Symptom Management and Quality of Life at the End of Life

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A coalition between the University and the hospices and hospitals in the community.

Center for Hospice, Palliative Care and End of Life Studies at USF: Partners

- Lifepath Hospice
- Hospice of Florida Suncoast
- Moffitt Cancer Center
- Tidewell Hospice
- Hope Hospice

>6,600 Patients per day receiving care in one of these hospices.

Symptom Experience

- Defined as: Perception and response to symptom occurrence and symptom distress.

Rhodes, McDaniel & Matthews, 1998

Florida
Symptom Experience

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

  Rhodes, McDaniel & Matthews, 1998

- **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 distress

  Rhodes et al., 1998

Systematic Assessment to Improve Hospice Outcomes

- Susan McMillan, PhD, ARNP  Nursing
- Bill Haley, PhD  Aging Studies
- Brent Small, PhD  Aging Studies
- Ron Schonwetter, MD  Lifepath

Funded by NINR
2004-2008

Data Source

**Sites**

- Hernando-Pasco Hospice
- Tidewell Hospice

**Patients on Admission:**

- Symptom intensity
- Symptom distress
- Depressive symptoms
- 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: 2006 vs 2002

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

### Most Common Symptoms: 2006 vs Active Treatment

- Fatigue: Hospice 85% Active Treatment *73%
- Pain: Hospice 85% Active Treatment *63%
- Dry Mouth: Hospice 71% Active Treatment *55%
- Dyspnea (SOB): Hospice 54% Active Treatment *22%
- Constipation: Hospice 45% Active Treatment 87%

*Portenoy et al., 1994*
Most Common Symptoms:

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Cancer</th>
<th>Cardiac ’06</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>85%</td>
<td>90%</td>
</tr>
<tr>
<td>Pain</td>
<td>73%</td>
<td>67%</td>
</tr>
<tr>
<td>Dry Mouth</td>
<td>71%</td>
<td>50%</td>
</tr>
<tr>
<td>Appetite</td>
<td>59%</td>
<td>17%</td>
</tr>
<tr>
<td>Dyspnea (SOB)</td>
<td>54%</td>
<td>57%</td>
</tr>
<tr>
<td>Constipation</td>
<td>45%</td>
<td>27%</td>
</tr>
<tr>
<td>Cough</td>
<td>45%</td>
<td>53%</td>
</tr>
<tr>
<td>Sleep disturbance</td>
<td>43%</td>
<td>47%</td>
</tr>
</tbody>
</table>

Common in Cancer but Less in Cardiac ’06:

- Swelling (57%)

Least Commonly Reported:

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

Highest Mean Severity Levels (1-4):

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Severity</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>2.7</td>
<td>1.0</td>
</tr>
<tr>
<td>Appetite</td>
<td>2.6</td>
<td>1.1</td>
</tr>
<tr>
<td>Constipation</td>
<td>2.5</td>
<td>1.1</td>
</tr>
<tr>
<td>Pain</td>
<td>2.3</td>
<td>1.1</td>
</tr>
<tr>
<td>Sleep</td>
<td>2.3</td>
<td>1.0</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>2.2</td>
<td>1.1</td>
</tr>
<tr>
<td>Drowsy</td>
<td>2.1</td>
<td>1.0</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>1.9</td>
<td>1.0</td>
</tr>
<tr>
<td>Numbness/Tingling</td>
<td>1.9</td>
<td>1.0</td>
</tr>
<tr>
<td>Cough</td>
<td>1.7</td>
<td>0.9</td>
</tr>
</tbody>
</table>

Among the 10 Most Common Symptoms

Pain at Its Worst (0-10):

- 14% = No pain
- 7% = 1 to 4
- 78% = 5 to 10
Symptom Experience

Symptom Distress or Bother

Relationship between 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

<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>
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<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

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>55%</td>
</tr>
<tr>
<td>Constipation</td>
<td>52%</td>
</tr>
<tr>
<td>Pain</td>
<td>49%</td>
</tr>
</tbody>
</table>

Depressive Symptoms

CES-D (SF) Scores (0-10)

Mean = 2.9; SD = 0.3

- 33% no symptoms
- 31% had symptoms
- 38% reach cut-off of 4; (have a high probability of depressive disorder)

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%

Less than 5% identified these as unmet needs

Most Common Unmet Need

Attend religious services 21%

Spiritual Needs

% Marking as Always/Frequently a Need

- Be with family 80%
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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>

Correlations Between Pts - Caregivers

<table>
<thead>
<tr>
<th>Item</th>
<th>r</th>
<th>r²</th>
</tr>
</thead>
<tbody>
<tr>
<td>How lonely you feel</td>
<td>.31</td>
<td>9.6%</td>
</tr>
<tr>
<td>Hope</td>
<td>.37</td>
<td>13.7%</td>
</tr>
<tr>
<td>Tired</td>
<td>.37</td>
<td>13.7%</td>
</tr>
<tr>
<td>Worried or distressed</td>
<td>.40</td>
<td>16.0%</td>
</tr>
<tr>
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<td>17.6%</td>
</tr>
<tr>
<td>How well you sleep</td>
<td>.47</td>
<td>22.0%</td>
</tr>
<tr>
<td>Pain relief you get</td>
<td>.51</td>
<td>26.0%</td>
</tr>
<tr>
<td>How well you eat</td>
<td>.66</td>
<td>43.6%</td>
</tr>
</tbody>
</table>
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

<table>
<thead>
<tr>
<th>MOST Important to Patients</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship with God</td>
<td>87</td>
</tr>
<tr>
<td>Support from family/friends</td>
<td>86</td>
</tr>
<tr>
<td>Surroundings (home)</td>
<td>83</td>
</tr>
<tr>
<td>Physical care receiving</td>
<td>81</td>
</tr>
<tr>
<td>Hope</td>
<td>81</td>
</tr>
<tr>
<td>Support from hospice team</td>
<td>80</td>
</tr>
<tr>
<td>Physical contact w. loved ones</td>
<td>79</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LEAST Important to Patients</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexuality</td>
<td>26</td>
</tr>
<tr>
<td>How tired you are</td>
<td>29</td>
</tr>
<tr>
<td>Usual amount of work can do</td>
<td>29</td>
</tr>
<tr>
<td>Anxious re: family/friends</td>
<td>36</td>
</tr>
<tr>
<td>How well you eat</td>
<td>40</td>
</tr>
</tbody>
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Hospice Focuses on Pain!
- Pain severity ranked 4th
- Pain distress ranked 3rd
- 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%.

Aim 2:
To examine the impact of a problem solving intervention (COPE) on quality of life of hospice patients with cancer.

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, and improved QOL.

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