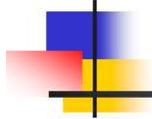


Innovative Practices in Care for People with Advanced Dementia

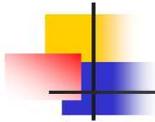


Laurel Coleman, MD

Advisory Council on Alzheimer's Research, Care and Services
Clinical Services Subcommittee

Oct. 27, 2014

Meetings of Experts on Advanced Alzheimer's Dementia

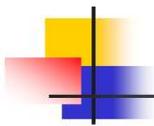


- Conducted by the Institute of Medicine for the U.S.D.H.H.S.
- In response to a recommendation of the Advisory Council that was included in the National Plan to Address Alzheimer's Disease: 2013 Update
- Objective: To convene experts to consider and make recommendations about how care providers can address patient-centered goals and improve the experience of care and outcomes for people with advanced dementia and their families



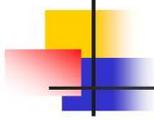
2nd meeting: Innovative Practices

- Sept. 8, 2014 at IOM in Washington DC
- Welcoming remarks by the meeting co-chairs and Linda Elam
- 7 presentations grouped by care setting (nursing home, community, hospice, hospital and emergency department) and information and training for families, care providers and the public
- Questions and discussion involving 7 experts on advanced dementia, the 10 presenters, and staff from 7 federal agencies (AoA/CL, AHRQ, ASPE, CMS, HRSA, NIA, and SAMHSA)
- ~ 25 observers in the room and 20 individuals on the phone



Snapshots by Setting: Nursing Home

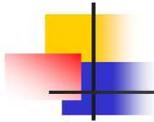
- Beatitudes Campus: Phoenix, presented by Tena Alonzo
 - Comfort Matters, initiated in 1998 in the nursing home and now spread throughout the Beatitudes Campus;
 - Focus on maintaining comfort for people with advanced dementia
 - Developed training approaches and competencies for all staff
 - Results: low use of medications; reduced hospital and ED use; high satisfaction of patients, families, and staff
- New York City Alzheimer's Chapter, Palliative Care in Nursing Homes, presented by Ann Wyatt
 - 30-month study to bring Comfort Matters to NYC nursing homes
 - Focus on increasing comfort and training staff to respond to behaviors as communication
 - Results due in 2015



Snapshots by Setting: Community

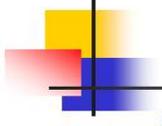
- IN-PEACE: Indianapolis, presented by Greg Sachs
 - Collaborative Care Model to provide palliative care for community-living people with moderate-severe dementia
 - Focus on symptom management and education and support for family caregivers
 - Published results: patients less likely to die in the hospital; significantly lower pain levels, reduced behavioral symptoms and distress

- VA Medical Foster Home, presented by Dayna Cooper
 - Veterans who cannot live independently are cared for 24/7 in the home of a VA foster caregiver
 - Focus on providing a home-like care setting
 - Ongoing medical care provided by the VA home care team
 - Allows for aging in place, palliative care, and hospice at “home”



Snapshots by Setting: Hospice

- Hospice of the Valley, Phoenix, presented by Maribeth Gallagher
 - Dementia program in a large, non-profit hospice
 - Began in 2003
 - Provides inpatient hospice care and training and consultations for hospice staff, nursing homes, families and community providers
 - Published results show lower use of restraints and feeding tubes; effective symptom management; reduced hospitalizations, and high family satisfaction



Snapshots by Setting: Hospital and ED

- **Advanced Dementia Consult Service, Beth Israel Deaconess Hospital, Boston, presented by Susan Mitchell**
 - Team consultations to improve care for patients with advanced dementia
 - Focus on appropriate clinical care, family counseling, and physician feedback
 - Published results show positive trends: increased family knowledge and satisfaction with care, and fewer burdensome treatments, feeding tube insertions, and rehospitalizations
- **ED Project, Mt. Sinai Hospital, New York City, presented by Ashley Shreves**
 - Consultations provided for family caregivers of patients with advanced dementia
 - Focus on goals of care discussions
 - Early results show increased % of families choosing comfort and quality of life goals, reduced % of families choosing of life prolongation goals, and no change in % of families choosing both goals



Information and Training for Care Providers, Families, and the Public

- **MemoryCare**, dementia care information and training programs, presented by Peggy Noel, Asheville, NC
 - Provides specialized medical care and support for people with dementia; information, counseling and referrals for families and the public; and training for care providers
 - Focus on identifying goals of care and anticipating and addressing common medical concerns, e.g., swallowing difficulties and feeding
 - Results show positive outcomes for patients, families, and care providers
- **How To Talk to Families about Advanced Dementia: A Guide for Health Care Professionals**, presented by Jody Comart, Boston
- **ADvancing Care and Care Advocate**: Newsletters of the New York City Alzheimer's Association Chapter, presented by Jed Levine



Observations of Attendees

- I didn't know about these programs.
- The programs are amazing. They convey such a positive message about what can be done for people with advanced dementia and their families.
- Some of the programs (e.g., at Beatitudes and Hospice of the Valley) have existed for years. Why haven't they spread to more communities?
- How can we go to scale with these programs so that many more people with advanced dementia and families can benefit?



Questions, Comments and Next Steps
