Raising the Bar: Creating a Dementia Capable Hospice Team

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Objectives

- Identify the disease-specific needs of individuals and families dealing with advanced dementia
- Outline the roles and responsibilities of members of the inter-disciplinary team in addressing the needs
- Delineate methods for ensuring proper education and clinical practice to effectively respond to the care needs of patients with advanced dementia
Background
The evidence reveals....

Most adults report they would not want aggressive medical interventions if they had advanced dementia.

And yet ...

Gozalo et al, 2011; Hanson et al, 2011; Volandes et al, 2009; Volicer, 2005

Background
People with end-stage dementia have
- Fewer completed advanced directives
- More distressing symptoms amenable to treatment (pain and neuropsychiatric symptoms)
- More costly & burdensome interventions with little to no clinical benefit (antibiotics, IVs, feeding tubes, restraints, labs)
- More transitions of care that can be avoided (Emergency room visits, hospitalizations, ICU)
- Less use of hospice services

Meier, 2015; Mitchell et al., 2012; Shega et al., 2008; 2009; Teno et al, 2011; Unroe & Meier, 2013
The Critical Question…

How do we bridge the gap between the care people say they want and what they actually receive?

Specific Challenge for Hospices…

How do we provide people with dementia the same excellent end-of-life care afforded those with more common hospice diagnoses?

People who have dementia as a primary or secondary hospice diagnosis have unique needs.

How do hospices become more dementia capable to serve these needs?
Our hospice’s endeavors

Hospice of the Valley (HOV) (Est. 1977)

- One of the largest non-profit hospices in U.S.
- Serves the Phoenix Metro area
  - Phoenix is a retirement destination for U.S. & Canada
  - Large number of retirement communities
- Daily census
- Free standing Patient Care Units (PCU)

Creating a *Dementia Capable* Hospice
Hospice of the Valley’s Dementia Program (Est. 2003)

Initial efforts….
- Consults via in-person visits, phone & virtual technology
- Discipline-specific education on the unique aspects of delivering dementia comfort care
- Creation of materials/resources to support ongoing integration of practices for lay & professional caregivers
- Innovate, evaluate, disseminate feasible & affordable approaches to advance excellence in dementia care
Dementia-specific care requires knowledge of:

- Disease progression & usual causes of death
  - Alzheimer’s disease & other common forms of dementia (DLB, vascular dementia, PDD and FTDs)
- Realistic goals of care & detailed health care decisions
- Common complications – to prevent, anticipate, & respond in a timely manner
- Risk/benefit analysis of all meds / treatment options
- Aggressive comfort care methods
- Customized non-pharmacological approaches
- Dementia caregiver support methods & resources

Staff Education Examples

- All new hires including volunteers
  - Mandatory dementia overview at orientation
  - Review Joining the Journey: A Guide to Dementia Comfort Care (Dougherty et al, 2006)
  - Anticipatory approach to care
- Nurses, CNAs, Patient Care Units (PCU) staff
  Additional in-depth dementia & delirium education
- Social Workers
  - Mental Status Assessments
  - Health Care Decisions for Advanced Dementia
  - Caregiver Grief and Support Methods
  - Community resources
Staff Education Examples (cont.)

- All clinical staff
  - Pain Assessment in Advanced Dementia (PAINAD) (Warden, Hurley & Volicer, 2003)
  - Non-pharmacological approaches

- Optional (but strongly encouraged)
  - Stimulation of Senses (S.O.S.) training
  - Music & Memory training
  - Dementia Care Part I & II workshops
  - Dementia Digests
  - Quarterly in-services on dementia-related updates

Dementia Care Domains

- Admission Period
- Symptom Management
- Quality of Life / Meaningful Connections
- Slow Decline / Death or Recertification
Admission Period
*Nurses & Medical Directors*

- Review patient’s hospice eligibility criteria
- Clarify goals of care with proxy decision-makers
- Establish functional, cognitive and behavioral baselines
  - **PAINAD score**
  - Identify presence of any behaviors / mood disorders
- Review all current medications & treatments

Palliative Pharmacological Considerations

Consider benefit / burden of each medication & simplify.

- Discontinue medications targeting long-term benefits
  (e.g., statins, tight BP & glucose control)
- Eliminate potentially inappropriate meds when possible
  (e.g., anticholinergics, benzodiazepines…)
- Anticipate & treat PAIN *(scheduled vs. prn)*
- Only use antipsychotics when absolutely necessary & frequently reassess to discontinue ASAP

AGS, 2012; AGS 2014
Clarifying Overall Goals of Care

Key conversation(s)...
Is the primary goal comfort?

Review the risks/benefits of any new diagnostic workups & all therapeutic interventions

Provide support for proxies in pursuing aggressive comfort care rather than burdensome, futile & costly interventions that will not enhance quality of life

(Meier, 2015)

Admission Period

Social Worker

- Complete documents detailing MPOA & advance directives
  - Mental Health Power of Attorney (in AZ)

Customize care to the individual & family
- Perform mental status assessment & communicate findings / tips with team
- Complete About Me form
- Assess & provide caregiver support needs
Discuss, educate and confirm details
Advance Health Care Directives

- CPR
- Hospitalizations
- Antibiotics
- Feeding Tubes

It is most effective to review these details when things are relatively stable, as dementia progresses, & as complications arise.


Ongoing Caregiver Education and Support

- Legal
- Financial
- Respite
- Community agency services
- Caregiver education (1:1 and workshops)
  - Psycho-educational & Skill-based training
- Caregiver support (incl. FTD & LBD groups)
- Caregiver assessments — grief, burden, perceived stress
- Self-care techniques
  - Mindfulness meditation classes
Admission Period
Chaplain, CNA, Volunteers

Chaplains
- Collaborate w/ team to tailor support to fit needs of patient and family
  - Determine best form of meaningful connection with patient & family

CNAs
- Bathing for Comfort form
- Consult w/ team to customize communication and distraction/comfort techniques

Volunteers
- Consult w/ team to customize approaches

Symptom Management
(may include delirium, pain, changes in sleep or appetite, falls, infection, resistance to care…)

As an example…
Behaviors have meaning and may be an expression of unmet need(s) or discomfort / distress

Demystifying Behaviors
Staff explore for underlying causes & remedy
- Delirium – infections, impaction, metabolic, meds, etc.
- Environmental or caregiver approach triggers
- Common unmet needs - hot/cold, thirst/hunger, toileting needs, boredom, fatigue, etc….

(Kovach et al, 2005)
Interventions

All will use PAINAD to ensure ongoing observations for pain in the non-verbal patient and report ASAP to nurse so analgesia is provided and evaluated.

Trial non-pharmacological methods first when appropriate

Differentiate psychotic / non-psychotic features

Remember…

“Antipsychotic medications for the treatment of behavioral and psychological symptoms of dementia (BPSD) should not be prescribed without assessing for the underlying cause(s) of the behavior.” (AGS, 2014)

Tampi et al, 2011; Warden, Hurley and Volicer, 2003

Optimizing Quality of Life / Maintaining Meaningful Connections

- Completed About Me form
- Stimulation of Senses (S.O.S.)
- Individualized Music (iPod program)
- Quiet Moments CNAs
- Memory Corps Volunteers
- Pet Therapy
Slow Decline / Death or Recertification

- Documentation of decline
- Management new / old symptoms
- Assess for delirium
- Ongoing education & support for family /caregivers through process of decline

Education to Improve Care Upstream
Addressing Community Needs

- Hospitals & private practices
- First Responders— Fire, Police, Sherriff
- Physicians & medical students
- Nursing, Social Workers, Chaplaincy programs
- Cultural organizations
- Faith Communities
- Long-term facilities & home care staff
- Lay dementia care partners
- News media, conferences & professional publications
Hospice of the Valley & those we serve have benefited from 12 years of having a comprehensive dementia program as evidenced by:

- High evaluation on satisfaction scores by staff and clients
- Quality indicators reveal ongoing integration of dementia comfort care knowledge and skills among all members of the hospice team
- Increased patient referrals in a very competitive market
- Widespread recognition

And our efforts continue…

More Recent Endeavors

- The first in-patient hospice unit specifically for people with dementia (est. 2013)
- Palliative Care for Dementia (pre-hospice care for all stages of dementia through a psycho-educational and support program for caregivers)
- Mindfulness meditation (based on MBSR)  
  - Hospice staff  
  - Dementia care partners
In Summary

- With the burgeoning numbers of people dying from dementia, hospices must become more *dementia capable* in order to meet the unique needs of patients and families.

- Inter-disciplinary hospice teams require extensive education and support to address these needs.

- To become dementia capable, hospices must provide the time and resources to facilitate best clinical practices in palliative dementia care.

Thank you. Questions?
References

- Goldfeld KS, Stevenson DG, Hamel MB, Mitchell S. Medicare expenditures among nursing home residents with advanced dementia. *Arch Int Med*. 2011; 171(9); 824-830

• Snyder EA, Caprio AJ, Wessell K, Lin FC, Hanson LC. Impact of a decision aid on surrogate decision-makers’ perceptions of feeding options for patients with dementia. *JAMDA.* 2013; (14) 2, 114-118
• Unroe KT, Meier DE. Quality of hospice care for individuals with dementia. [Editorial] *AGS.* 2013; 61:1212–1214