Caring for Members with Advanced Dementia

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Objectives

- To appreciate dementia as a terminal diagnosis
- To recognize the signs of pain or distress in memebers with dementia
- To advocate for members who seem distressed or uncomfortable to address client needs
- To recognize physical changes indicating a member may be dying

Member Case: Mr. S

- Mr. S is a 88 year-old male member with Alzheimer's Dementia who has lived with his daughter for the past 8 years since his wife passed away.
- He requires cueing for all basic activities of daily living, however eats independently. He is able to use his wheel chair with minimal assistance for transfers.
- His caregiver reports that lately he is having difficulty sleeping at night and "talking to someone in the room who is not there".

Discussion Points

- What is dementia?
- How is this member coping with the diagnosis of dementia?

Stages of Dementia

MILD	
Function	-independent of all ADLS, may need assistance with complex task
Cognition	-difficulty learning new information -memory loss interferes with everyday functions -mild word finding difficulty but maintain social conversation -mild judgment impairment
Behavior	-mild personality changes
MMSE	$\geq$19

Stages of Dementia

MODERATE	
Function	-independent of all ADLS, may need reminders or minimal assistance -assistance or complete dependence with IADLs
Cognition	-substantial memory loss, disoriented in time and often to place -conversation disorganized, rambling -impaired judgment
Behavior	-may have psychotic behavior, wandering, agitated verbal or physical symptoms -sleep disturbance -appears well enough to be taken to functions outside of home environment
MMSE	12-19

Stages of Dementia

SEVERE	
Function	-dependent of all IADL -dependent of ADLs (incontinent, may need assistance with eating)
Cognition	-oriented to person only -only fragments of memory retained -severe language impairment -inconsistent recognition of familiar people -vary short attention span
Behavior	-emotional lability -restlessness -inability to focus on tasks -appears to ill to be taken to functions outside of the home environment
MMSE	0-11

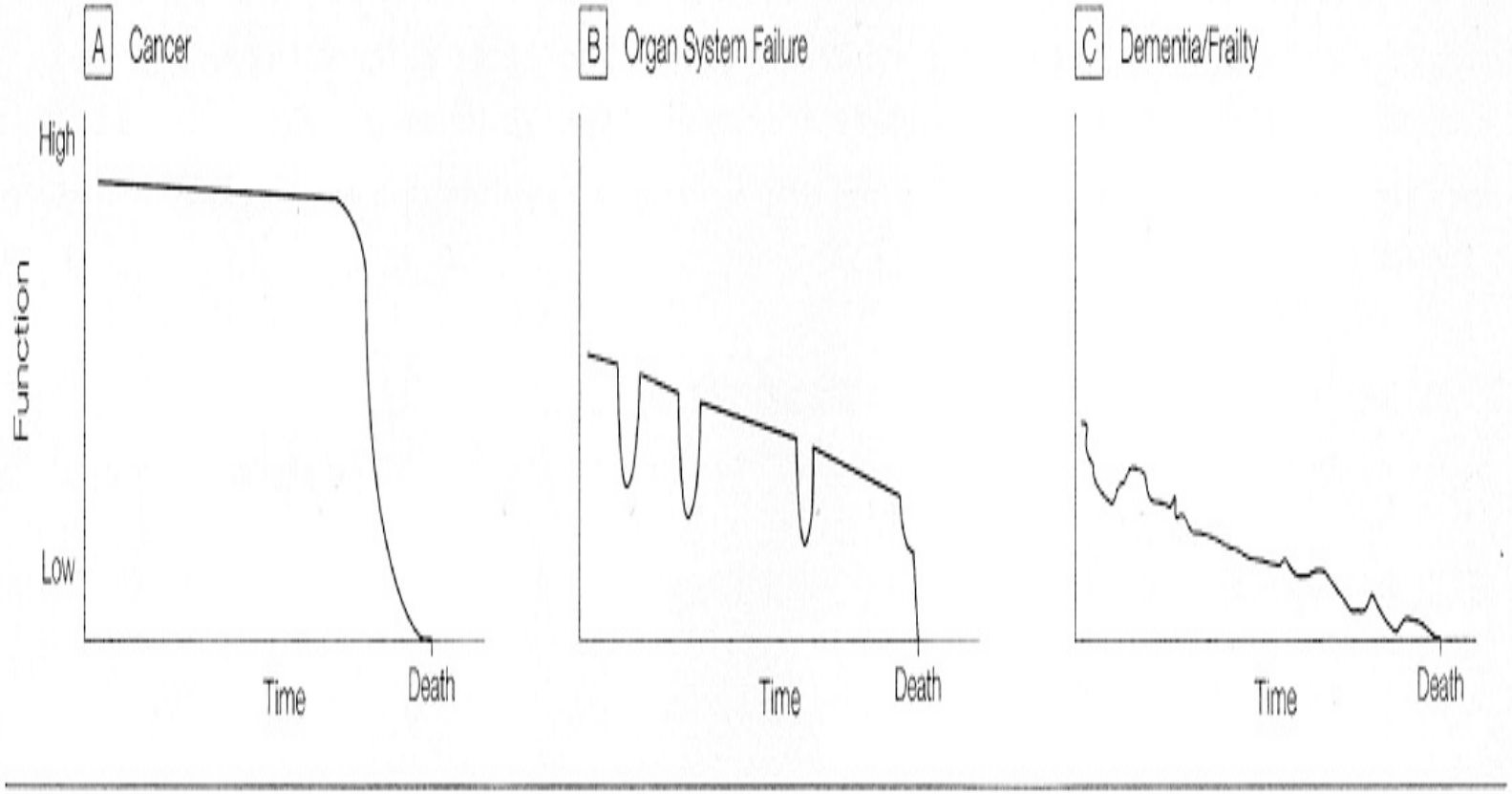
Advanced Stages of Dementia

PROFOUND	
Function	-dependent of all IADL -dependent of ADLs (loss of ambulation, feeds with assistance)
Cognition	-speaks <6 words -consistent difficulty in recognizing familiar people
Behavior	-repetitive vocalizations, calling out
MMSE	<11

TERMINAL	
Function	-inability to walk or sit up without assistance -inability to smile or hold head up ≥10% body weight loss, pressure ulcers >stage 2, UTIs, aspirations pneumonias
Cognition	-few words spoken
Behavior	-passive
MMSE	Not testable

Cotter, VT, et al. Dementia. Geriatric Secrets 3rd Edition. Hanley & Belfus. 2004, pp53. Adapted from Cotter, VT: Forgetfulness. Goolsby, MJ. Nurse Practitioner Secrets. Philadelphia, Hanley & Belfus, 2002, pp64-70.

Trajectory of Chronic Illness



Mr. S Continued: Previous 6 months

- Functional decline noted by both daughter and caregiver.
- Less cooperative with care.
- Less talkative and less appropriate with answers.
- Needing more assistance with all basic ADLs.
- He has lost 20 lbs over the past 2 months.

Discussion Points

- Does our member have advanced dementia?
- Do you have a member that you are concerned about who meets these criteria?

Mr. S Continued: Hospital Stay

- Found to have ARF thought to be pre-renal due to dehydration and poor intake→resolves with IVF.
- As well as UTI-->resolves with antibiotics.
- During her hospitalization she develops a stage 3 pressure ulcer.
- Patient no longer able to get out of bed and requires maximum assistance with all ADLs. She is also not cooperating with physical therapy.

Evidence Based Medicine for Dementia Prognosis… What there is of it!

- 1997 Luchins' Study published in JAGS around the same time as development of Dementia Criteria for hospice admission

- 2004 Mitchell Study published in JAMA

Functional Assessment Staging

Stages

1. No difficulties
2. Subjective forgetfulness
3. Decreased job functioning and organizational capacity
4. Difficulty with complex tasks, instrumental ADLs
5. Requires supervision with ADLs
6. Impaired ADLs, with incontinence
7. *A. Ability to speak limited to six words*
   B. Ability to speak limited to single word

   C. Loss of ambulation
   D. Inability to sit
   E. Inability to smile
   F. Inability to hold head up

Fast Fact and Concept #150: Prognostication in Dementia. Sing Tsai MD and Robert Arnold MD
http://www.aahpm.org/cgi-bin/wkcgi/view?status=A%20&search=185&id=659&offset=225&limit=25

Luchins' Study

- Followed two cohorts separated by time and place (N=47) of hospice patients for 2 years
- Of both groups: median survival time of 4 months, average of 6.9months, and 37% survived longer than 6months
- Score >7c had mean survival time of 3.2months
- Score <7c had mean survival time of 18months

Mitchell's Dementia Prognosis Study

Table 1. Description of Functional Assessment Stages and Comparable Minimum Data Set Variables

Functional Assessment Stage	Minimum Data Set Variable
6a = Improperly putting on clothes without assistance/cueing occasionally or more frequently over the past weeks	Limited or more extensive assistance required to dress on at least several occasions during the last 7 days
6b = Unable to bathe properly (eg, difficulty adjusting water temperature) occasionally or more frequently over the past weeks	Supervision or more assistance required to bathe during the last 7 days
6c = Inability to handle the mechanics of using the toilet occasionally or more frequently over the past weeks	Limited or more extensive assistance required to use the toilet on at least several occasions during the last 7 days
6d = Urinary incontinence occasionally or more frequently over the past weeks	Urinary incontinence at least twice a week
6e = Bowel incontinence occasionally or more frequently over the past weeks	Bowel incontinence at least twice a week
7a = Ability to speak limited to ≤1 intelligible word in an average day	Rarely/never makes self understood
7b = All intelligible vocabulary is lost	Rarely/never makes self understood
7c = Nonambulatory	Extensive assistance (or total dependence) required for locomotion (ie, move between locations) during the last 7 days

Palliative Performance Scale (PPS)

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
100	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90	Full	Normal Activity Some Evidence of Disease	Full	Normal	Full
80	Full	Normal Activity with Effort Some Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable Normal Job / Work Some Evidence of Disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby / House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40	Mainly in Bed	As Above	Mainly Assistance	Norma or Reduced	Full or Drowsy or Confusion
30	Totally Bed Bound	As Above	Total Care	Reduced	Full or Drowsy or Confusion
20	As Above	As Above	Total Care	Minimal Sips	Full or Drowsy or Confusion
10	As Above	As Above	Total Care	Mouth Care Only	Drowsy or Coma
0	Death	-	-	-	-

Anderson, Fern et al. (1996) Palliative Performance Scale (PPS) a new tool. Journal of Palliative Care 12(1), 5-11

Family Discussion

- Family does not wish to pursue aggressive work-up.
- Due to the progressive decline over the past 6 months the team discusses options, including feeding tube.

Discussion Points

- How do we as a team come together with the family on nutrition at the end of life?
- How do we know how to feed in patients with advanced dementia?

Member Case Continued: Mr. S

POA, daughter, feels that comfort goals of care is the most appropriate and would support her father's previously expressed wishes. She would like to focus on pain and symptom management, maintaining dignity and peacefulness.

Back to Our Member Mr. S

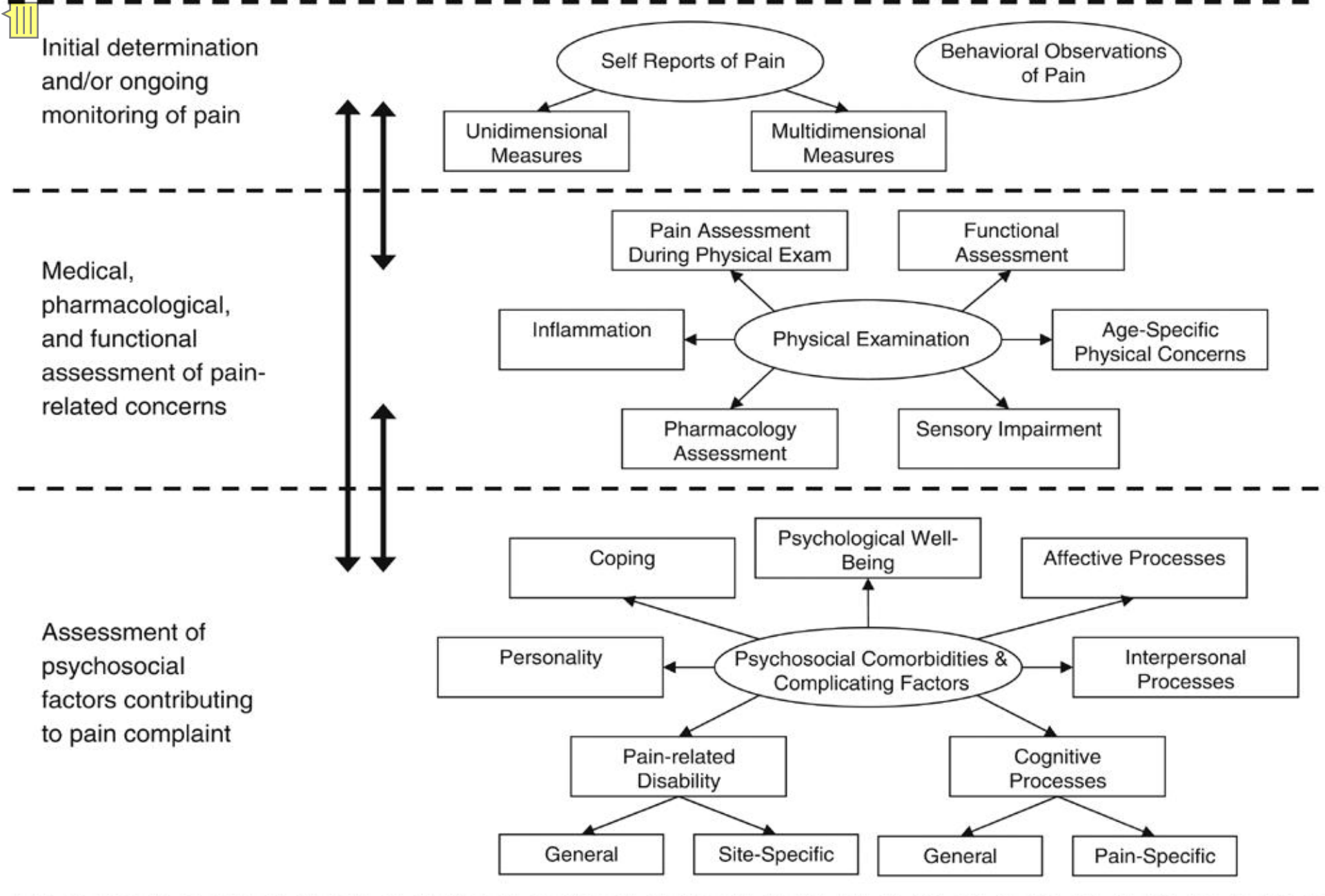
- He receives home visits from RN 1-2x/week and agency caregiver for 20hours/week.
- He is mainly bed bound and is put in a reclining chair with hoyer lift 2-3x/week.
- His daughter is concerned about pain or symptom management issues during this time.

Pain and Symptom Assessment

- How can you tell if Mr. S is in pain or uncomfortable?
- How do you communicate this with his family and medical team?

Adequate Pain Assessment

- Requires repeat comprehensive assessments
- Older adults under-report pain→"normal aging"
- Scales—choose a scale that is appropriate based on cognitive and communication abilities of the individual (re-assess using the SAME scale)
  - 1-10
  - Faces
  - Non-verbal assessment



Hadjistavropoulus T., et al. An Interdisciplinary Expert Consensus Statement on Assessment of Pain in Older Persons.

Clinical Journal of Pain. January 2007 Supplement. Volume 23 (1):S1-43.

Pain Assessment IN Advanced Dementia (PAINAD)

5 Categories (uses scale 1-10)

- Breathing
- Negative vocalization
- Facial expressions
- Body language
- Consolability

Warden, Hurley, Volicer, JAMDA 2003; 4(1): 9-15

Back to Our Member: Mr. S

- Restless at rest (moving his legs)
- Nonverbal, barely opening her eyes
- Grimacing with any movement of his body

Plan of Care for Mr. S

- His caregiver felt that he was in pain from pressure points.
- After negotiating a plan of care with the family, all agreed to started her schedule acetaminophen (tylenol).
- A few days later, he was still uncomfortable…scheduled morphine was added with good relief.

Is Mr. S Dying?

What signs and symptoms would you look for in any Member?

Signs and Symptoms of Dying

- Pain
- Difficulty breathing (dyspnea, irregularity)
- Oral secretions
- Confusion (delirium)
- Nausea/Vomiting
- Poor appetite (anorexia/cacchexia)
- Tired/weak (fatigue)
- Spiritual Suffering
- Anxiety/Depression
- “Unfinished business”

Syndrome of Imminent Death

Early

- Bed Bound
- Loss of appetite or ability to take anything by mouth
- Cognitive changes: more sleeping and/or delirium

Middle

- Further decline in mental status to obtundation
- Pooling of oral sections that are not cleared due to loss of swallowing reflex

Late

- Coma
- Fever (felt to be from aspiration pneumonia)
- Altered respiratory pattern
- Mottled extremities

Preparing a Family to Know When Death Has Occurred

- No breathing and heartbeat
- Loss of control of bowel or bladder
- No response to verbal commands or gentle shaking
- Eyelids slightly open; eyes fixed on a certain spot
- Jaw relaxed and mouth slightly open

1 Week Later…

Mr. S died at home peacefully and comfortably with his daughter at his side.

Summary

- To appreciate dementia as a terminal diagnosis
- To recognize the signs of pain or distress in member with dementia
- To advocate for members who seem distressed or uncomfortable to address client needs
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- Fast Fact and Concept #150: Prognostication in Dementia. Sing Tsai MD and Robert Arnold MD http://www.aahpm.org/cgi-bin/wkcgi/view?status=A%20&search=185&id=659&offset=225&limit=25
- Hadjistavropoulus, Thomas PhD et al. An Interdisciplinary Expert Consensus Statement on Assessment of Pain in Older Adults. Clin J Pain. Vol 23, No 1, January 2007 Supplement.
- Warden, Hurley, Volicer, JAMDA 2003; 4(1): 9-15