

# End-of-life Care Experiences for Individuals With Alzheimer's Disease and Their Family Caregivers

Anne P. Glass, Ph.D.  
Associate Director  
Institute of Gerontology  
College of Public Health  
University of Georgia



# Alzheimer's Disease

- 5.4 million Americans currently have Alzheimer's disease (AD)
- 14.9 million unpaid caregivers facing formidable challenges
- \$183 billion in annual costs
- Little is known about end-of-life care for these individuals

(SOURCE: 2011 Alzheimer's Disease Facts and Figures)

# Severe Consequences

- Person will spend more years in most severe stage than any other (40% of total years)
- NH admission by age 80 likely for those with Alzheimer's:  
**75%** vs. 4% of general population
- Sixth-leading cause of death

(SOURCE: 2011 Alzheimer's Disease Facts and Figures)

# Site of Death

- Most individuals state a preference to die at home
- Majority (67%) of dementia-related deaths occur in nursing homes (Mitchell, Teno, Miller, & Mor, 2005)
- Compares to:
  - 20% of cancer patients
  - 28% of people dying from all other conditions

# Providing Excellent End-of-Life Care for Those With Dementia

- **Challenges** (Sachs, Shega, & Cox-Haley, 2004):
  - Unwillingness of physicians and families to designate as terminal
  - Inability to predict time of death
  - Mismatch between course of care and healthcare financial incentives
- **In one nursing home study** (Mitchell et al, 2004):
  - Less likely to have DNR order (**55%** vs. 86.1%)
  - More likely to have feeding tube (**25%** vs. 5%)

# Use of Hospice

- Dementia trajectory much less clear
- ALOS has increased; in 2008:
  - For those with AD dementia = 105 days
  - For those with non-AD dementia = 89 days

# Medicare Decedents' Use of Hospice for 3 or More Days (2007)

- 30.1% used hospice
- 43.3% of those with cancer
- Use increasing for those with dementia:
  - Growth slope since 2001 especially sharp:  
14.4% in 2001 → **33.6%**

(SOURCE: NHPCO, 2012)

# Primary Diagnosis

Dementia is now among top 4 primary diagnoses for patients admitted to hospice...

Primary Diagnosis	2010	2009
Cancer	35.6%	40.1%
Non-Cancer Diagnoses	64.4%	59.9%
Heart Disease	14.3%	11.5%
Debility Unspecified	13.0%	13.1%
Dementia	13.0%	11.2%
Lung Disease	8.3%	8.2%

# Use of Hospice

- Alzheimer's Association "firmly recommends" use of hospice and palliative care
- Feeding tube and hospital transfers should be discouraged

## Four Case Studies – Families' Perceptions

- Qualitative in-depth interviews
- Taped and transcribed
  - Mr. M – male (wife)
  - Mrs. R – female (husband)
  - Mr. S – male (daughter)
  - Mrs. H – female (granddaughter)
- Age at death ranged from 65 to 80s

## Mr. M

- Frustrating rounds with doctors and ineffective medications
- Died in a nursing home
- Little warning
- Hospice not involved
- Family was not present
- Staff stayed with him
- Time with the body



# Death in Nursing Homes

*I suggested that there be some kind of a notice when people died, that we really appreciate their lives, and they said, “No, we can’t do that, because people are dying here all the time. We’d have something out there everyday and it would make people depressed.” So there isn’t very much about death and dying, even though you know it’s all around you.*

## Mrs. R

- Husband took care of her at home with help from daughter for about five years
- Frustrating rounds with doctors and ineffective medications
- Hospice became involved about three months before death
- She was in a lot of pain by the time she lost the ability to walk

## Mrs. R

- *Her muscles had just deteriorated and there was no substance to her body....when she was sitting, it was like she was sitting on her hipbones rather than any cushioning.... Most of her pain was sitting.*
- *[When asked if she ever became bedfast]... No, I kept getting her up in the wheelchair every day so we could feel we were together and not just me sitting by the bed.*

## Mrs. R

- Developed bedsores but cleared with help from hospice
- Freedom to adjust meds
- Would not have wanted more information
- *I didn't want to know all the torturous things to happen*
- *I wanted to have her at home. Our sleeping together every night was important.*

## Mr. S

- Died three years after diagnosis
- Spent last year in Alzheimer's special care unit
- Deteriorated substantially in the three to six month period before he died

## Mr. S

- Hospitalized three or four times in final year – last time for his agitation → psych ward
- Fell and hit his head – *He never really came out of it*
- Was sent to medical wing – started on antibiotics for possible prostate infection
- Moved back to psych ward
- Brought in hospice at this point

## Mr. S

- Recognized the psych ward was not the place for him to be – not geared for end-of-life care
- *We did talk about taking him home to die instead of back to the nursing home, but my mother didn't want him to die there and we all agreed.*

## Mr. S

- Moved into a hospice room at the nursing home – very pleasant
  - Comfortable, convertible chairs
  - Microwave, refrigerator
  - Family was able to stay every night
- Issues
  - Stopping the antibiotic
  - Giving morphine

## Mr. S

- Family found hospice staff were *more willing to say things*
- Nurse told Mrs. S that the dying person *can't pick the day, but can pick the moment, and that he may not want you to [be there]*
- Died peacefully in company of his son
- Nurse helped Mrs. S: *Remember – that's just a moment – you've had 55 years*

## Mrs. H

- Mr. H took care of his wife for about seven years
- Kept her at home

*He was not going to be one of those guys that sat around the nursing home and watched his wife in the bed, that he would rather have her at home where it was a familiar place, and where he knew who was taking care of her and what was happening.*

## Mrs. H

- She became *very blank*
- Once bed bound – began to spiral downward
- Family in agreement about no ICU or other extreme measures
- Developed a bedsore

## Mrs. H

- Brought in hospice but felt more help was needed
- Decided to pay privately for additional aides – 24 hours a day
- *Packing a wound on your wife is pretty tough*
- *It's not like they didn't want to help provide care, it's just that they didn't feel comfortable with it*
- Bedsore was healed

## Mrs. H

- Died at home
- Lots of family support
- Seemed to have adequate information
- At time of death, there was doubt



## Mrs. H

*That was the best thing that could have happened for my grandfather. I think he really does feel like he did the best he could and she was the most comfortable at home. He was so glad she never had to be in a home, and having hospice alleviated having to put her in a nursing home. I think now he is worried that he will have to be in a home.*

## Conclusions From This Small Sample

- Those providing home care did not use community resources until late in the disease process → hospice
- Use of hospice is feasible and helpful
- None of these families chose to use extreme measures
- Highlights challenges of working with healthcare system

# Conclusions

- “There’s no place like home” ??
- May depend on:
  - Families being willing and able to provide care
  - Health of caregiver
  - Condition and responsiveness of individual
  - Housing and support situation



### **Care for the Dying Individual**

- Routine activities of daily living
- Pain control
- Ease of breathing
- Other comfort care – including:
  - Oral care
  - Preventative skin care

### **Support and Information for the Patient and Family**

- Referral to hospice in a timely manner
- Address fears/concerns of the patient
- Address fears/concerns of the family
- Supply adequate caregiving training so the family can be responsible for providing at least some of the care
- Provide enough information so they know what to expect to help them be prepared and understand what is happening in the stages of active dying
- Help/support is on call and available when needed, 24 hours/day, every day
- Spirituality concerns are addressed
- Time with the body, if desired

### **Environment**

- Privacy
- Enough room for family
- Open 24 hours a day for family and close friends to visit as desired
- Comfortable – hospital bed for patient, accommodations for family to sleep in room
- Music available
- Pleasant gentle lighting
- Pleasant views/windows

(Adaptations to Teno's (2000) model)

# Application

- Increased understanding of this stage of dementia care is desperately needed
- Families bear heavy burden
- Different coping styles (described in Marwit & Datson, 2002)
  - Information seeking (“monitoring”)
  - Information avoidance (“blunting”)
- Encourage use of hospice
- Add consideration of environment to models (e.g., Teno and colleagues)

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- Contact information: [aglass@uga.edu](mailto:aglass@uga.edu)

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