

# Defining and measuring quality outcomes for individuals with Alzheimer's disease

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



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# 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

# Annals of Internal Medicine: Evidence-based literature review of quality indicators for AD

## 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<sub>12</sub> 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

- I) 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)**

