



The National
CONSUMER VOICE
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WHAT DOES GOOD 'DEMENTIA CARE' LOOK LIKE?

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Objectives

- Answer the following questions:
- What does good dementia care look like?
- How can you tell?
- How does that compare with dementia care now in different settings?
- How can you make care better?
- *Visualize in your mind's eye how good care looks and make it happen!*

79 Year-old man with Alzheimer's

- Tied to bed and Geri- chair with vest restraint, given ativan, haldol PRN agitation. On pureed diet due to aspiration risk. Developed pressure ulcer in last week. Bladder catheter placed for incontinence.
- Has not left room for last six days except for x-ray.

Background

- Dementia a growing public health concern
- Huge potential impact on individuals, families, health care delivery, economy
- The way that health care providers, family care givers are taught to understand and respond to people with dementia is lacking in many key respects and results in harm, diminished quality of life, needless frustration, guilt, etc.
- The way that health care is provided in U.S. results in older patients in general and those with dementia especially having less access to care, receiving worse care (overtreatment and undertreatment), and worse outcomes

Challenges

- Care environment
- Fragmented care
- (Health care) culture
- Care delivery/staffing
- Education and Training
- Communication

Care Environment

- Industrial/hospital model
- Shared private spaces
- Cohorting/segregating of people with dementia
- Emphasis on '(bed)room'
- Restrictive environment

Wandering

- 92 year-old woman with Alzheimer's wanders into other resident's/patient's rooms. Found sleeping in someone else's bed, wearing someone else's sweater

Fragmented Care

- Care fragmented by body part (medical, nursing specialization)
 - Ignorance a consequence, benefit of specialization
- Care of a single episode of illness fragmented across multiple settings, providers
 - Communication problems, errors
 - Ethics, standards, regulations, culture differ by site of care

Fragmented Care

- 79 year-old man with Alzheimer's on Aricept, has BPH, started on oxybutynin by urologist for incontinence. Hospitalized for worsening confusion. Diagnosed with 'UTI' started on antibiotic. Started on depakote in hospital, physically restrained. Given Haldol IM prior to transfer to SNF. Discharge summary lists seizure diagnosis. Unable to urinate. Sent to ER. Returns with foley catheter and told to make urology appointment.

Health Care Culture

- Culture of fear, conformity, blame
- Patients expected to behave, conform
- Emphasis on technology, medication
- Apprenticeship tradition
- Actively resists change
- Unhealthy
- Blame patients, family, health care workers

84 year-old man found down at home by neighbor

- 911 called. Sent to ER. Admitted to hospital with 'UTI', 'sepsis'.
- Becomes 'belligerent' when awakened for blood draw at 4 am. Discharged 'AMA' a few hours later

Care Delivery/Staffing

- Care provision, staffing based on efficient task performance
- Not on supervision, continuous contact
- (a significant change in last 20+ years
- Excess capacity of staff actively avoided

32 Year-old nurse with two young children

- Drives sixty miles round trip to and from work, child care each day.
- Reports for work on time after dropping children off at day care. Is told the census is low and she can go home without pay or take a 'vacation' day today.

Education and Training

- Apprenticeship
- Taught to do things 'the right way' and never vary
- See one, do one, teach one
- Hospital focus
- Emphasis on provider, not patient (defensive)
- Focus on eval, treatment of one problem only
- Minimal exposure to geriatrics, settings outside of hospital, clinic
- Minimal or no dementia training

44 Year-old hospitalist physician

- Told nursing home refuses to accept patient back from hospital on IM haldol, mitt restraints. Calls state health department to report facility for neglect, refusal to accept patient.

Communication

- Poor communication between health care workers in any setting across shifts, disciplines, between settings
- Medication reconciliation
- Diagnoses, prognosis, goals
- Advance directives
- Information often incorrect, missing
- Results in undertreatment, overtreatment, error

What does good dementia care look like?

Principles of good (dementia) care

- Person-centered
- Promotes highest level of functioning and well-being
- Enduring, loving care relationships
- Minimizes use of medications
 - Dosing based on age, size, other meds, diagnoses
- Understands the individual
- Treats family as well as patient with love

Person-Centered Care

- Patient is empowered
- Patient gets choices
- Care focused around patient's stated wishes, preferences, goals, life
- Sleep, food, activity, interests
- Home-like environment
- Focus on living the way you want to
- Respect for patient regardless of choice

Person-Centered Care with Dementia

- Patient may be unable to comprehend, make, communicate choices, goals, preferences

75 year old woman with dementia and osteoarthritis

- 'Constantly wandering, agitated'
- Has norco 5/325 PRN. Only given by night shift nurse

How can you tell if care is person centered?

- When do people go to bed?
- When do they wake up? Bathe? Eat?
- What do they do when awake? Where do they do it?

Behavior and Dementia

- Behavior is communication
- Behavior is not a disease
- What are they trying to say?

How can you tell if care is good?

- Observation
- Questions
- Quality measures

How can you make care better?

- Be present
- Know the patient as person, their life, their family
- Lead by example
- Teach, support, praise others
- Demonstrate the care you want
- Communicate success as well as concerns along with expectations
- Communicate love and caring