

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 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 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 ?

