A Program of Research: Cancer Symptom Management

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Academic Life

Oncology

Teaching

Research

Service
The Beginning

Descriptive studies, largely unfunded provided a foundation.
My first research interest was pain management!
Descriptive Pain Studies

• Conducted in various settings where cancer patients receive care:
  – Pain poorly managed;
  – Patients complain of pain all day;
  – Nurses administer about one third of ordered analgesic while patients still in pain

• Surgical units
• ICUs
• Cancer units
• Hospices
Moving into Hospice Research

- Hospice Patient Services Committee in ‘87
- 80% of hospice patients had cancer.
- *Persuaded* to conduct oncology symptom research beginning in ‘91.
Hospice Outcomes:
Improved patient and family quality of life!

Hospice Patient Services Committee
Quality of Life of Patients and Caregivers

• Developed the Hospice Quality of Life Index and
• The Caregiver Quality of Life Index

Validated instruments on hospice patients with cancer and their family caregivers.

McMillan & Mahon, 1994
If symptom outcomes are not ideal:

Why might this be happening?
Nurses’ Knowledge and Attitudes

Have a major impact on how pain is managed.

What do nurses know?

What are their attitudes?

Knowledge

Attitudes

Practice

VA Funded
Nurses Knowledge and Attitudes

Have a major impact on how pain is managed.

What do nurses know?
What are their attitudes?

N=85 nurses working in units where cancer patients were receiving care
Knowledge About Pain Management (n=85)

- Range of scores  21-81%
- Mean score  61%

Nurses knew least about:
- Physiology of pain
- Pharmacology of analgesics
- Treatment goals
- Non-pharmacologic methods

McMillan et al., 2000
Attitudes About Pain Management (n=85 nurses)

• Disagreed that around the clock dosing is better; 84%
• Agreed that around the clock dosing increases risk for sedation and respiratory depression; 82%
• Agreed that Doctor or nurse assessment more valid than patient assessment of pain. 51%
Attitudes About Patients in Pain  
(n=85 nurses)  

In a 25 y.o. man post-op day 1 reporting pain of 8 (0-10):  

- Would reduce dose of analgesic if patient laughing with visitors 59%  
- Would allow concerns about addiction, tolerance, dependence or respiratory depression to change the amount of analgesic given from what was ordered; 41%  
- If man was grimacing in pain, but had stable vital signs, would reduce the dose or give no analgesic even though it was ordered. 46%
Attitudes About Patients in Pain (n=85)

If man was older (72 years) and c/o pain of 8 (0-10 scale):

- Would reduce dose of analgesic below what was ordered; 63%
- Would allow concerns about addiction, tolerance, dependence or respiratory depression to change the amount of analgesic given; 58%
How did that translate into pain management by these same nurses?
Pain Relief in Hospitalized Cancer Patients (n=90)

METHODS:

• Admitted for ≥ 48 hours:
• Pain assessed 3X in 24 hours to get daily mean;
• VAS – 0-100 for pain intensity

McMillan et al., 2000
Pain Relief in Hospitalized Cancer Patients (n=90)

RESULTS:

• Daily pain:
  – Range = 0-98
  – Mean = 32.5
  – SD = 25.3

• Patients often under-medicated for pain;
• Patients with very high daily VAS received no pain medication;
Knowledge About Pain Management

REPEATED (n=41)

- Range of scores 39-81%
- Mean score 63%

Only 17% of nurses had scores higher than 70% (F grade)

Nurses knew least about:
- Physiology of pain
- Pharmacology of analgesics
- Treatment goals

Latchman, 2014
Attitudes About Pain Management

REPEATED (n=41 nurses)

- Disagreed that around the clock dosing is better;
- Agreed that around the clock dosing increases risk for sedation and respiratory depression;
- Agreed that patients in pain can tolerate higher doses of opiates without sedation or respiratory depression.

Latchman, 2014
Pain is not the only symptom!
(n=275 hospice patients with cancer)

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>PERCENT</th>
</tr>
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<tbody>
<tr>
<td>Fatigue</td>
<td>83</td>
</tr>
<tr>
<td>Pain</td>
<td>73</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>71</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>60</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>56</td>
</tr>
<tr>
<td>Shortness of Breath</td>
<td>55</td>
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</tbody>
</table>

McMillan & Rivera, 2009
Pain not the most **severe** symptom!

(n=275 hospice patients with cancer)

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>Severity*</th>
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<tbody>
<tr>
<td>Fatigue</td>
<td>6.8</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>6.3</td>
</tr>
<tr>
<td>Constipation</td>
<td>6.3</td>
</tr>
<tr>
<td>Shortness of Breath</td>
<td>6.0</td>
</tr>
<tr>
<td>Difficulty Sleeping</td>
<td>6.0</td>
</tr>
<tr>
<td>Pain</td>
<td>5.8</td>
</tr>
</tbody>
</table>

* 0-10 scale

McMillan & Rivera, 2009
Pain not the most **distressing** symptom!

(n=275 hospice patients with cancer)

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>Distress*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>6.8</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>6.3</td>
</tr>
<tr>
<td>Constipation</td>
<td>6.3</td>
</tr>
<tr>
<td>Difficulty Sleeping</td>
<td>6.0</td>
</tr>
<tr>
<td>Cough</td>
<td>6.0</td>
</tr>
<tr>
<td>Pain</td>
<td>5.8</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>5.8</td>
</tr>
</tbody>
</table>

*0-10 scale

McMillan & Rivera, 2009
Assembled a Team

- Brent Small, PhD, Aging Studies (1,2,3,4,5)
- William Haley, PhD, Aging Studies (1,2,5)
- Cindy Tofthagen, PhD, ARNP, FAAN, Nursing (3,4,5)
- Ronald Schonwetter, MD, Hospice (1, 2)
- Melissa Leggatt, Program Manager (23 years)
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- Ronald Schonwetter, MD, Hospice (1,2)

Melissa Leggatt, Program Manager
Symptom Management Using COPE

- Caregivers of cancer patients (NCI)
- Caregivers of Heart Failure patients (NINR)
- Patients with cancer (PCORI)
- Chemotherapy-Induced Peripheral Neuropathy (Tofthagen, PI)
COPE Problem-Solving Approach to Cancer Symptom Management

*Homecare Guide for Cancer*
(Houts & Bucher (2012); available through ACS)

- Creativity
- Optimism
- Planning
- Expert Guidance
• CG training to support symptom management for patients; this study focused on:
  – pain,
  – dyspnea, and
  – constipation.
• Patients too debilitated for intervention;
• N=329 patient/caregiver dyads.

NCI: 5R01 CA077307 (1999-2004)
COPE: for Caregivers of Hospice Cancer Patients

- Apparently one of the first funded projects to collect data directly from patient/caregiver dyads.
- Reviewers not experienced with hospice research; concerned about projected attrition

Lesson learned: Justify everything!

NCI: 5R01 CA077307, 1999-2004
Intervention:

• Three home visits by nurse (45, 30, 30 minutes each); home health aide stayed with patient;
• Reviewed different PRIORITY symptom each visit;
• Applied problem-solving approach to each problem:

  Creativity
  Optimism
  Planning
  Expert Guidance
Spouses
Adult Children
Results: COPE Intervention for Caregivers

**Caregiver Outcomes (Proximal):**
- Increased CG QOL,
- Decreased burden from tasks,
- Decreased distress from symptoms

McMillan et al., 2006

**Patient Outcome (Distal):**
- Decreased symptom distress

McMillan & Small, 2007
Systematic Assessment In Hospice: A Clinical Trial

• **Premise:** If interdisciplinary team members do adequate assessments, symptom management will be better;
• 709 patient/caregiver dyads accrued to study;
• Data collected by RN-LCSW teams at two hospices;

R01 NR008252 – 2004-2009
Systematic Assessment In Hospice: A Clinical Trial

Results:

• Significant improvement over time in patient depression scores (CES-D);
• Symptom scores improved but not significantly
Cardiac COPE: Study Results

• No improvement in any variables:
  – CG QOL or Burden
  – Patient QOL
  – Patient symptoms

How could this happen?
Saved by Qualitative Data!

10 HF caregivers interviewed after COPE

• “Everything they were discussing, we were already doing”.

• “I already knew everything; we needed this at the beginning”.

Buck, Zambroski et al., 2013
Lesson Learned:

Cancer researchers should **NOT** conduct cardiac research!

Focus!
Moving upstream:
• Qualitative data: COPE is needed sooner, when patients are diagnosed with HF;
• Networking with other investigators led to studies being conducted in other parts of the U.S.
Medication-Induced Constipation

• Purpose: To determine the severity and trajectory of constipation among cancer patients at risk for constipation due to opioids.

Funded by NINR (5R01 NR008270)
Methods

Sample: 255 outpatients from an NCI-designated comprehensive cancer center;

– With a variety of types of cancers;
– At risk for constipation due to opioids.
# CAS Scores by Week

(Possible Range 0-16)

<table>
<thead>
<tr>
<th>Week</th>
<th>N</th>
<th>Range</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>255</td>
<td>0-14</td>
<td>3.8</td>
<td>3.2</td>
</tr>
<tr>
<td>2.</td>
<td>216</td>
<td>0-13</td>
<td>3.4</td>
<td>3.1</td>
</tr>
<tr>
<td>3.</td>
<td>202</td>
<td>0-16</td>
<td>3.1</td>
<td>3.0</td>
</tr>
<tr>
<td>4.</td>
<td>185</td>
<td>0-13</td>
<td>3.0</td>
<td>3.0</td>
</tr>
<tr>
<td>5.</td>
<td>175</td>
<td>0-12</td>
<td>2.8</td>
<td>2.7</td>
</tr>
<tr>
<td>6.</td>
<td>168</td>
<td>0-14</td>
<td>2.8</td>
<td>2.9</td>
</tr>
<tr>
<td>7.</td>
<td>167</td>
<td>0-14</td>
<td>2.7</td>
<td>2.9</td>
</tr>
<tr>
<td>8.</td>
<td>161</td>
<td>0-14</td>
<td>3.0</td>
<td>3.1</td>
</tr>
</tbody>
</table>

Attrition = 94 (37%)

63% reported constipation
CAS Mean Score Trajectory over 8 weeks*

*(P=.05)
If COPE was needed upstream for HF patients, why not for cancer patients?
Upstreaming led to:

• “COPE for cancer patients: a clinical trial”
• Revised COPE manual again for use by cancer patients rather than caregivers;
• Funded 2013-2016.

PCORI 4025
Patient Self-Management: COPE

• Results: No significant improvements
• We hypothesize that while 3 sessions works for caregivers, it was not enough for patients;
  – Patients overwhelmed and distracted
  – Chemo-brain likely a problem
Most Important Lessons Learned

• Be Persistent
• Be flexible but **focused**
Questions?
Thank you for your attention!