Defining and measuring quality outcomes for individuals with Alzheimer’s disease

Quality of life for individuals and families living with Alzheimer’s Disease

January 15, 2010

Colorado Alzheimer’s Coordinating Council Meeting

A Presentation of the Colorado Health Institute
303 E. 17th Avenue, Suite 930
Denver, Colorado 80203
www.coloradohealthinstitute.org
Domains of quality

• **Patient-level outcomes (Better health)**
  – Morbidity and mortality
  – Functional status
  – Quality of life

• **Processes of care (Better care)**
  – Technical aspects of care, e.g., use of restraints
  – Care coordination and care transitions from hospital to home
  – Decision quality, e.g., was care aligned with patients’ preferences
  – Patient’s experience of care
Medical versus social outcomes

- National voluntary standards for nursing home performance measures developed by Centers for Medicare and Medicaid (CMS)
- National Quality Forum
- Annals of Internal Medicine quality indicators
- QOL-AD measures
- State-specific quality measurement efforts, e.g., Wisconsin
National NH performance measures endorsed by National Quality Forum (NQF)

- Derived by consensus of 200 hospitals, consumer groups, professional orgs, etc.
- Used by …
  - consumers, to facilitate selection choices
  - discharge planners
  - Physicians
  - nursing home staff for quality improvement
  - policymakers for quality oversight
NQF-endorsed performance measures

Quality and outcomes associated with:

- Assistance with activities of daily living
- Pain management
- Use of physical restraints
- Prevalence of urinary tract infections
- Worsening of depression or anxiety
- Average risk of acquiring a pressure sore
- 3 post-acute hospitalization measures
- Rate of pneumococcal vaccines
14 judged to be valid by an expert panel

1) Early cognitive and functioning screening of vulnerable elders
2) (and 3) If signs of dementia, review medications list
3) If a diagnosis of dementia, serum levels of vitamin $B_{12}$ and thyroid levels tested
4) If signs of dementia then offer neuroimaging
5) If mild-to-moderate AD, then discuss treating with cholinesterase inhibitors
6) Physician should discuss or refer patient and family for discussion about patient safety, education about AD and community resources
7) If dementia with CVD, should be offered prophylaxis against stroke
8) (and 10) Screen for depression during initial evaluation
9) Advise against driving
10) (also 13-14) Conditions for using restraints specified
Quality of life outcomes for people with AD: Wisconsin’s approach

- Focus on community-based LTC system
- 23 member advisory committee including a consumer and 2 family caregivers
- Two years to develop a QOL tool for planning that supports the best quality of life possible
- Beyond care to celebrating life
- All indicators and outcomes stated in the first person
- Developed guiding principles to personalize and focus care planning and monitoring
- Values guiding dementia care: Consumer-focused and disease progression
Wisconsin QOL outcomes and indicators

1) As a person with dementia, I have the best possible physical well being
   - I am well hydrated
   - A am well nourished
   - I am comfortable, free from pain
   - I am physically active
   - I am clean
   - I am safe
   - My medical needs are being treated by knowledgeable people with the least restrictive interventions
Wisconsin QOL outcomes and indicators (cont.)

2) As a person with dementia, I have meaningful relationships, I am supported in maintaining ongoing relationships and I am provided opportunities to develop new ones with:

- Family
- Friends
- Formal caregivers
- Pets
- Other generations
Wisconsin QOL outcomes and indicators (cont.)

3) As a person with dementia, I have hope because my future is valued and supported
   – I participate to my capacity in all decisions affecting my life
   – I am useful and make contributions of value
   – I plan and do things I want to do while I still can
   – I have emotional support and encouragement
   – I have positive things to look forward to
   – I have a legally supported plan for my future needs and wishes
   – My previous wishes are honored as my capacity diminishes
   – I continue practices that nourish me spiritually
Wisconsin QOL outcomes and indicators (cont.)

4) As a person with dementia, I am accepted and understood as an individual

- I am treated as a person not a disease and acknowledged as present
- I am cared for by people who understand me and about my dementia
- I have regular opportunities to access and share my rich and meaningful past
- I continue my own cultural lifestyle
- My environment is anchored in things I value that are familiar to me
Wisconsin QOL outcomes and indicators (cont.)

5) As a person with dementia, I am involved in life
   – I engage in activities daily that are meaningful to me
   – I have the opportunity to participate in the life of my community
   – I am able to communicate with others to my highest capacity
   – I am able to do things independently with safe supports
   – I enjoy the tastes, smells, sounds and feelings of the real world
   – I have the opportunity to be outdoors
MEASURING WISCONSIN’S QOL OUTCOMES (SEE HANDOUT)