Dementia and Hospice

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HADI Hawai‘i Alzheimer’s Disease Initiative

A PROJECT OF THE UH CENTER ON AGING

www.hawaii.edu/aging/hadi
Objectives:

- Review criteria & benefits of hospice care
- Explore common complications in end stage dementia
- Understand importance of educating caregivers
- Identify characteristics of persons with dementia
- Explore means of care including counseling and spirituality
- Provide tips for caregivers
DSMIII classifies Dementia as Organic Brain Disorder. (OBD)
DSMV classified Dementia as Neuro-Cognitive Disorder (NCD) ---
this is important distinction in evaluating non-Alzheimer’s
dementia
>we continue to learn about Dementia – (research continues with trail
and error-e.g. study on Indians)
>fact is we have people with Dementia that need our care and attention.
What do we need now with what we have?
Scope of the Problem in the USA

- 2012 - 5,200,000 people with dementia
- 2025 – 6,700,000 people with dementia
- Alzheimer’s dementia was the 5th leading COD in people >65 in 2010

I’ll bet with age would come wisdom. If only we could remember a few things.
Benefits of Hospice

- Lower probability of hospitalization (19% vs 39%)
- Regular treatment for daily pain (44% vs 27%)
- Greater family satisfaction with care

Givens 2011, Kiely 2010
Hospice Criteria

- FAST 7A and
- The occurrence of at least one of six specified medical complications in the prior year:
  - Aspiration pneumonia
  - Pyelonephritis
  - Septicemia
  - Multiple decubitus ulcers ≥ stage 3
  - Recurrent fever after antibiotics
  - Inability to maintain sufficient fluid and calorie intake
Empowering & Educating Caregivers

- Discussing what’s expected as disease progresses
- Providing support, education in dealing with common symptoms
- Offering spiritual, social & volunteer support
- Reassurance that we are not “giving up”
323 nursing home residents with advanced dementia & HC proxies
Followed for 18 months

Endpoints
- Survival, clinical complications, symptoms and treatments
- Determine proxies understanding of prognosis and expected clinical complications

Mitchell, 2009
Mean survival 1.3 years; 55% cohort died by the end of study

- Pneumonia, febrile episodes & eating problems were common
- Distressing symptoms occurred more frequently near EOL
- 40% had Burdensome Intervention (hospitalization, ER visit, parenteral therapy or tube feeding) in last 3 months of life
- 22% all pt referred to hospice (30% of those that died)
## Choices, Attitudes and Strategies for Care in Advanced Dementia

<table>
<thead>
<tr>
<th></th>
<th>Pneumonia</th>
<th>Febrile episode</th>
<th>Eating Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients affected</td>
<td>41%</td>
<td>52%</td>
<td>85%</td>
</tr>
<tr>
<td>6 month mortality</td>
<td>46%</td>
<td>44%</td>
<td>38%</td>
</tr>
</tbody>
</table>
Infections & Fever

- Natural part of disease progression
  - Common pathway to death
- Pneumonia – the old man’s friend?
  - Antibiotics lived 273 days longer
  - Those receiving antibiotics had worse comfort
- Treatment should be based on Goals of Care
Table 2. Burdensome Interventions in Nursing Home Residents during Their Last 3 Months of Life According to Health Care Proxies’ Understanding of Prognosis and Expected Clinical Complications.²

<table>
<thead>
<tr>
<th>Proxy’s Understanding of Prognosis and Expected Complications</th>
<th>Residents Who Died during 18-Mo Study Period (N=177)</th>
<th>Residents Who Underwent Any Burdensome Intervention during Last 3 Mo of Life</th>
<th>Odds Ratio for Burdensome Intervention during Last 3 Mo of Life (95% CI)†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>no. (%)</td>
<td>no./total no. (%)</td>
<td>Unadjusted</td>
</tr>
<tr>
<td>Believed resident had &lt;6 mo to live</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>46 (26.0)</td>
<td>14/46 (30.4)</td>
<td>0.45 (0.19–1.04)</td>
</tr>
<tr>
<td>No</td>
<td>131 (74.0)</td>
<td>58/131 (44.3)</td>
<td>Reference category</td>
</tr>
<tr>
<td>Understood expected clinical complications</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>146 (82.5)</td>
<td>52/146 (35.6)</td>
<td>0.30 (0.15–0.62)</td>
</tr>
<tr>
<td>No</td>
<td>31 (17.5)</td>
<td>20/31 (64.5)</td>
<td>Reference category</td>
</tr>
<tr>
<td>Believed resident had &lt;6 mo to live and understood expected clinical complications</td>
<td>37 (20.9)</td>
<td>10/37 (27.0)</td>
<td>0.13 (0.04–0.44)</td>
</tr>
<tr>
<td>Either believed resident had &lt;6 mo to live or understood expected clinical complications, but not both</td>
<td>118 (66.7)</td>
<td>46/118 (39.0)</td>
<td>0.23 (0.10–0.57)</td>
</tr>
<tr>
<td>Neither believed resident had &lt;6 mo to live nor understood expected clinical complications</td>
<td>22 (12.4)</td>
<td>16/22 (72.7)</td>
<td>Reference category</td>
</tr>
</tbody>
</table>

* Burdensome interventions included any hospitalization or emergency room visit, parenteral therapy (administration of intravenous or subcutaneous hydration, intravenous antimicrobial agents, or intramuscular antimicrobial agents), and tube feeding. Of the 177 residents who died during the 18-month study period, 72 (40.7%) underwent at least one burdensome intervention in the last 3 months of life. CI denotes confidence interval.
† Both the unadjusted and adjusted odds ratios were calculated with the use of generalized estimating equations to account for clustering at the facility level. The adjusted odds ratios were also adjusted for pneumonia (in 66 of the 177 residents [37.3%]), febrile episode (57 [32.2%]), and other sentinel events, such as hip fracture (8 [4.5%]) in the last 3 months of life.
PATIENT-CENTERED CARE

Concept by Sachin Jain, Art by Matthew Hayward © 2014 All Rights Reserved
Demented not dead (a patient who used to be an avid swimmer)

Long term memory – stimulation (a familiar passage or a song)

Perception of reality (trying to get food out of TV)
“Essential self did not die”

Embodied Self
People with dementia retain a sense of physical embodiment within their surroundings, able to distinguish self from non-self.

Meaning is found in the moment

Reality Orientation to Validation Therapy
(Joyce Simard)

Reality Orientation to Present Orientation
entering into their world rather than trying to bring them to your world – e.g. asking for a person who died
Ten Tips for Communicating with a Person with Dementia

Set a positive mood for interaction
Get the person’s attention
State the message clearly
Ask simple, answerable questions
Listen with your ears, eyes, and heart
Break down activities into a series of steps
When the going gets tough, distract and redirect
Respond with affection and reassurance
Remember the good old days
Maintain your sense of humor

courtesy of Family Caregiver Alliance
Sensory Activities (Joyce Simard)

Feeding (safe) Families feel good when they are able to feed their loved ones
Massaging loved one’s hands and feet (provide lotion) – it is all about the gentle touch

Complimentary Therapies:
- Healing Touch
- Reiki
- Aroma Therapy
- Pet Therapy
- Music
**Early Stage**: recognizes family and friends, religious or other traditions, - find out what spiritual practices bring meaning to that person

**Middle Stage**: Sometimes recognizes loved ones • Enjoys reminiscing with old photos, Enjoys food (maybe finger food), socializing • Enjoys singing, reciting scripture • **Find ways to minister without words** • They may not remember you visited but will feel the good feeling for a long time

**Late Stage**: Love, touch, music, spirituality – we don’t know… • Value the person! • Roll with how she sounds, reflect her mood and tone • Be fully present; synch your breath with her breath • **Occasional coherent sentences** “I’m still the same” “Don’t go away” • For people of faith, have ready familiar hymns, prayers, scriptures and sacraments •

*Source: Janice Hicks, Spiritual Care of the Person with Dementia, 2018*
Guilt & Gratitude: guilt for the past and guilt for the present. What did I do to deserve this? And feeling guilty to leave the bedside for the fear of abandoning the love ones.

Shame & Safety – I don’t want you to visit her,….. She doesn’t recognize you anyway – on the other hand telling the neighbors would help (watch out from wandering)

Grief & Glad - (grief is not like a river, but in this situation it would be like a lake) – for some it feels like they died before they died?
Some Tips for Caregivers

Not being alone: If your loved one is in a hospice care, ask help from volunteers or other agencies like project Dana, Kapuna Care who could help.

“Blessed are the care partners, who are flexible: For they shall not break” (Joyce Simard)

Seek counseling:

SW & Counselors on the team will help with family dynamics coping up with stress - emotional support, address deeper questions, such as loss of identity

Join a support group:
Educate to ensure families are empowered in care
Palliative care is an essential for people with AD
Attentive to the “essential self” which is very much alive
It is important to seek support and guidance when caregiving becomes challenging
Identify which means of care, complimentary therapies and spiritual care and social support would be beneficial to you and to the person with dementia
Care givers need to care for themselves in order to better care for others
Works Cited or Referenced


Joyce Simard, The End of Life Namaste Care Program for People with Dementia, Baltimore: Health Professional Press, 2007


www.caregiver.org

Janice Hicks, “Spirituality of the persons with Dementia”. Spirituality, Religion and Health, January 2018

www.youtube.com