



The Palliative Medicine Approach to End of Life Care for People with Dementia

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Issues in Persons with Dementia

- **Initial diagnosis**
 - Screening evaluation
- **Communication**
 - Advanced directives
- **Predicting outcomes**
 - Staging (FAST)
 - The clinical course
 - When to intercede
 - What to offer
- **Palliative Medicine**
 - Its role in dementia



Dementia: The Syndromes

- **Primary**
 - Incidence---65% and increase as age increases
 - Alzheimer's disease
 - Frontotemporal (10%;~55-65y/o;personality,behavior; language)
- **Vascular**
 - 2nd most common ~40% or >; step wise progression
 - survival 60% 5years
 - Multi-infarct---- occurs in medium size vessels
 - Binswanger's Disease uncommon variant; small vessels involved; basal ganglion & periventricular white matter)
- **Lewy body (eosinophilic inclusion bodies) dementia**
 - 3rd most common; rigidity, fluctuating [common here]; visual hallucinations severe, Parkinson like tremors
 - Parkinson's; progressive supranuclear palsy
- **Ingestion-Alcohol ingestion**
- **Infections-Fungi (crypto); spirochetes (Syphilis); virus (HIV)**
- **Prions-Creutzfeldt-Jacob disease**
- **Structural disorders--tumors; NPH; chronic sub-dural hematoma, Dementia pugilistica**



Prognostication in Dementia: The Physician's Dilemma

- It is the number one fundamental parameter for health care professionals to decide about
 - CURE or CARE
- Avoids the risk of over or under treatment
- Other issues:
 - QOL
 - Economics
 - Specific features, e.g. nutrition, dyspnea, delirium
- The Question: "...how long do I have Doctor?"



Palliative Medicine: WHO*

Definition

“the active total care of patients, whose disease is not responsive to curative treatment. control of pain and other symptoms and of psychological, social, and spiritual problems is paramount. the goal of palliative care is achievement of the best quality of life for patients and their families.”

***WHO Cancer pain relief and palliative care. TR 804, WHO,1990.**

Dementia: The Patient's Story(1)



- **Ms. H., an 87 y/o retired teacher, who had noted an inability to remember “things”. A neurologic evaluation suggests that she has Dementia, Alzheimer’s Type. Today, 5 years after the original Dx, she unable to do IADL’s but is still able to do ADL’s. She resides in an assisted living housing program.**
- **CC: Shortness of breath; cough. Sputum is thick and yellow. No fever or chills**
- **P.E. see picture. MMSE 19/30.**
- **LAB and Plan of Rx---**





Screening for Dementia*

■ Screening

■ 368 physicians

- 24% did routinely
 - 85% lack of time; 58% fear of offending; 22% test??

■ Testing

■ MMSE

- 30 point test
- Takes about 10 minutes to administer
- 91% sensitivity/92% specificity
- < 24/30 positive test

■ MINI-COG

- Remember 3 things + Clock drawing
- 3 minutes to administer
- Scoring-0-2 items recalled & CDT 1(mild) to 3(severe)
- 99% sensitivity/93% specificity
- *Scanlan,J & Borson,S. The Mini-Cog. Int J Geriatr Psychiatry 16:216-222,2001

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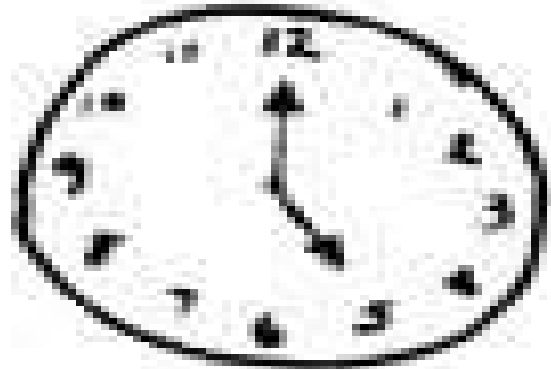
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2



3





Diagnostic Criteria in Dementia*

- A. impairment in short (3 things for 5 min.) & long term(president,birth place) memory**
- B. one of the following:**
 - Impaired abstract thinking(word definition)
 - Impaired judgment(plans to deal with issues)
 - Aphasia (language), apraxia (motor),agnosia (failure to recognize objects),construction difficulty
 - Personality change
- C. Disturbance in A or B significantly interferes with function**
- D. not occurring during the course of delirium**

* Dig.&Stat.Man.Mental Disorders 3rd edition



The Functional Assessment Scale (FAST)--1

1. **No difficulty either subjectively or objectively.**
2. **Complains of forgetting location of objects. Subjective work difficulties.**
3. **Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.***
4. **Decreased ability to perform complex tasks, e.g., planning dinner for guests, handling personal finances (such as forgetting to pay bills), difficulty marketing, etc.**
5. **Requires assistance in choosing proper clothing to wear for the day, season or occasion, e.g. patient may wear the same clothing repeatedly, unless supervised.***
6. **A) Improperly putting on clothes without assistance or cueing (e.g., may put street clothes on over night clothes, or put shoes on wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks.**
B) Unable to bathe properly (e.g., difficulty adjusting bath-water temperature) occasionally or more frequently over the past weeks.*
C) Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.*
D) Urinary incontinence (occasionally or more frequently over the past weeks). *
E) Fecal incontinence (occasionally or more frequently over the past weeks).~

The Course of Alzheimer's type Dementia

Fast stage	3	4	5	6	7
MMSE	29-25	19-14	5	0	0
Years	0	7-9		10-13	13-19
FAST Sub stage				a---e	a---e C-usual point of death



Dementia: Treatment

R_x

Early Issues in Persons with Dementia*

- **Advanced directives**
 - **Care planning while able**
 - **The physician's role is to:**
 - **What does the patient wish? Now and future**
 - **Listen to the persons involved**
 - **Have a referral source available!!!**
 - **Establish**
 - **Who will answer when patient can't; power of attorney for health care**
 - ******no "right" answer!!!!**
 - **Family Care Concerns**
 - **No treatment = "Killing the patient"**
 - **Feeding**
 - **Is palliative care "abandonment"**
 - **The Physician's Concern**
 - **Safeguarding the vulnerable patient**

* Solomon, M & Jennings, B. in *Hospice Care for Patients with Advanced Dementia*. Springer, NY, NY, 1998



Predicting Survival in People with Dementia*

- **1991-2003 in urban health centers in United Kingdom**
 - **65-74 and >75 yrs old in = #'s**
 - **Median age 84 y/o; 71% women; 50% men**
 - **MMSE 0-17**
- **Results**
 - **81 % died**
 - **Median survival from Dx 4.1 yrs men**
 - **4.6 yrs women**
 - **Note the older the shorter survival > 90 y/o 3.8 yrs**
- **Implications**
 - **Hospice eligible?**
 - **When to “start” planning” for outcome of individual**
 - **Will**
 - **EOL decisions**
 - **Palliative care vs curative care**

*Xie,J et al Survival time in people with dementia. BMJ 336:258-262,2008



Dementia: The Patient's Story(2)

Ms. H., an 87 y/o retired teacher, who had noted an inability to remember "things". A neurologic evaluation suggested that she has Dementia, Alzheimer's Type. Today, 12 years after the original Dx, she is unable to do IADL's or ADL's. She speaks little and is bed ridden. She resides in a facility with a dementia unit.

CC: None. Moans and tosses in bed.

P.E. MMSE 0/30.

Lab and Plan of Rx---



Pain: A Palliative Medicine issue in Persons with Dementia

1. Evaluation

**what issues need to be evaluated at this
time in this person's history?**

2. Consider is the person:

- confused?**
- agitated?**
- showing signs of obstructed bladder
outlet?**
- or maybe constipation?**
- or having pain?**



Evaluating Pain: in People with Dementia

- **Quantifying pain in the cognitively impaired**
 - **Tools**
 - Level of impairment
 - Ease of use
 - Choice in your institution
 - **Types**
 - VAS
 - PPI
 - None, mild, moderate, severe, can't tolerate
 - Observation of person

PATIENTS UNABLE TO PROVIDE A SELF REPORT OF PAIN

Face	0 Face muscles relaxed	1 Facial muscle tension, frown, grimace	2 Frequent to constant frown, clenched jaw	Face Score:
Restlessness	0 Quiet, relaxed appearance, normal movement	1 Occasional restless movement, shifting position	2 Frequent restless movement may include extremities	Restlessness Score:
Muscle Tone*	0 Normal muscle tone, relaxed	1 Increased tone, flexion of fingers and toes	2 Rigid tone	Muscle Tone Score:
Vocalization**	0 No abnormal sounds	1 Occasional moans, cries, whimpers or grunts	2 Frequent or continuous moans, cries, or grunts	Vocalization Score:
Consol ability	0 Content, relaxed	1 Reassured by touch or talk. Distractible	2 Difficult to comfort by touch or talk	Consol ability Score:

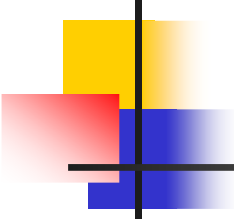
Pain Assessment Behavioral Scale Total (0 to 10)



Dementia: A Case History(3)

- **Ms. H., an 87 y/o retired teacher was diagnosed with Dementia, Alzheimer's Type, 15 years ago. Today you note shortness of breath; sputum thick and yellow. She is unable to speak, incontinent, unable to sit alone, no facial expressions.**
 - **PMH– as described**
 - **MMSE 0/30**

Is this the time to evaluate her for hospice eligibility?



The Functional Assessment Scale (FAST)—2*

7.

A) Ability to speak limited to approximately a half a dozen intelligible different words or fewer, in the course of an average day or in the course of an intensive interview.

B) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview (the person may repeat the word over and over).

C) Ambulatory ability is lost (cannot walk without personal assistance).

D) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests (arms) on the chair).

E) Loss of ability to smile.

F) Loss of ability to hold up head independently.

*Reisberg, B. Functional assessment staging (FAST). *Psychopharmacology Bulletin*, 1988~ 24:653.659.



Hospice Eligibility for the Person with Dementia

- **Must have:**
 - **FAST Stage----7**
 - **1. ALL of the following are necessary and include:**
 - **Unable to dress, ambulate, bath, smile, sit-up, swallow**
 - **Incontinent of bowel and bladder**
 - **Speaks < 6 words/day**
 - **2. Co morbid and 2nd ary conditions**
 - **must accompany the Dx and can include:**
 - **dysphagia, aspiration pneumonia, failure to thrive, pressure ulcers, urinary tract infections**
 - **other major illnesses**
 - **heart failure, COPD, renal failure**

The Course of Alzheimer's type Dementia

	3	4	5	6	7
Fast stage					
MMSE	29-25	19-14	5	0	0
Years	0	7-9		10-13	13-19
FAST Sub stage	-----		-----	a-cant dress b-bathe c-toileting d-urinary incontinence e-fecal incontinence	a-1/2 dz. Wrds/dy b-1 wrd/dy c-unable to ambulate d-sit e-smile f-hold up head
Progress. of Illness	7 years	2 years	18 months	5-10 Months	6 months



Clinical problems in Advanced Dementia

- **Gastrointestinal**
 - Oral hygiene
 - Feeding
 - Fluids
 - Constipation/diarrhea
- **Infection**
 - Bladder
 - Pulmonary
 - Skin



Clinical problems in Advanced Dementia: Infection

■ 6(UTI) to 54%(pulmonary) “cause of death” because:

- Predisposing factors
 - Immune change, diagnostic dilemmas(~80% have fever), aspiration-increased by tube feeding
- Treatment of infection include:
 - “Prevention”
 - Urinary catheters, increase bladder emptying
 - Vaccination—pneumo. poor response
 - Antibiotics
 - in advanced stages no difference with or with out antibiotics in survival
 - (Fabiszewski,et al JAMA 263:3168,1990)
 - Palliative Measures
 - MS---Can be given orally(not rectal) or sub-q
 - Dry secretions—scop patch, atropine eye drops, glycopyrrolate



Pneumonia in a LTCF*

- **108 patients over 12 months**
- **ADL score(6 items scored 1-3 from normal to severe impaired total 18)**
- **> 3 co morbid illnesses(dementia; COPD; PUD; PVD; hemiplegia)**
- **Mortality @ 14 days**
 - **5% ADL<10; 10% ADL 11-15 & 27% >15 ADL score**
- **Mortality @ 12 months**
 - **ADL < 10--33%; 11-15—60%; >15—65%**
- **Survival**
 - **81% @ 30 days ever though 1/3 in hospital & >90% received antibiotics**
 - **The < the ADL the less likely to survive**
 - **Functional status did not improve**

* Muder,RR, Brennen,C,Swenson,DL & Wagener,M Arch Int Med 156:2365-2370,1996



Clinical problems in Advanced Dementia

- **Pulmonary**
 - **Dyspnea**
 - **Cough**
 - **Respiratory distress**
 - **Gurgling, edema**
- **Neurological**
 - **Pain**
 - **Depression**
 - **Agitation**
 - **Delirium**



Dementia: Psychiatric Issues

- **Delirium**
 - Can occur early in disease
 - Paranoia
- **Terminal restlessness**
 - Twycross---unresolved issue/s
- **Hallucinations**
 - Early in Lewy Body Disease
 - Can be visual as well as auditory
- **Rx**
 - **Agitation**
 - Haloperidol—1-2 mg/any route
 - Mirthazapine—15mg p.o. QHS
 - Risperidone—0.25-5.0mg QD
 - **Sedation**
 - Midazolam-- 10-20mg IV over 15 minutes. Than Q24hrs SQ
 - Lorazepam— 5-10mg given/ oral route





Dementia: Classification

- **Primary**
 - Alzheimer's disease
 - Frontotemporal
- **Vascular**
 - Lacunar (Binswanger's disease); multi-infarct
- **Associated with Lewy bodies**
 - Parkinson's; progressive supranuclear palsy
- **Ingestion**
 - Alcohol ingestion
- **Infections**
 - Fungi (crypto); spirochetes (Syphilis); virus (HIV)
- **Prions**
 - Creutzfeldt-Jacob disease
- **Structural disorders**
 - Tumors; normal pressure hydrocephalus; chronic sub-dural hematoma