PALLIATIVE CARE FOR PERSONS LIVING WITH DEMENTIA

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Supported in part by a cooperative agreement No. 90AL0011-01-00 from the Administration on Aging, Administration for Community Living, U.S. Department of Health and Human Services. Grantees carrying out projects under government sponsorship are encouraged to express freely their findings and conclusions. Therefore, points of view or opinions do not necessarily represent official AoA, ACL, or DHHS policy. The grant was awarded to University of Hawaii Center on Aging for the Alzheimer’s Disease Initiative: Specialized Supportive Services Program.
HADI Hawai‘i Alzheimer’s Disease Initiative
A PROJECT OF THE UH CENTER ON AGING
www.hawaii.edu/aging/hadi
Goals of this presentation

• Help you understand the course of dementia
• Describe the unique approach of palliative care – and how it differs from “usual care”
• Explain the challenges of navigating the health care system when you have dementia
• Convince you that palliative care is the best “framework” for care of people living with dementia
• Encourage you to consider how you might apply this information where you work, or with people you know.
What is Palliative Care?

- **Specialized care for people with serious illnesses.**
- Focus on improvement of symptoms and better quality of life for the patient and the family/caregivers.
  - At any phase of the disease
  - Can be provided simultaneously with curative treatments
  - Involves a multi-disciplinary team – nurses, doctors, social workers, clergy, etc. Works alongside other parts of the medical team so previous medical relationships are maintained and honored.
- It’s a LOT more than pain management
- Focus on advance care planning and patient preferences is a hallmark of this type of care.
What is dementia?

- A group of symptoms (usually including memory impairment) that affects thinking and social abilities severely enough to impair one’s ability to function independently.

- Dementia Syndrome?

- Over 5 million Americans currently have dementia - but many fewer have been formally diagnosed.

- There are approximately 2 million people in the U.S. with advanced dementia and are dependent on others for all their activities of daily living.

- Research suggests that more than 15 million Americans are full or part-time caregivers for someone with dementia.
Dementia is unique

• While many other conditions do not have cures or effective treatments- persons with dementia usually lose insight into their disease as it progresses.

  • This means greater caregiver burden, and greater costs for both formal and “informal” care.

  • This means less ability to ask the person what their preferences for care are over time
Health care providers

• Rarely discuss advance care planning with persons living with dementia – it’s hard!

• Struggle to find time/opportunity to speak with caregivers when patient isn’t present

• Even more rarely discuss end of life care
  • Feeding issues, infections, falls, and common things to expect

• Doctors routinely over-estimate prognosis
Why palliative care rather than usual care?

- Focuses on patient preferences and quality of life
- We spend a tremendous amount of money on “usual” care for persons with dementia - with poor outcomes as measured by families and by traditional measures.
  - 75% of hospitalizations may be medically unnecessary or are discordant with patient preferences
  - pacemakers placed in PWD at almost twice rate of non-demented patients
  - survival after hip fracture and pneumonia is very poor in persons with advanced dementia
  - 16% of persons w dementia die in hospitals
  - 20% of persons in LTC w adv. dementia had a burdensome transition near the end of life
- Research shows that symptom management is generally poor for people with dementia.
  - Less medication for hip fracture than non-dementia patients
Palliative care for early/moderate dementia

- **Advance care planning** – discuss disease progression with patient or with caregiver if patient not able or willing to participate. Delicate but honest conversation.

- Support system as disease progresses – bring up caregiver stress
- Safety: cooking, driving (plan for retirement), wandering, finances
- Goals of care:
  - What is your definition of quality of life?
  - If you were not able to have that, what kind of care would you like?
- Choices of medications
  - Do you want medications designed for life prolongation – making severe dementia more likely?
    • Discuss cholesterol, hypertension, diabetes drugs – pros and cons.
- Plan for hospitalizations – Explain that physical deterioration occurs – not just brain.
  • Use scenarios of common problems: Falls, infection, stroke, MI
Specialized directives for dementia!

- Dementia-directive.org
- Developed by Dr. Gaster at Univ. of Washington

- Mild, moderate, adv. dementia description then choices -
- □ To live for as long as I could. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.
- □ To receive treatments to prolong my life, but if my heart stops beating or I can’t breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.
More dementia advance directives

• □ To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill. If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.

• □ To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness. I would not want any care that would keep me alive longer.
Dementia is a terminal illness

• Causes of death include those that are sudden –
  • Accident, falls, heart attack, stroke or infection

• And those that have slower onset
  • Weight loss/eating problems, malnutrition, recurrent infections, organ failure, non-compliance with medical treatments for other diseases.

• Prognosis is difficult
  • Especially in early and moderate stages of the process
    • Even in severe dementia, it is hard to tell when someone is within 6 months of dying (hospice criteria)
Issues in advancing dementia

- **Ongoing** discussions about Goals of Care with family and caregivers
  - Goals of care WILL change over time – need to keep asking
  - How should we treat the OTHER diseases – treatment causes burden and discomfort for many patients. (blood draws, finger sticks, diets)
  - What medications to offer and what are the side effects/burden of administration?

- Explicit discussions about caregiver burden and its consequences
  - Health consequences are real for caregivers. Also, bankruptcy, loss of job, loss of retirement income, are all consequences of caregiving.

- More detailed discussions of finances and care options
  - “the promise” and why we should discuss it honestly as disease progresses.
Hospitalizations and advanced dementia

• The ultimate “square peg in a round hole” because hospital processes are not designed for a person with dementia.

• Delirium and falls are much increased with hospitalization.

• Family involvement and constant presence is a big factor in avoiding hospital complications – a hospitalization cannot be a “break” for caregivers.

• People with advanced dementia are more often hospitalized than those without dementia – but with worse outcomes.

• **Share your experience**: “I’ve noticed that most people with advanced dementia don’t rebound to their previous level of functioning after a hospitalization”
More about hospitalization…

- 6 month mortality is greatly increased (over non demented controls) with hospital admission for hip fracture or pneumonia (about $\frac{1}{2}$ of study group had died within 6 months of hospitalization).

- We should be aware the hospital doesn’t really “fix” the major problem, and may worsen outcomes. Families don’t hear this message – and even if they do, our system is not designed to help them in other ways.

- **All paths seem to lead to the hospital.**
Acute illness challenges…

• Why?
  • Barriers to get in to the PCP quickly
  • ER is default – caregiver under stress!
  • Hard to get home nursing quickly to provide IV’s or meds
  • We have to be able to respond quickly with mini “hospitals at home” to prevent hospital admissions.

• Longer hospital stays and frequent re-admissions are much more common for people with advanced dementia.
Pain management

• As communication abilities deteriorate and a person’s ability to remember how often or how severe their pain WAS… then likelihood of good pain management declines.
  • Dynamic (real time) assessment strategies
  • Scales that use facial expressions or other methods
  • Trials of medication – prescribe differently, more scheduled dosing

• Studies have shown PWD get less pain medication for given diseases – but certainly do have same amount of pain for the same diagnosis.

• Pain can be a source of agitation and challenging behaviors (yelling, pacing, restlessness) – and trial of treatment for pain is suggested.
Weight loss and eating problems

• Difficulty swallowing is caused by the disease over time
  • Many good strategies and approaches are available to help a PWD enjoy the taste of food and try to prevent weight loss.
• Weight loss can occur even with good intake of calories
• Feeding tubes are not the answer
  • NO consistent evidence of longer survival, less pneumonia, improved skin healing or improved quality of life for the patient.
• Yet – the system has fiscal rewards for use of feeding tubes
  • Increased reimbursement for LTC (changing)
  • More tubes placed by larger hospitals, for profit hospitals, and by sub-specialist doctors than by primary care/geriatrics.
Fevers and infections

- More common as dementia advances – why?
  - Less awareness of early symptoms
  - Increased risk of aspiration and pneumonia
  - Alteration of immune system due to stress or disease itself
- Antibiotics are given frequently—especially in nursing home patients
  - 2008- over 18 months at 21 LTC facilities
  - Average was 4 courses of Abx per patient w adv. dementia
  - Many patients die “while taking” antibiotics
  - Significant contributor to antibiotic resistance
- Decision to treat w antibiotics
  - Oral treatments may be as effective – but sometimes harder to do in home setting (caregiver burden, fear of the illness, isolation)
System barriers to good palliative care

• Hospitalizations raise likelihood of movement to SNF care
• In 2006, 40% of patients who died in long term care with advanced dementia had used SNF benefit in last 90 days of life.
  • This means no access to hospice care (can’t have SNF/hospice)
  • Ultimately shorter hospice stays when they do enroll
  • With hospice care a much decreased likelihood of death in a hospital bed.
• No structured system for palliative care – hard to access, especially in the outpatient setting, despite evidence of benefit.
• Heroic caregivers have few options when dealing with an acute illness or distress… Emergency Room is often only option.
Palliative care for dementia

- Makes sense because of terminal disease process and emphasis on discussing goals of care and quality of life as a priority. Helps make a “plan” rather than a reaction.
- “Usual” medical care is a poor fit for a person with dementia – but currently there are few options.
- Very little incentive for providers to spend time with families to discuss important issues – Advance Care Planning code for provider reimbursement is helping.
- Our systems should be re-designed to promote palliative care throughout the disease process.
  - Improved satisfaction, more caregiver support
  - More options for care outside a hospital or nursing home
In absence of a cure, a palliative approach to care can have a significant and profound positive impact not only on the life of the person with dementia, but for their families and friends, and for staff as well.
Questions/discussion ?