Palliative Care for Advanced Dementia

A Practice and Cost Study: Does Training Make a Difference?

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Acknowledgements

Institute for the Future of Aging Services

BHHS Legacy Foundation

Hospice of the Valley

Session Objectives

1. Describe the Palliative Care for Advanced Dementia model training curriculum that teaches staff new and improved ways to deliver a person-directed, palliative care for elders with advanced dementia

2. Report the results of a practice study & cost analysis that focused on adopting a model of palliation in a long-term care setting

3. Discuss the impact that staff training and changing practice had for elders with advanced dementia and the organizations where they reside
Demographics of Dementia

- 5.3 million Americans have Alzheimer's disease. 5.1 million are age 65 and older
- Estimated 7.7 million by 2030
- Overall, 1 in 8 persons have some form of dementia at age 65 & that number doubles every 5 years; half of those 85 & older have dementia
- 7th leading cause of death for all ages with death occurring 4-6 years after diagnosis
- The direct and indirect costs of Alzheimer's and other dementias to Medicare, Medicaid & businesses amount to more than $172 billion each year (Alzheimer's Association, 2010)

Progression of Dementia

<table>
<thead>
<tr>
<th>Stage</th>
<th>Symptoms</th>
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<tbody>
<tr>
<td>Mild</td>
<td>Impaired memory; Personality changes; Spatial disorientation</td>
</tr>
<tr>
<td>Moderate or Mid-Stage</td>
<td>Confusion; Agitation; Insomnia; Aphasia; Apraxia</td>
</tr>
<tr>
<td>Severe or Late Stage</td>
<td>Resitiveness; Incontinence; Eating difficulties; Motor impairment</td>
</tr>
<tr>
<td>Terminal</td>
<td>Bedfast; Mute; Intercurrent infections; Dysphagia</td>
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</tbody>
</table>

Advanced Dementia Care in America

- Frustrated facility caregivers who feel "This is just the way it is & there isn't much we can do about it…"
- Behavioral concerns are common
- Medical providers and families believe that weight loss is inevitable
- Pain isn’t recognized & controlled
- Use of psychotropic medications has continued to increase
- Families are frequently disappointed & dissatisfied
- Lack of advance directives & lack of staff knowledge on advance directives specific for dementia
- Dementia specific care measures and evaluation methods are not always available or utilized in long-term care facilities
- What can be done?

What is needed is palliative care!
Comfort care that is holistic in nature and includes interventions which address symptom control, psychological needs of patients and families, quality of life, dignity, safety, respect for personhood, and an emphasis on the use of intact patient abilities and manipulation of the environment.


How do we live?

Palliative Care- Is it just for end-of-life?

Palliative Care for Advanced Dementia (PCAD): A Model Teaching Unit

- 4-year project funded by BHHS Legacy Foundation in Phoenix, Arizona
- Year 1 - 4: more than 400 staff (830 learning encounters) representing all skilled care disciplines were trained at 6 LTC facilities and 2 Assisted Living Centers. Trained MD, DO and nurse practitioners at each organization
- Year 3 - 4: 196 medical residents (MDs & DOs) were trained in medical management
- Year 3: trained nursing educators on comfort-focused behavior management
- Year 4: 65 3rd year medical students trained
- Training program is 6 months in length with multiple training components
- Research & evaluation measures to determine impact on practice

Training Elements of the Program

- Key Concepts for Dementia
- Peer 1:1 Training – all disciplines including medical staff
- Self-Study & creation of training materials, facility manuals
- Targeted Training:
  - Pain Management Training
  - Stimulation of Senses Training
  - Comfort-Focused Behavior Training
- Medical management consultation for physicians & nurse practitioners
The Studies – Overall Goals

1. Change in practice to improve resident care
2. Change in facilities
3. Change in staff knowledge, attitudes & beliefs

This presentation will focus on 1 & 2 for one Learning Facility

Demographics

<table>
<thead>
<tr>
<th>Facility capacity</th>
<th>225</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia unit capacity</td>
<td>41</td>
</tr>
<tr>
<td>Stages</td>
<td>Moderate: 14 Advanced: 20</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>88% White 9% African American 3% Not-specified</td>
</tr>
</tbody>
</table>

Study: Artifacts – Purpose & Research Questions

- *Artifacts of Culture Change for Dementia Care: Focus on Advanced Dementia*
- 55-item survey / self-report instrument with ‘yes / no’ questions & comments section; adapted from CMS (Edu-Catering, 2006) & approved for use by Human Subjects/IRB. Also includes observations of the unit & residents.
- Time interval: baseline & 6-month intervals
- Onsite survey & additional data collected as a subset of several MDS quality measures
Study: Artifacts

Primary components: Structure, process & outcome

- Facility Characteristics
- Administrative Artifacts
- Milieu Artifacts
- Care Practices Artifacts
- Community & Family Artifacts
- Workplace Artifacts: Training Collaboration & Teamwork
- Quality Measures: antipsychotic use, weight, 9+ meds, pain, restraints, falls using MDS 2.0

Research Questions

- #1: Objectively measure change in practice for residents & the facility…OR…Does training make a difference?
- #2: Instrument development for benchmarking

Study: Artifacts

Artifacts Results & Trends in Learning Facility:

- Structure: policies & procedures in place, improved milieu - more appropriate music, stocked refrigerator, assessments & care conferences, feeding tube wishes were documented, revised pain charting & more…
- Process: better positioning with more ‘resting’, liberalized diets & more snacks offered, person-directed toileting & more…

Outcomes

- weight maintenance / stability
- less sundowning (from 32 to 0)
- restraint reduction (from 14 to 5 persons)
- less incontinence (from 78 to 61 persons)
- more appropriate medication use
Study: Artifacts

- 6 MDS 2.0 quality measures were evaluated quarterly over one year
- MDS Coordinators computed run charts that calculated percentage of residents triggering the measure & compared to facility, state, & national rates
- 1 example shown…

**Artifacts Key Findings:**

- Improvements noted:
  - Changes in overall methods in caring for persons with advanced dementia: structural indicators in place, processes are improving, outcomes attainable
  - Improved medical management
  - Overall, positive results related to the training program & change in practice
  - Limitations: MDS data, observation, new instrument, change takes time
- Opportunities for improvement:
  - Milieu, in selected geographic areas
  - Anticipation of need
  - Advance directives
  - Activities program
  - Falls that may relate to restraint reduction (physical & chemical)
  - Efforts in sustainability
Study: Cost Analysis Purpose & Research Questions

- Determine cost effectiveness of the Palliative Care training program
- Research Question:
  - What were the costs of the Learning Facility prior to the training program and what changes occurred over time?
- OR...Does training make a difference?

Cost Study: Research Methodology and Cost Report Form

- 111-item pre-survey and 92-item post survey
  - Cost of training (pre-survey only): turnover, retention, absenteeism, laundry costs; incontinence supplies; dietary costs; quality of care; utilization of services
- Time interval: baseline and 1-year follow-up (6 months after training program)

Limitations of Data

- Small sample size
- Trends
  - Economic downturn
  - Change of middle management (Director of Dementia Unit)
  - Participation in another study during evaluation
Key Findings – RN/LPN Turnover

Expectation: Lower turnover rate among licensed nursing staff (RN & LPN)

Key Findings – CNA Turnover

Expectation: Lower turnover rate among CNAs

Key Findings – Turnover Costs

- Expectation: Lower turnover costs
- Findings
  - RN/LPN turnover costs reduced by $25,000
  - CNA turnover costs similar
Key Findings – Retention

- Expectation: Improved retention
- Findings:
  - One-year retention rate for RNs/LPNs and CNAs increased
  - Mixed six months or less retention: RN/LPN retention rate for six months or less decreased, but CNA retention rate for six months or less increased

Key Findings – Medications

- Expectation: Reduce use of psychotropic medications & maintain or possibly increase use of antidepressant, over-the-counter, & prescriptive pain medications.
- Findings:
  - Less use of anxiolytic and antipsychotic medications
  - More use of antidepressants and prescriptive pain medications
  - Low use of sedatives/hypnotics before & after training

**Medication Utilization**

<table>
<thead>
<tr>
<th>Drug classification</th>
<th>Baseline utilization</th>
<th>Post training utilization</th>
<th>Percentage of change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sedatives</td>
<td>166</td>
<td>53</td>
<td>68.07% decrease</td>
</tr>
<tr>
<td>Antipsychotics</td>
<td>688</td>
<td>436</td>
<td>36.63% decrease</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>418</td>
<td>419</td>
<td>0.24% increase</td>
</tr>
<tr>
<td>Non-opioid analgesics</td>
<td>1,236</td>
<td>801</td>
<td>35.19% decrease</td>
</tr>
<tr>
<td>Opioids</td>
<td>1,019</td>
<td>2,288</td>
<td>124.53% increase</td>
</tr>
</tbody>
</table>
### Medication Costs

<table>
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<th>Baseline Cost</th>
<th>Post Training Cost</th>
<th>Percentage of Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sedatives</td>
<td>$1.12</td>
<td>$0.02</td>
<td>79.99% decrease</td>
</tr>
<tr>
<td>Antipsychotics</td>
<td>$3.35</td>
<td>$2.12</td>
<td>36.74% decrease</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>$1.04</td>
<td>$1.22</td>
<td>16.72% increase</td>
</tr>
<tr>
<td>Non-opioid analgesics</td>
<td>$0.34</td>
<td>$0.45</td>
<td>34.74% increase</td>
</tr>
<tr>
<td>Opioids</td>
<td>$0.58</td>
<td>$3.78</td>
<td>553.81% increase</td>
</tr>
</tbody>
</table>

### Key Findings – Utilization of Services

- **Expectation:** Low use of services
- **Findings:**
  - Less hospital visits (from 10-7) and days spent in hospital (from 66 to 14 days - 52 less days in the hospital)
  - Less ER visits (from 18 to 7)
  - Less lab work
  - No change in x-ray (low use)
  - No change in urinary analysis (low use)

### Overall Costs and Savings

- **Expectation:** Training program will result in cost savings or be budget neutral
- **Findings:**
  - Pre-Training costs: ~$61,200
  - Post-Training costs: ~$40,300
  - Cost to participate in training: ~$5,300
  - Savings: ~$15,600
  - With drug costs: ~$14,000
Cost Key Findings:

- Improvements noted:
  - Turnover rates, nursing turnover costs & long-term retention
  - Absenteeism rates & replacement costs
  - Restraints & incontinence
  - Utilization of services (hospital, ER, and lab work)
  - Low use or reduction of anxiolytic, antipsychotic, and sedative/hypnotic medications
  - Increase use of antidepressant & prescriptive pain medications
  - Continued high staff commitment

- Opportunities for improvement:
  - Pressure ulcers
  - Laundry use
  - Dietary (supplement use)
  - Cost and use of incontinence supplies & products
  - Appropriate medication use
  - Improve advance directives – specificity & completion

Does the PCAD Program really deliver cost-effective care with evidence-based results?

- Validating practices & linking them to outcomes is necessary
- Training programs need to be validated through measurement
- Residents – staff – facilities benefitted
- Value of using good tools to measure change & to use varied tools to verify the impact
- Value of trending data to monitor change
- There are threats to validity in uncertain times

Summary

- Persons with advanced dementia require comfort & dignity
- Education can support this premise
- There are opportunities for cost-savings
- Facilities can enact measures to change and embed practice
- We can help persons with dementia attain the best of life at the end-of-life

Newsweek, 2007
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