Welcome to Today's Webinar!

HOT TOPICS

CULTURE CHANGE *in* ACTION WEBINARS

Engaging in Person-Centered Care – The Path to Regulatory Compliance:

Eliminating Suffering for Residents with End Stage Dementia (Focus on Death and Hospice/End of Life CEP)

FEBRUARY 15, 2018

GUIDE:

Maureen Nash, MD, MS

Board Certified physician in both internal and psychiatry, and Medical Director of Providence Elderplace Oregon, A Program of All Inclusive Care of the Elderly

Maureen C. Nash, MD, MS, FAPA, FACP
Fellow, American Psychiatric Association
Fellow, American College of Physicians

Medical Director, Providence ElderPlace Oregon
A Program of All-Inclusive Care for the Elderly

American Psychiatric Association Council on Geriatrics

Board Certified: Internal Medicine & Psychiatry

Disclosures

No Financial Conflict of Interest
Off-label use of medications may be discussed

***Off-label is a phrase for using a medication to treat someone with a diagnosis for which the company did not seek or achieve an "indication" from the FDA.**
"Off-label" does NOT mean or imply illegal, ill-advised, or non-evidence based.
A "label" is unrelated to the presence or absence of evidence.

Dementia is a complex neuropsychiatric disorder.

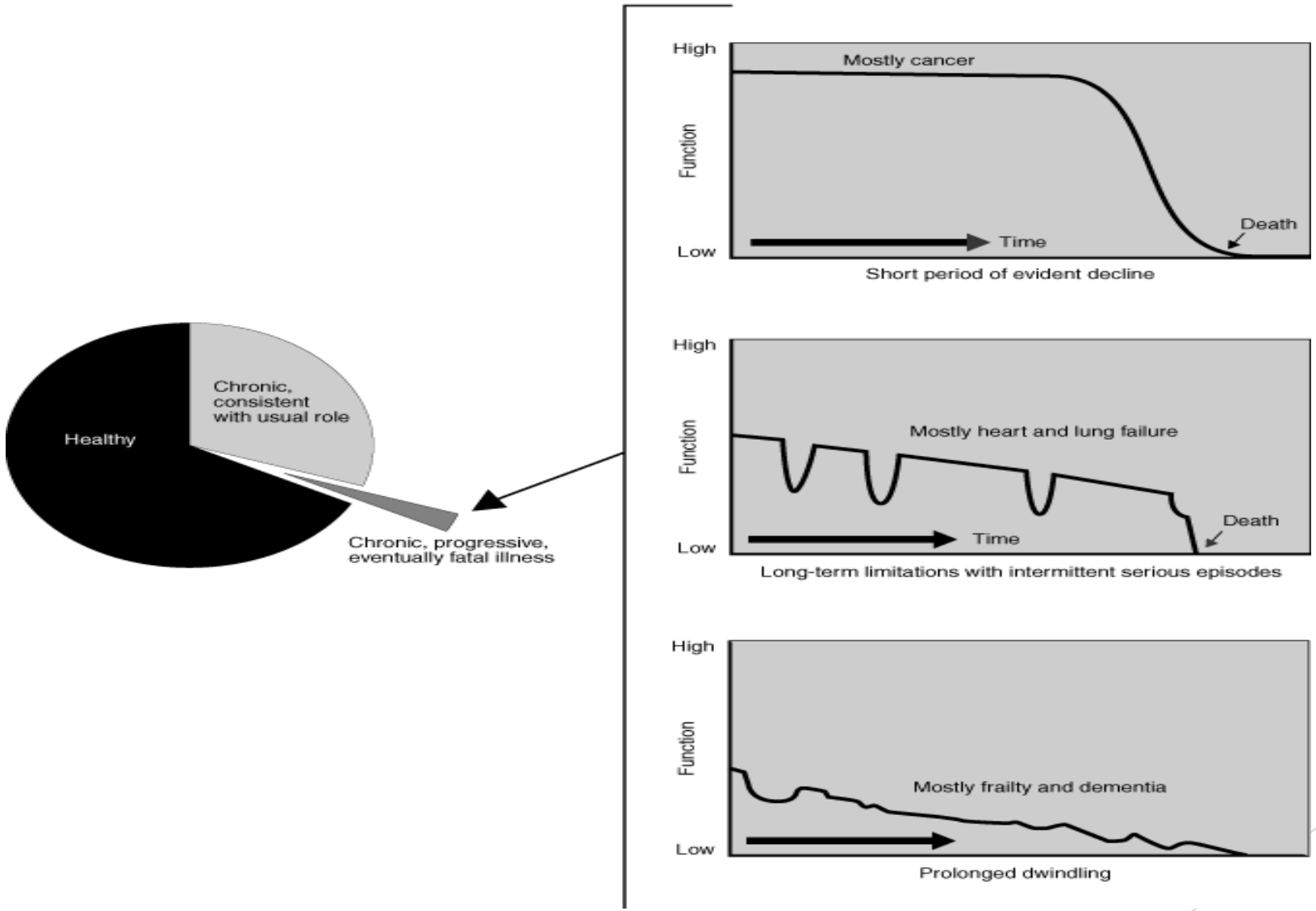
It can be described as Chronic brain failure.

How do people with dementia die?

- with inadequate pain control
- with feeding tubes in place
- Without the benefits of palliative or hospice care

- Sachs GA, Shega JW, Cox-Hayley D. Barriers to Excellent End-of-life Care for Patients with Dementia. **J Gen Int Med: 19(10)** 1057–1063, 2004

Trajectory of EOL for terminal illnesses



- The current policy emphasis …on living well with dementia has been accompanied by a shift in research away from a focus on loss to one of maintaining and promoting personhood (see, for example, Hyden et al., 2014)

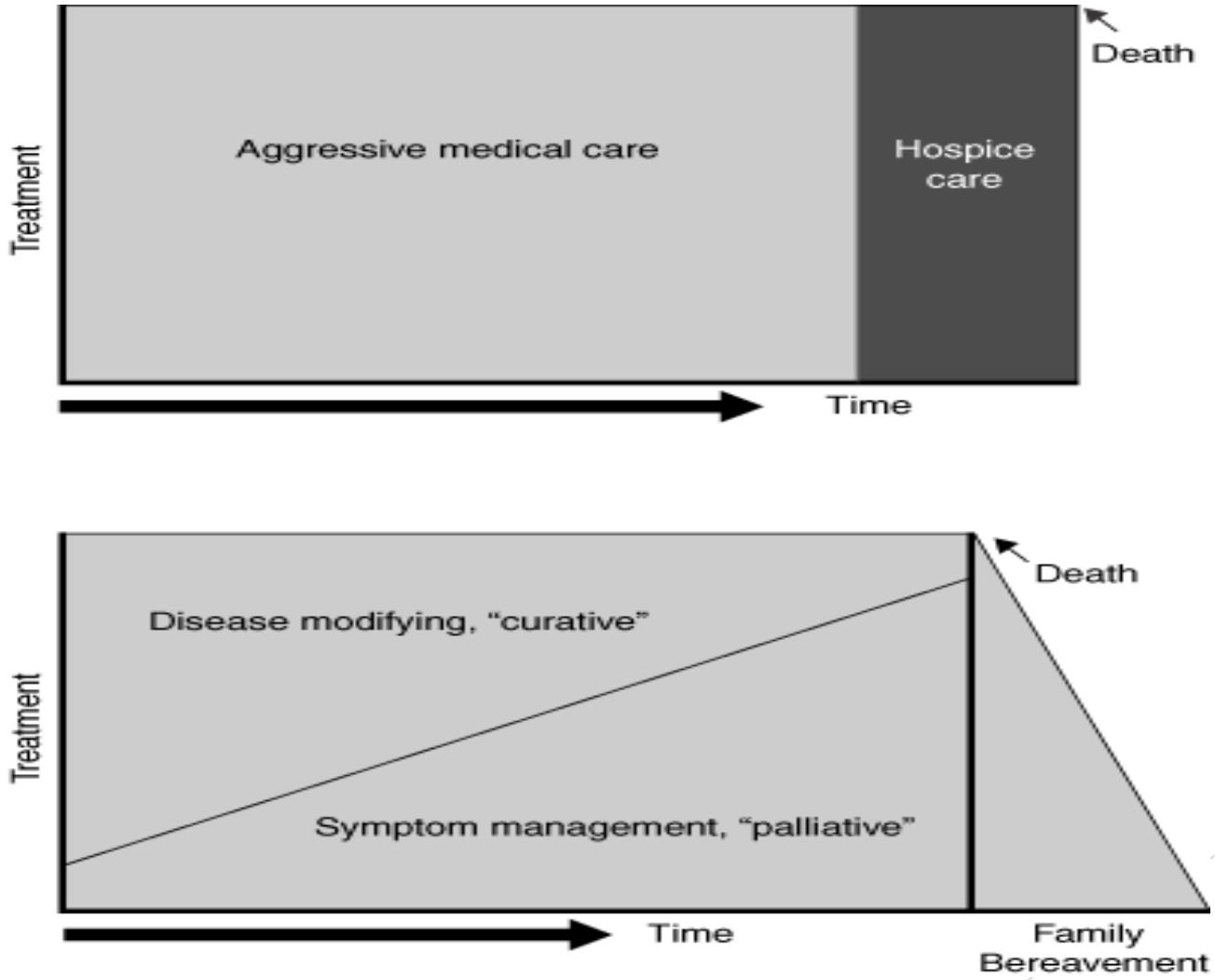
- This “positive” approach to a terminal disease carries a risk that the suffering experienced by people with dementia will be denied

- Understanding and recognizing suffering is important to both the person and the family
- It allows us to then call for change and social action
- Acknowledging suffering is part of embracing the humanity of those with dementia, not denying their humanity

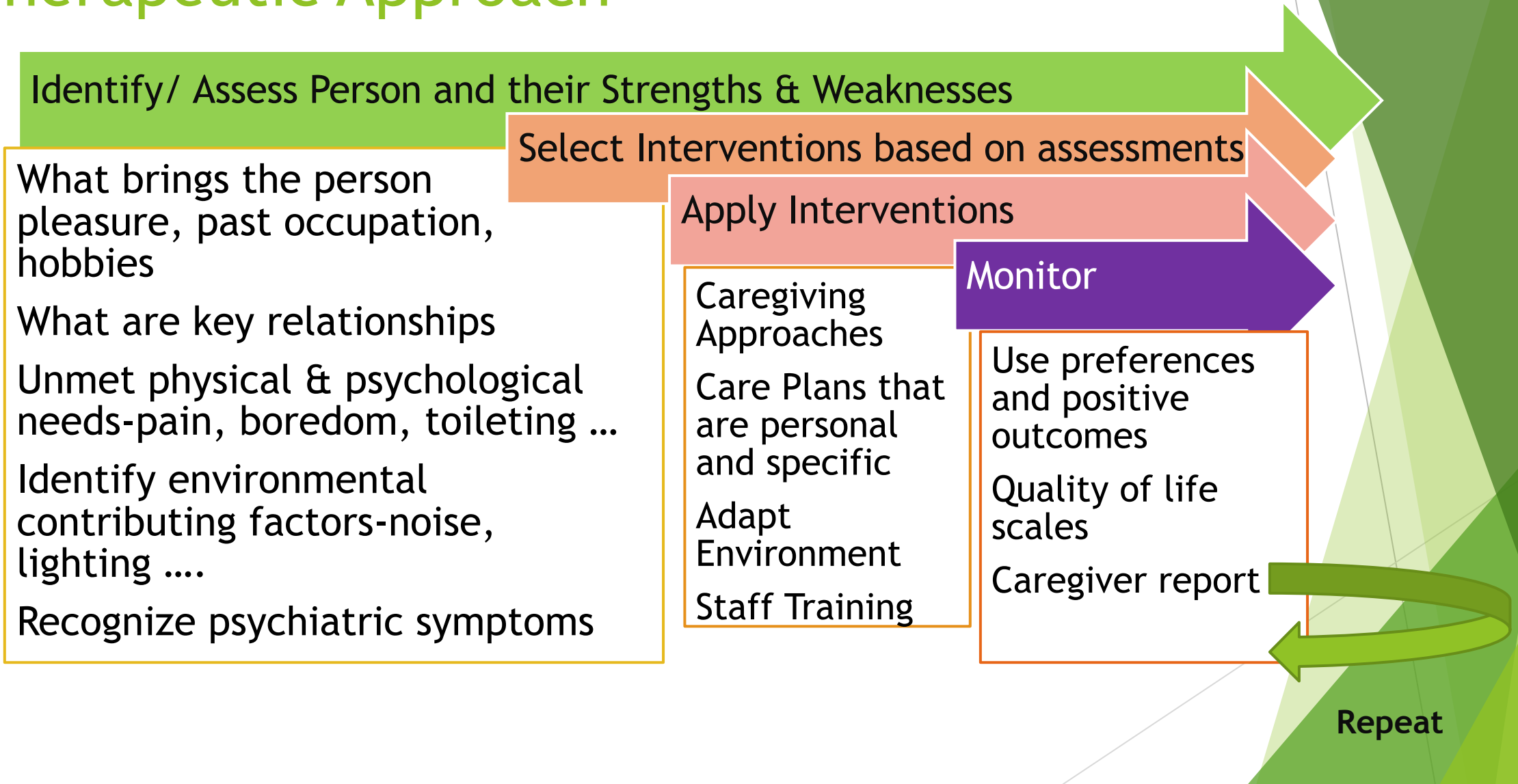
- Keith Oliver has early onset Alzheimer's and has recordings on the Dementia Diaries

- Information is important but not too much information… the experience of the illness is much more than just memory difficulties…

Traditional versus Palliative Care



Therapeutic Approach



What do these symptoms mean?

- Sadness, Crying
- Pacing
- Clenched fists
- Hitting
- Pushing away
- Calling out/Screaming
- Inconsolable

PAIN – AD scale (developed for dementia)

Items	0	1	2
A) Breathing independent of vocalization	Normal	Occasional labored breathing.	Noisy labored breathing.
B) Negative vocalization	None	Occ. moaning. Speech w/ negative or disapproving quality.	Repeated calling out. Loud moaning or groaning. Crying
C) Facial expression	Smiling or inexpressive	Sad. Frightened. Frowning.	Facial grimacing.
D) Body language	Relaxed	Tense. Distressed. Pacing. Fidget	Rigid. Fists clenched. Pull/push away. Hitting
E) Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.

Words & language for those with dementia

- Our brains are hardwired to attend to words
- This can be misleading in an illness that attacks the language centers of the brain
- Alzheimer's Disease and Frontal Temporal Dementias directly involve the parts of the brain used to produce and understand language

Words & language for those with dementia

- What is the purpose of your language:
  - Content vs relationship?
- Many times the emotion you express is more important than the exact content of the words
- If there is a mismatch between words and expressed emotions, listen to the emotion
- If there is a mismatch between words and actions, listen to the actions

Behavior as communication – telling us about people's basic needs

Millie

Millie has lived in an assisted living for years. Recently Millie has become verbally hostile, including scratching and biting with care. At the hospital, Millie screams every time someone enters room for care. She refuses all interactions, medication, and care.

Treatment Planning

- Advanced directives recognizing that dementia is a fatal progressive illness
  - Identify residents goals, discuss realistic details of what the disease entails and where the resident is in the disease trajectory
    - Ex. If a person hopes to die in their sleep, then a pacemaker may not be what they want
- Identify symptoms (use a scale like BEHAVE-AD or Neuorpsychiatric Inventory or NPI) etc
- Assess (and document) if resident and/or family believe symptoms are addressed

What is caregiver education?

- Providing direct caregivers with the tools to provide appropriate interventions
- Caregiver Support Groups
  - Research shows it decrease stress and improves quality of life
- Designing and providing stage specific treatment plans
  - Uses current evidence
  - Based on clinical expertise

Cooper et.al. 2012; Kverno et al 2009; O'Neil et al., 2011

Person Centered

- Identify the world in which they live, avoid reality orientation
- **People with dementia cannot change, you can**
- Respect personality, likes, interests
- Retain composure, non reactive responses

Example: 84 year old man with dementia spends the day washing floors with his hands and taking the molding off walls. He says he “has to work”

FAST scale used to qualify dementia patients for hospice

FAST = Functional Assessment Staging criteria

Low scores are most functional

Scored from 1 to 7

FAST scoring for Dementia

- 7a < 6 meaningful words/day
- 7b 1 intelligible word in any average day
- 7c unable to walk without assistance

Predicting mortality in end stage dementia is not done well

- The National Hospice Organization eligibility guidelines for patients with dementia
  - are based primarily on the Functional Assessment Staging (FAST) criteria
  - not derived from empirical data from patients with dementia
  - do not accurately predict 6-month survival
  - cannot be applied to the majority of patients with dementia whose disease does not progress linearly

Mitchell et al, JAMA 2004

- FAST 7c – if reached in a stepwise fashion, 71% died within 6 months of enrollment

- FAST 7c but not 7a and then 7b, only 30% died within 6 months of enrollment with a median survival time of 10.7 months

Mitchell et al 2004: How to better predict mortality in end stage dementia in those newly admitted to NH

- They used a risk score based on 12 variables from the Minimal Data Set (MDS).

- Advanced dementia defined as having a diagnosis of dementia and a Cognitive Performance Score of 5 or 6 (corresponds to a MMSE of 5 or less)

Model Using Info from the MDS

Positive Predictive Value 80%, NPV 73%, Specificity 99%, Sensitivity 6%

- Dependence for ADLs
- Bedbound
- Bowel incontinence
- Cancer, CHF, O2 dependent, dyspnea
- Medical instability
- Eating < 25% of all meals
- Sleeping most of the day
- Male
- Age > 83

Mini Suffering State Examination (MSSE)

A simple tool to measure suffering in those with end stage dementia

Aminoff et al Arch Gerontol Ger 2004; 38: 123-130

Mini Suffering State Examination

Suffering Item	Explanation	Yes= 1 point
Not calm	1st significant expression without verbal communication	
Screams	Sign of desperation and call for help that indicates suffering	
Pain	Difficult to recognize in end-stage dementia- watch facial expression while percussing, palpating etc.	
Decubitus ulcers		
Malnutrition	Reflected by Total Protein, Albumin, Cholesterol, Hemoglobin …	

Suffering Item	Explanation	Yes= 1 point
Eating Disorders	Refusal to eat, oropharyngeal dysphagia, anorexia, PEG	
Invasive action	Frequent blood tests, intubation, catheterizations, constant fluid transfusions, hemodialysis, mechanical ventilation, etc.	
Unstable Medical Condition	Acute medical status such as pneumonia, urosepsis, electrolyte imbalance in the last few months	
Suffering (medical opinion)	Suffering is not a diagnosis	
Suffering (family opinion)	Do you believe that your loved one is suffering?	

MSSE score interpretation

- Low level of suffering 0-3
- Intermediate level of suffering 4-6
- High level of suffering 7-10

- High level of agreement on 7 items

- High level of disagreement on “not calm” and “suffering according to physician’s opinion”

The MSSE predicts mortality

(Aminoff BZ Adunsky A. Their last 6 months: suffering & survival of end stage dementia pts, 2006; Age and Aging. 597-601)

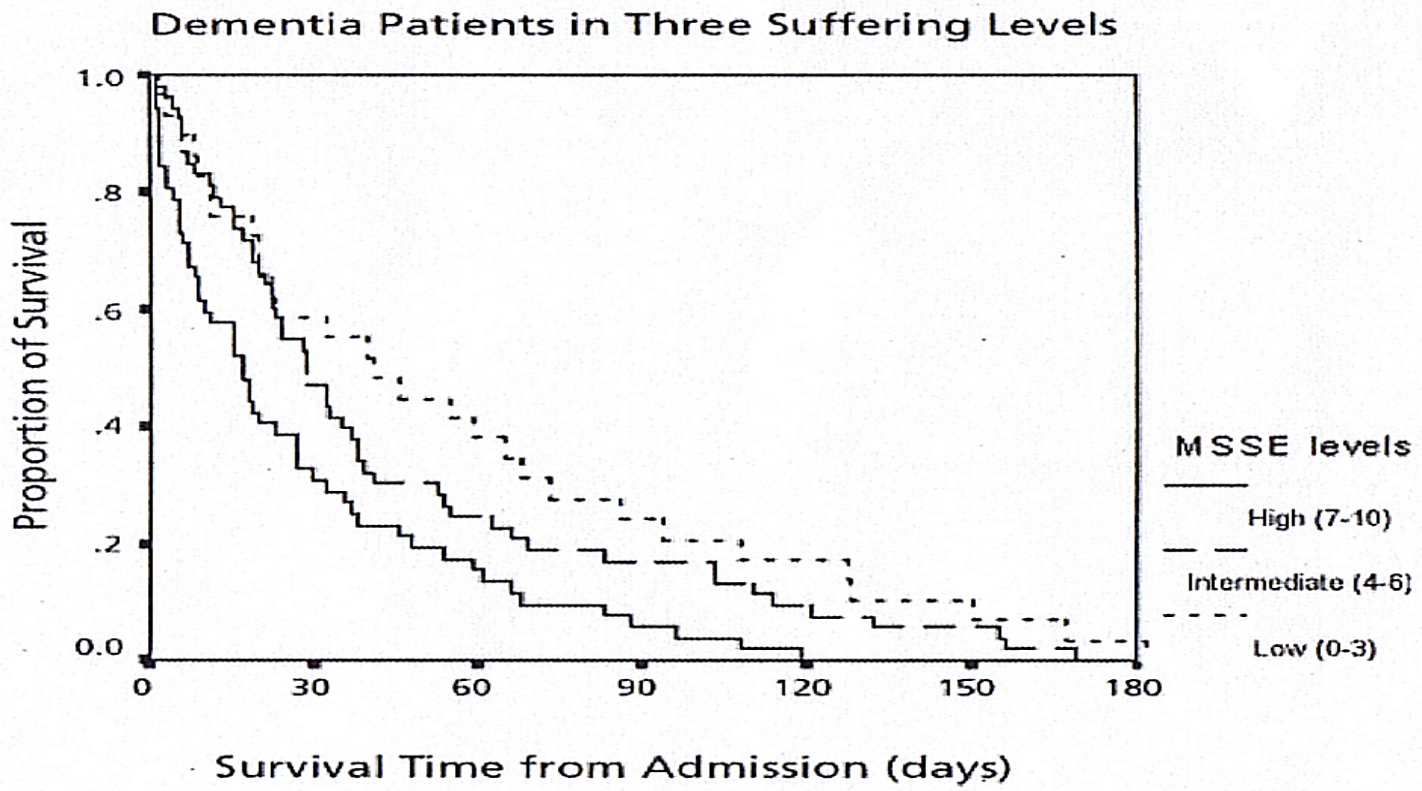


Figure 1. Kaplan–Meier 6-month survival curves for end-stage dementia patients in three suffering levels.

Psychiatric Symptoms amenable to treatment with medications

- Paranoia and delusions
- Hallucinations
- Sometimes depression, if a depressive illness – consider EOL
- Sometimes anxiety, if an anxiety disorder – consider EOL
- Pain
  - Arthritis vs neuropathy vs constipation vs urinary retention …
  - Actual medication depends on what type of pain
- Aggression – consider EOL

Symptoms not usually amenable to medications

- Wandering
- Calling out (not related to pain) – consider EOL
- Repetitive questions
- Anxiety related to having memory loss or other symptoms
- Psychomotor agitation-unless it is from pain – consider EOL
- Sleep problems
  - Increase exercise and early morning light
  - We all try medications with decreasing effectiveness as illness progresses, consider stopping them if person isn't sleeping

2015 European Academy of Neurology Guidelines: Use Combined Treatment

- 4 trials including 1549 AD patients in the **moderate to severe disease**
- Beneficial effects of combination therapy compared to ChEI monotherapy (SMD) -0.20; 95% (CI) -0.31; -0.09],
- cognitive functioning (SMD -0.27, 95% CI -0.37; -0.17) and
- behaviour (SMD -0.19; 95% CI -0.31; -0.07).
- **The quality of evidence was high for behaviour**, moderate for cognitive function and GCI and low for ADLs.
- The evidence was weak for cognition, GCI and ADL so that the general recommendation for using combination therapy was weak.

Schmidt R[1], et al. **EFNS-ENS/EAN Guideline on concomitant use of cholinesterase inhibitors and memantine in moderate to severe Alzheimer's disease.** Eur J Neurol. 2015 Jun;22(6):889-98.

Dementia Specific Medications

- Cholinesterase inhibitors (donepezil, rivastigmine, galantamine)
  - Evidence exists that they can effectively treat psychosis, agitation, paranoia, delusions, apathy, depression
- Memantine
  - Evidence that it helps sleep, appetite, anxiety, agitation, aggression

Clinical Pearl-etiology of aggression

- Aggression in those with dementia occurs primarily at 2 times:
  - Person is denied something or something is taken away
  - With personal cares
- 32/82 pts “violent.” Norway.
- Majority of incidents were by minority of residents. Injury to anyone rare.
- Most frequent intervention to defuse situation:
  - Talking with person

Almvik R; Rasmussen K, Woods P. Challenging behaviour in the elderly—monitoring violent incidents. Int J Geriatr Psychiatry 2006; 21: 368–374.

Take Home Message

- Dementia is a progressive, terminal illness
- Physicians should consider palliative care at diagnosis
- Discussions need to be honest and open with caregivers
- Treat the person, not the symptom
- Quality of life includes engagement in meaningful activity, connection with caregivers, and controlled pain

REFERENCES

- Hyden, L., Lindemann, H. and Brockmeier, J. (2014). Beyond Loss: Dementia, Identity and Personhood. Oxford: Oxford University Press.
- Jones, G., Van Der Eerden-Rebel and Harding, J. (2006). Visuoperceptual-cognitive deficits in Alzheimer's disease: adapting a dementia unit. In B. Miesen and G. Jones (eds.), Care-giving in Dementia: Research and Applications, Vol. 4 (pp. 3–58). London: Routledge.
- Kitwood, T. (1997). Dementia Reconsidered: The Person comes First. Buckingham: Open University Press.
- Peisah, P., Weaver, J., Wong, L. and Strukovski, J. A. (2014). Silent and Suffering: A Pilot Study Exploring Gaps Between Theory and Practice in Pain Management for People with Severe Dementia in Residential Aged Care Facilities. http://www.ncbi.nlm.nih.gov/pmc/articles/ PMC4205115/; last accessed 10 November 2016.

Questions

HOT TOPICS

CULTURE CHANGE *in* ACTION WEBINARS

Pioneer Network™

Our Next Webinar in the Hot Topics Series

THURSDAY, MARCH 15, 2018

Engaging in Person Centered Care:
The Path to Regulatory Compliance

A Person-Centered Approach to Infection Prevention (Focus on Urinary-Catheter-UTI and Urinary Incontinence CEP)

Guide:
Lynn Meyer, BSN, MPH, CIC
(Certified Infection Preventionist)

Pioneering a New Culture of Aging CONFERENCE

Denver, Colorado • August 12-15, 2018

Connect with the Network!

connect with the NETWORK

www.PioneerNetwork.net

Learn the latest news about our annual national conference, webinars, research news, events nationwide and more.

Find us on Facebook too!