Symptom Management at
the End of Life: Cancer

Susan C. McMillan, PhD, ARNP, FAAN
Professor, College of Nursing &
Center for Hospice, Palliative Care and
End of Life Studies at USF
Tampa, FL
Symptom Experience

• **Defined as:** Perception and response to symptom occurrence and symptom distress.

• **Symptom Occurrence** includes the frequency and severity or intensity with which the symptom occurs and its duration or persistence.

Rhodes, McDaniel & Matthews, 1998
Symptom Experience

- **Symptom Distress** = amount or level of physical or mental upset, anguish, or suffering experienced by a person with a specific symptom.

Rhodes, et al., 1998
Symptom Experience

- symptom occurrence
- Symptom intensity
- symptom distress.

Rhodes et al., 1998
Systematic Assessment to Improve Hospice Outcomes

- Susan McMillan, PhD, ARNP  Nursing
- Bill Haley, PhD  Aging Studies
- Brent Small  Aging Studies
Systematic Assessment to Improve Hospice Outcomes

Sites

• Hernando-Pasco Hospice
• Tidewell Hospice
Systematic Assessment to Improve Hospice Outcomes

Patients on Admission:

• Symptom intensity
• Symptom distress
• Depression
• Social Support
• Spiritual well-being
Demographic Data (n=161)

- Mean age: 71.8 (range 31-93)
  - Male: 61%
  - Female: 39%
- White: 95%
- African American: 2%
- Hispanic: 2%
- Other: 1%
Most Common Cancers:

- Lung: 31%
- Pancreas: 12%
- Colon: 7%
- Prostate: 6%
- Liver: 6%
- Breast: 4%
- Lymphoma: 4%
- Other: 30%

N=161
Hospice Samples ’94-’02
Most Common Cancers

1994 (n=31)  Lung, Prostate, Colorectal
1996 (n=118) Lung, Colorectal, Prostate
1999 (n=242) Lung, Prostate, Colorectal
2000 (n=231) Lung, Colorectal, Breast, Prostate
2002 (n=70)  Lung, Colorectal, Breast, Pancreas
Symptom Experience

Symptom Occurrence

Data from Memorial Symptom Assessment Scale-Hospice
Most Common Symptoms:

n=161

- Fatigue 85%
- Pain 85%
- Dry Mouth 71%
- Drowsy 59%
- Appetite 59%
- Dyspnea (SOB) 54%
- Constipation 45%
- Cough 45%
- Sleep disturbance 43%
- Numbness and tingling 43%
Most Common Symptoms:

- Fatigue 2006 85% (2002 89%)
- Pain 85% (83%)
- Dry Mouth 71% (78%)
- Drowsy 59%
- Appetite 59%
- Dyspnea (SOB) 54%
- Constipation 45%
- Cough 45%
- Sleep disturbance 43%
- Numbness and tingling 43%
Most Common Symptoms:

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Hospice</th>
<th>Active Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>85%</td>
<td>*73%</td>
</tr>
<tr>
<td>Pain</td>
<td>85%</td>
<td>*63%</td>
</tr>
<tr>
<td>Dry Mouth</td>
<td>71%</td>
<td>*55%</td>
</tr>
<tr>
<td>Dyspnea (SOB)</td>
<td>54%</td>
<td>*22%</td>
</tr>
<tr>
<td>Constipation</td>
<td>45%</td>
<td>87%</td>
</tr>
</tbody>
</table>

*Portenoy et al., 1994
Most Common Symptoms:

- Fatigue: 85% (Cancer) vs. 82% (Cardiac) ★
- Pain: 73% (Cancer) vs. 37% (Cardiac)
- Dry Mouth: 71% (Cancer) vs. 26% (Cardiac)
- Appetite: 59% (Cancer) vs. 49% (Cardiac)
- Dyspnea (SOB): 54% (Cancer) vs. 76% (Cardiac) ★
- Constipation: 45% (Cancer) vs. 14% (Cardiac)
- Cough: 45% (Cancer) vs. 45% (Cardiac)
- Sleep disturbance: 43% (Cancer) vs. 31% (Cardiac)
- Swelling: 57% (Cardiac) ★

Chart Review
n=51
Less Commonly Reported:

- Feeling Sad  41%
- Worrying  38%
- Difficulty Concentrating  36%
- Nausea  31%
- Feeling Bloated  31%
- Feel nervous  29%
- Urination problems  27%
Least Commonly Reported:

- Feel irritable 25%
- Swallowing difficulty 22%
- Itching 22%
- Vomiting 17%
- Sexual problems 15%
- Diarrhea 12%
Symptom Experience

Symptom
Severity or Intensity
Among the 10 Most Common Symptoms

Highest Mean Severity Levels (1-4)

- Fatigue: 2.7 SD=1.0
- Appetite: 2.6 SD=1.1
- Constipation: 2.5 SD=1.1
- Pain: 2.3 SD=1.1
- Sleep: 2.3 SD=1.0
- Dyspnea: 2.2 SD=1.1
- Drowsy: 2.1 SD=1.0
- Dry mouth: 1.9 SD=1.0
- Numbness/Tingling: 1.9 SD=1.0
- Cough: 1.7 SD=0.9
Pain at Its Worst

• 14% = No pain
• 7%  = 1 to 4
• 78% = 5 to 10

HQLI ‘06
Symptom Experience

Symptom
Distress or Bother
Relationship betw. Symptom Distress and Quality of Life

(n=178 hospice patients with cancer)

Found total distress score from MSAS-H was the best predictor of overall quality of life (p=.001) accounting for 35% of variance.

(McMillan & Small, 2002)
# 10 Most Common Symptoms

## Highest Mean **Distress** Levels (0-4)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Distress</th>
<th>Intensity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>2.5</td>
<td>(2.7)</td>
</tr>
<tr>
<td>Constipation</td>
<td>2.5</td>
<td>(2.5)</td>
</tr>
<tr>
<td>Pain</td>
<td>2.4</td>
<td>(2.3)</td>
</tr>
<tr>
<td>Appetite</td>
<td>2.2</td>
<td>(2.6)</td>
</tr>
<tr>
<td>Sleep</td>
<td>2.2</td>
<td>(2.3)</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>2.1</td>
<td>(2.2)</td>
</tr>
<tr>
<td>Drowsy</td>
<td>2.1</td>
<td>(2.1)</td>
</tr>
<tr>
<td>Numbness/Tingling</td>
<td>1.8</td>
<td>(1.9)</td>
</tr>
<tr>
<td>Cough</td>
<td>1.7</td>
<td>(1.7)</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>1.5</td>
<td>(1.9)</td>
</tr>
</tbody>
</table>
3 Most Distressing Symptoms

Percent of Patients with **Distress @ Levels of 3 or 4**

- Fatigue 55%
- Constipation 52%
- Pain 49%

Top Three
Depressive Symptoms

CES-D (SF) Scores (0-10)
Mean = 2.9; SD = 0.3

- 38% reach cut-off of 4; (have a high probability of depressive disorder)
- Only 25% reported distress from sadness @ level of 3 to 4
Social Support: Patients

High satisfaction early in hospice experience;
94% marked “very satisfied”
Religious Affiliation

- Non-Catholic Christian 52%
- Catholic 31%
- Jewish 2.5%
- Shamanism 0.6%
- None 13%
Spiritual Needs

% Marking as Always/Frequently a Need

- Be with family 80
- See smiles of others 71
- Think happy thoughts 71
- Laugh 65
- Talk about day to day things 63
- Be with friends 52
Spiritual Needs

% Marking as Always/Frequently a Need

- Be with family: 80%
- See smiles of others: 71%
- Think happy thoughts: 71%
- Laugh: 65%
- Talk about day to day things: 63%
- Be with friends: 52%

Less than 5% identified these as unmet needs
Most Common Unmet Need

Attend religious services    21%
What is the best way to learn about patients’ symptom experiences?
Our Preliminary Work

• Surveyed hospice nurses to learn how often they depend on CGs for patient symptom data;

• Result: When patient is alert and oriented, they ask the CG 85% of the time.

How dependable is that data?
## Correlations Between Pts - Caregivers

<table>
<thead>
<tr>
<th>Item</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>How lonely you feel</td>
<td>.31</td>
<td>.003</td>
</tr>
<tr>
<td>Hope</td>
<td>.37</td>
<td>.000</td>
</tr>
<tr>
<td>Tired</td>
<td>.37</td>
<td>.000</td>
</tr>
<tr>
<td>Worried or distressed</td>
<td>.40</td>
<td>.000</td>
</tr>
<tr>
<td>How sad you feel</td>
<td>.42</td>
<td>.000</td>
</tr>
<tr>
<td>How well you sleep</td>
<td>.47</td>
<td>.000</td>
</tr>
<tr>
<td>Pain relief you get</td>
<td>.51</td>
<td>.000</td>
</tr>
<tr>
<td>How well you eat</td>
<td>.66</td>
<td>.000</td>
</tr>
</tbody>
</table>
Conclusion:

The best source of information about the patient is the patient. Use other sources only if the patient is unable to respond.
Before the Development of the Center:

- Quality of Life Research conducted at local hospices;
- Allowed evaluation of what aspects of quality of life were most important to cancer patients receiving hospice homecare.
What is Important to Patients?

SYMPTOMS
• How tired
• Pain relief
• Dyspnea
• Sleep
• Constipation

FEELINGS:
• Anxious
• Sad
• Hope

RELATIONSHIPS:
• Support from family/friends
• Support from hospice team
• Relationship with God
• Physical contact with loved ones
MOST Important to Patients

- Relationship with God 87
- Support from family/friends 86
- Surroundings (home) 83
- Physical care receiving 81
- Hope 81
- Support from hospice team 80
- Physical contact w. loved ones 79
LEAST Important to Patients

- Sexuality 26
- How tired you are 29
- Usual amount of work can do 29
- Anxious re: family/friends 36
- How well you eat 40
Hospice Focuses on Pain!

• Pain severity ranked 4\textsuperscript{th}
• Pain distress ranked 3\textsuperscript{rd}
• Pain relief importance NOT near top!
Hospice Focuses on Pain!

- Pain severity ranked 4th
- Pain distress ranked 3rd
- Pain relief importance not near top!

While pain management is important, we need to continue to focus on other issues as well.
A Caregiver Intervention to Improve Hospice Outcomes

Funded by NIH 1999-2004
SC McMillan, PI
Co-investigators:

- Michael Weitzner, MD - Moffitt Cancer Ctr.
- Bill Haley, PhD - Sch. of Aging Studies
- Linda Moody, PhD, RN - College of Nursing
- Ron Schonwetter, MD - Geriatric Medicine
- Mary Tittle, PhD, RN - College of Nursing
- Brent Small, PhD - Sch. of Aging Studies
- Ann Holzheimer, ARNP - LifePath Hospice

Funded by NCI & NINR

1R01-CA77307
Problems: Accrual & Attrition

• Screened every patient admitted to the hospice and accrued <5% to study;
• Attrition by Time 2 was 50%;
• Attrition by Time 3 was 70%.
STRESSORS

Caregiver stressor: Patient Symptoms

MEDIATORS

Caregiver appraisal of stressors

Caregiver Coping

Patient Quality of Life

OUTCOMES

Caregiver Quality of Life

Conceptual Framework
Aim 2: To examine the impact of a problem solving intervention (COPE) on quality of life of hospice patients with cancer (intermediate outcomes).
Study Sample:

• 328 hospice patients
• Divided into 3 groups
• Inclusion: adults, with cancer, in homecare with a family caregiver, literate, cognitively intact.
Memorial Symptom Assessment Scale (MSAS-H)*

- Assesses distress as a result of patient symptoms
- 24-item self-report scale
- Items rated 0-4
- Range 0-96

*Modified for hospice patients.
Symptom Intensity

- Pain numeric rating scale (0-10)  
  (Single item)
- Dyspnea numeric rating scale (0-10)  
  (Single item)
- Constipation Assessment Scale (0-16)  
  (8 items)
Quality of Life

• Hospice Quality of Life Index (HQLI) (28 items)
• Validated on hospice patients with cancer.
Experimental Conditions

I. Standard care
II. Standard care + supportive visits
III. Standard care plus COPE
COPE INTERVENTION

Creativity
Optimism
Planning
Expert guidance
Data Collection Points

• Admission
• At day 14
• At day 30
Hypothesis:

Patients in the group receiving standard care plus COPE will have significantly decreased symptom intensity, symptom distress and higher QOL compared to patients in the other two groups.
Caregiver Findings:

• The COPE intervention decreased the caregiver’s distress from patient symptoms, improved QOL and increased mastery.

But what about the patients??
Patient Results:

- Age: 70.3 Years
- Males: 60%
- Years of Education: 12.2
- PPS Score: 53.0
- Mental Status (0-10): 8.8
Patient Results:

- No differences found in symptom intensity or quality of life,
- A significant reduction in symptom distress was found in the COPE intervention group (p=.009).
Symptom Distress Scores

- Baseline
- Day 16
- Day 30

- Standard Care
- Support
- COPE
What’s Next?

• Replicate the COPE intervention with a group of cardiac patients and caregivers receiving hospice care.