-PC a public health priority
  – Develop new Minimum Data sets that include quality integration (approx 30 in Belgium)
Declaration of Partnership

ADVANCING HIGH QUALITY, HIGH VALUE PALLIATIVE CARE IN ONTARIO

A Declaration of Partnership and Commitment to Action

December 2011

Six Priorities Articulated = 94 action items

• Broaden Access & Increase Timelessness of Access
• Strengthen Caregiver Supports
• Strengthen Service Capacity & Human Capital in all Care Settings
• Improve Integration & Continuity Across Care Settings
• Strengthen Accountability and Introduce Mechanism for Shared Accountability
• Build Public Awareness
Declaration of Partnership

Vision

Adults and children with progressive life-limiting illness, their families and their caregivers will receive the holistic, proactive, timely and continuous care and support they need, through the entire spectrum of care both preceding and following death, to:

• help them live as they choose, and
• optimize their quality of life, comfort, dignity and security.

Triple Aim Goals

<table>
<thead>
<tr>
<th>Quality:</th>
<th>Population Health:</th>
<th>Sustainability:</th>
</tr>
</thead>
<tbody>
<tr>
<td>To improve client/family, caregiver and provider experience by delivering high quality, seamless care and support</td>
<td>To improve, maintain and support the quality of life and health of people with progressive life-limiting illnesses</td>
<td>To improve system performance by delivering better care more cost-effectively and creating a continuously self-improving system</td>
</tr>
</tbody>
</table>
A Foundation of Primary Care

According to the MOHLTC, a sustainable model for Ontario is a primary level “palliative care approach” integrated with chronic disease management and complemented by “specialized palliative care” when required.

- The most successful palliative care programs include three levels of palliative care: primary, secondary (intermediate), and tertiary (complex)
- A “palliative care approach” is good basic palliative care delivered by existing primary health care providers / teams or specialists who are not palliative care specialists (e.g. oncologists, internists, etc.)
- A “specialized palliative care” is provided by specialist palliative care clinicians or teams

C Represents the smallest proportion of the services and consists of palliative experts with advanced education and skills in palliative care. This level is largely responsible for caring for the most complex cases (smallest volume) and advancing the field academically through education initiatives and research.

B Interventions are made by palliative consultation services in support of primary teams or hospital attending teams in order to empower and enable the primary teams to provide palliative care.

A All primary level health professionals in all care settings should have at least some basic palliative care competencies so that the large majority of palliative care is provided at the primary health care level (with the support of secondary or tertiary level specialized teams as needed, particularly for the management of more complex cases).
Advice

- Lets learn more together
  - Health Canada, CHPCA - The Way Forward campaign, Speak Up Campaign; Ontario LHINs, HealthLinks, Cancer Care Ontario

- Stop the train....
  - Of unilateral health system/palliative care service development
  - Of organizational or service capital

- Tie performance evaluation to these health promotion constructs

- Capacity building within health care
Tangible steps

1. gain further clarity on health promoting palliative care, public health and palliative care, Compassionate communities model
2. translate the Ottawa Charter for ourselves
3. develop a critical mass of champions
4. systems research and social care/health care research
   - Adopt a frailty/complexity index and study
   - Early identification
   - Set up systemic performance evaluation based on benchmarks
   - Study the outcomes of enhancing social capitol
What did success look like...

- A greater sense of ‘normalization’ around DDLB
- Increase in community involvement, education, and empathy in DDLB (i.e., care mentors, neighborhood watch, world café, memorial days)
- Government policy changes—as in Australia, Scotland, Ireland, England, India
- Sustainable models and programs
- “A healthcare provider is a poor excuse for a friend”
Question Period