PALLIATIVE CARE FOR PERSONS LIVING WITH DEMENTIA

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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 with dementia die in hospitals
  - 20% of persons in LTC with advanced 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 ½ 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 ?