Softening the Journey: Palliative Care and Alzheimer’s Disease

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Dementia

- Is described as a syndrome of progressive decline in cognitive and intellectual functioning (including profound loss of memory, language, mobility, emotional and executive functioning, and personality and behavioral changes) that can last from 2 - 10 years.

  - Shuster, 2000
Alzheimer’s Disease

- The most common cause of dementia, and other disease related dementias, affects an estimated 4-5 million or 10% of individuals aged 65 or older, and 25% of those aged 85 or older.

  - Beers and Berkow, 2000
By mid-century, the number is expected to grow to 14 million elders living with AD alone

Olson, 2003

Elders with dementia are particularly vulnerable to depression and anxiety, confusion, and geriatric symptoms such as urinary incontinence, eating problems, and the risk of falls.

Beers and Berkow, 2000
Progressive neurological disorders

- Such as Alzheimer's disease, vascular dementia, Parkinson's disease, multiple sclerosis, and amyotrophic lateral sclerosis (ALS) ultimately lead to total dependence and death.
Dementia..

- Cognitively impaired elders may be unable to communicate their concerns, needs, and preferences as the disease progresses.

- Older adults with dementia also commonly experience periods of confusion, delirium, hallucinations, and agitation.

  (Shuster, 2000)
Other challenges

- Although invariably fatal, dementia disorders are varied and unpredictable in course and progression.

- The resulting uncertainty complicates prognostication, prevents anticipatory planning and creates “ambiguous loss” where families are unable to experience closure or begin to grieve the loss of a previously present and functioning parent, partner, or other relative.
Goals of palliative care

- To provide comfort – for patients AND family
- Quality of life
- Maintain dignity
- Pain/symptom control
Implications for palliative care with older adults

- While there is much in common with good palliative care in general, several areas of knowledge and expertise are essential.
Implications (cont.)

- Knowledge of aging, health, and palliative care
- Comprehensive geriatric assessment
- Clinical Case Management and care transitions
- Family-Centered practice
- Interdisciplinary practice
Supportive and Palliative Care

- Suggests a broader framework, viewing dementia from the time of diagnosis until death and bereavement

- During early stages - keeping patients and caregivers educated and supported

- During advanced stages - recognizing and treating needs of both
Broad areas of concern

- Advance Care planning
- Psychological support, including bereavement
- Management of acute events
- Terminal Care
Mental Health Issues

- Grief
- Depression
- Anxiety
- Delerium

Higher levels of depression are most attributed to people caring for individuals with dementia

- Schultz, O’Brien, Bookwals, & Flessiner, 1995
Grief and dementia.

- “Grief is the constant yet hidden companion of Alzheimer’s disease and other related dementia’s.”
  - Ken Doka

- Grief is experienced by the individual in the early stages of the disease as they experience and anticipate symptoms.

- For family members, grief increases as they witness the deterioration of memory and slow decline of their loved one.
Cascading losses..

- The loss of the past as memory deteriorates
- Loss of memory affects current relationships
- Loss of roles
- Loss of independence
- Additional losses (death of a loved one, but they cannot remember)
For the family...

- Families experience a continuous and profound sense of loss and grief that becomes more intense as the patient’s symptoms increase.
  - Ponder and Pomeroy, 1996

- Families experience the death of the person who “once was”.
  - Doka and Aber, 2002
Delirium and Dementia

- Concomitant confusion, wandering, sun-downing, agitation, and belligerence add significant distress for everyone involved.

- Successful management of these difficulties make an invaluable contribution to the care of the dying.
Clinical presentation, screening, and treatment

The Functional Assessment Staging (FAST) tool is used to assess level of dementia, with a score of 7 being the criterion for admission for many hospice programs.

To be admitted to hospice with a diagnosis of dementia, the patient must have symptoms including:

- incontinence of bowel and bladder
- inability to dress without assistance
- Inability to speak more than 6 intelligible words in and average day
- progressive weight loss of 10% body weight over the preceding 6 months
Caregiving

- The experience of caregiving may complicate grief.

- Caregivers may experience secondary losses such as loss of social and recreational roles, work roles, and relationships with others.

- Losses and increased demands of caregiving may result in “chronic sorrow” and a reactive depression.

Impact of Caregiving on Caregiver’s Physical Health

- Caregivers may have increased blood pressure and insulin levels, impaired immune systems, and be at risk for cardiovascular disease.

- Elderly spousal caregivers (aged 66-96) who experience caregiving-related stress have a 63% higher mortality rate than noncaregivers of the same age.

- Many caregivers themselves are in poor health: one third of caregivers provide intensive care although they themselves are in “fair to poor” physical health.
  
Mental and Emotional Effects of Caregiving Experiences by Caregivers

- Psychological health appears to be the aspect most affected by caregiving:
  - Higher levels of depressive symptoms and mental health problems among caregivers vs. their non-caregiving peers.
  - Depression is the most common psychological disorder, with 20% - 50% of caregivers reporting symptoms.
Mental and Emotional Effects (cont.)

- Particularly stressful caregiving situations may put caregivers at risk for engaging in harmful behaviors toward the care recipients.

- While caregiving is stressful, studies show that there are beneficial effects, including feeling positive about helping, feeling appreciated, and feeling that their relationship with the recipient of care has improved.

  Beech, Schulz, Williamson, Miller, Weiner, Lance, 2005
Fears among caregivers

- The future
- Progression of illness
- Death
- Death that doesn’t come
How palliative care can help

- **Support, support, support**
  - Offering validation, and a sense of control-for patients in the early stages of dementia
  - Patients in the early stages of dementia have very clear awareness of symptoms of decline
  - Later in the illness, they may have vague feelings of loss of capabilities
  - Empathic listening, expressions of support, reassurances of remembrance by reaffirming relationships, and when appropriate, touch.
Palliative care

- Can offer aggressive symptom management throughout the continuum of the disease
- Can help to clarify goals of care with the patient, as they are able, and as illness progresses, with surrogate decision makers
- Can assist in completing Advance Directives and POLST’s
- Can assist in providing education about the underlying condition and interpret symptoms
In Advanced Stages of Alzheimer’s Disease

- Challenges:
  - Recognizing when patients are near the end of life
  - Evaluating symptoms in patients that are non-verbal (i.e.: pain and/or distress)
  - Further issues: use of antibiotics, antipsychotics, and other medications, and feeding tubes
  - Use of advance care plans
Recognizing when someone with AD is near the end of life

- May seem more agitated or confused than before
- Other changes in behavior
- Difficulty breathing
- Lack of interest in eating or drinking
Anxiety and restlessness

- May be related to medical factors:
  - Infection
  - Constipation or diarrhea
  - Urinary retention
  - PAIN (history of arthritis?)
  - Feet
  - Skin
Assessing pain in the person with AD

- Both people with and without AD have the same areas of the brain where pain is processed.

Guiding principles:
- Observation of patient behaviors: facial expressions, verbalizations/vocalizations, body movements, changes in activity patterns, mental status changes-are potential pain indicators in older people with dementia.
  - American Geriatric Society, 2002
Other behaviors associated with pain

- Grimacing, moaning, groaning, rubbing a body part
- Agitation, restlessness, irritability, confusion, combativeness
- Surrogate reporting: CNA’s or family caregivers are often the first to recognize changes
In addition to medications, other things can provide pain control for patients who can hear and respond:

- guided mental imagery
- hypnosis
- relaxation
- counseling for stress and anxiety
- spiritual support
- music
Signs that the Patient may be Dying

- Pain
- Difficulty breathing
- Lack of interest in eating or drinking
- Pressure sores
Communicating with a late stage alzheimer’s patient

- Trust your instincts
- Seek advice and support
- Contact support organizations
- Continue to implement self-care
Dealing with your feelings after the death of a loved one

Take care of yourself
Allow yourself to grieve
Accept support