Palliative Care in Dementia

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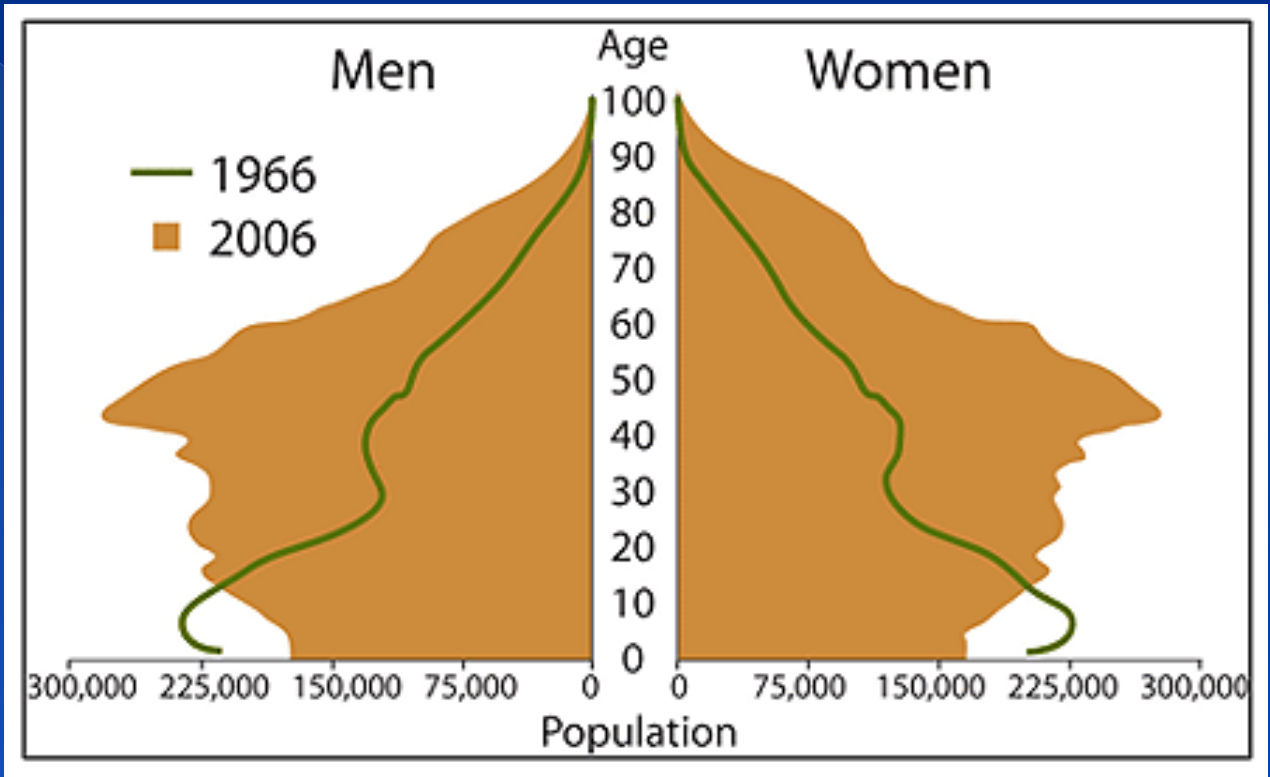
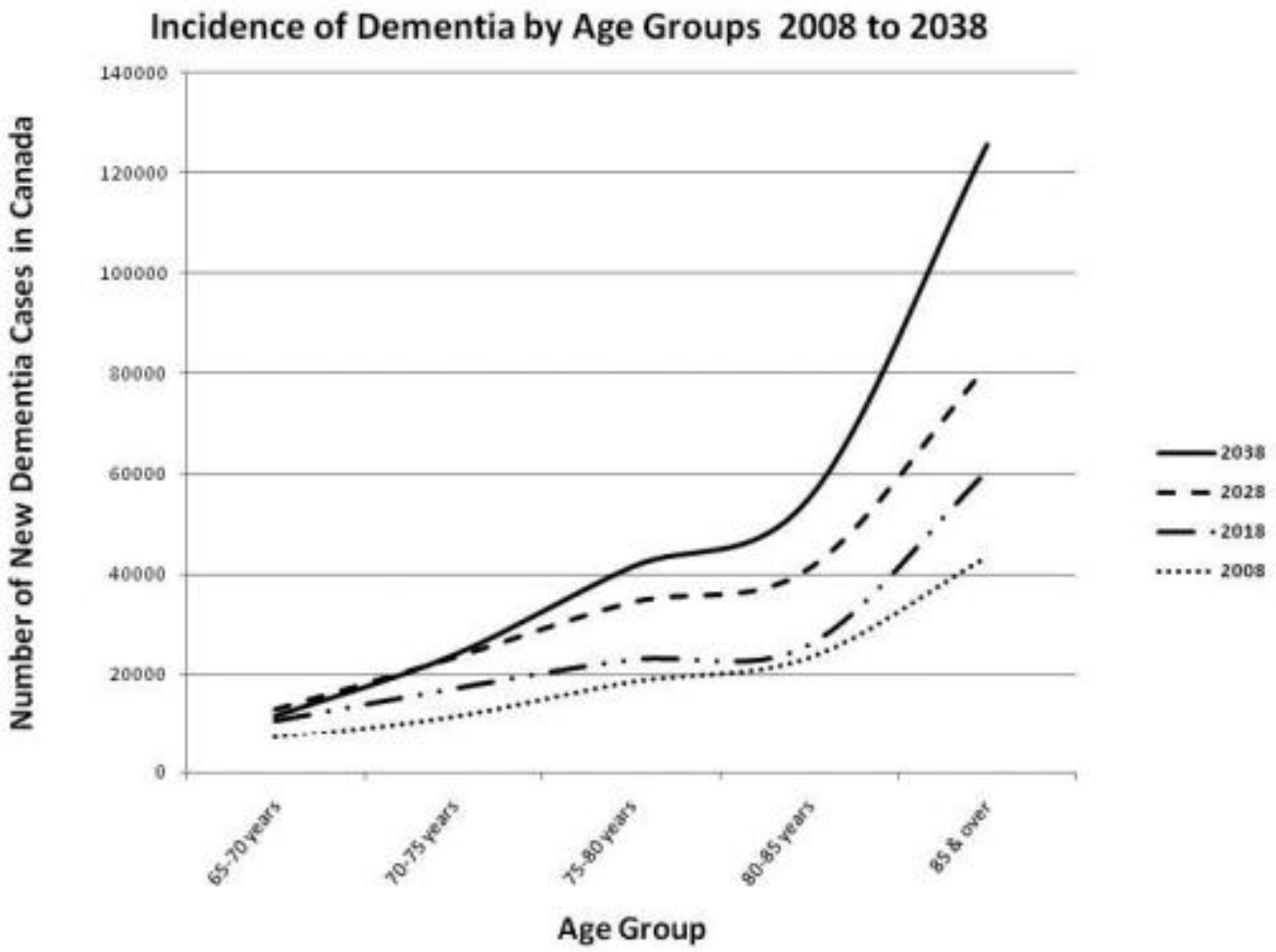
Objectives

- Brief review of dementia
- Dementia as a "terminal illness"
- Review the role for palliative care in patients with end stage dementia
- Discuss common therapeutic challenges in providing palliation to patients with dementia



By 2015, for the first time in its history, Canada will have more older people, age 65 and over, than young people under age 15. Aging will be one of the most significant social forces shaping our society over the next 20 to 30 years.

Source: CIHR



The Rising Tide- the impact of dementia on Canadian Society, 2010

Box 2: Diagnostic criteria for dementia

The presence of an acquired impairment in memory, associated with impairment in one or more cognitive domains, including:

- Executive function (e.g., abstract thinking, reasoning, judgment)
- Language (expressive or receptive)
- Praxis (learned motor sequences)
- Gnosis (ability to recognize objects, faces or other sensory information)

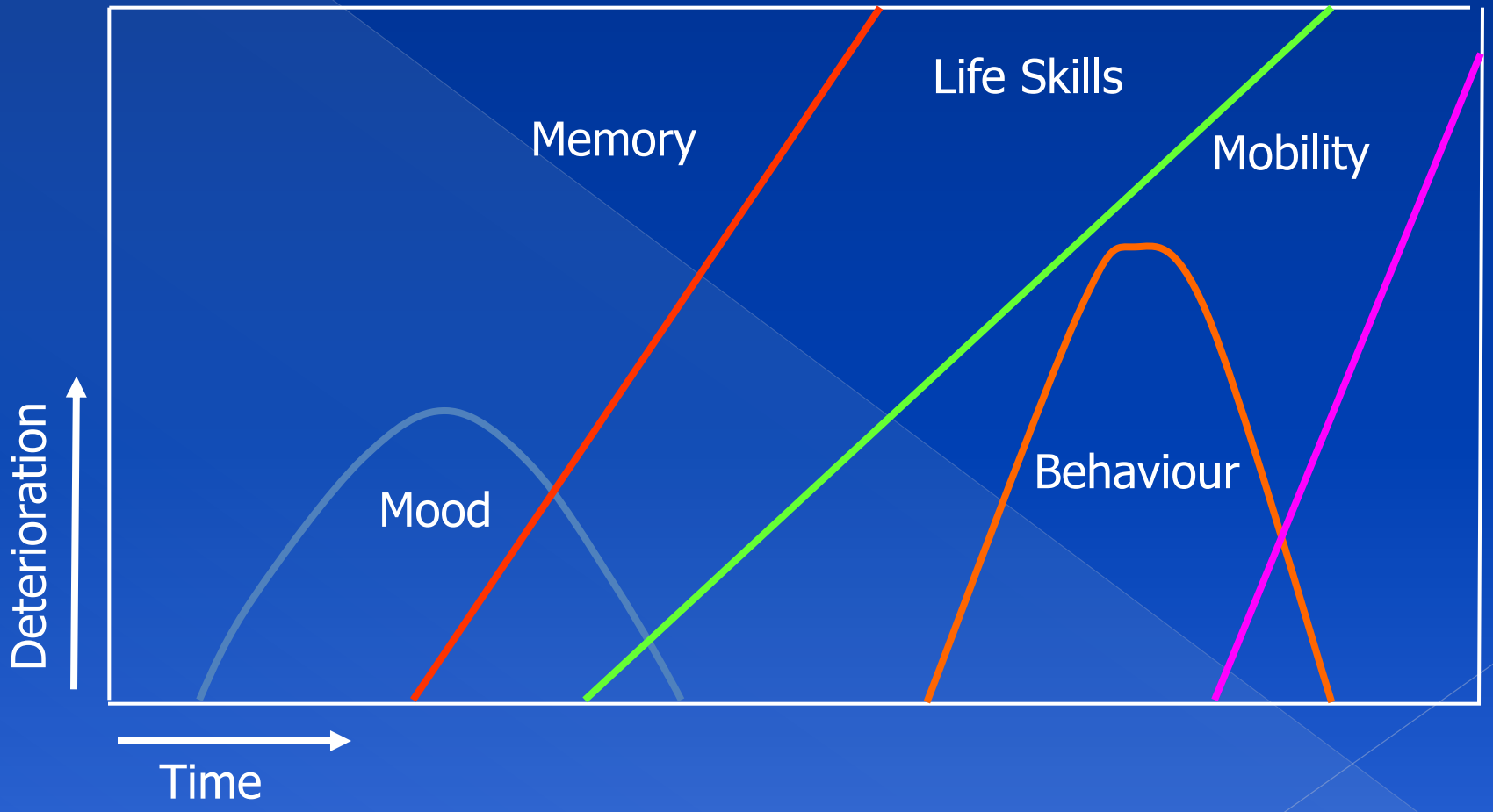
Impairments in cognition must be severe enough to interfere with work, usual social activities or relationships with others.

Source: *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition, text revision.[7]

Feldman, H. H. et al. CMAJ 2008;178:825-836

CMAJ · JAMC

Symptoms of AD Over Time



Lovestone, Gauthier, Martin Dunitz Ltd, London, 2001

GLOBAL DETERIORATION SCALE (GDS)

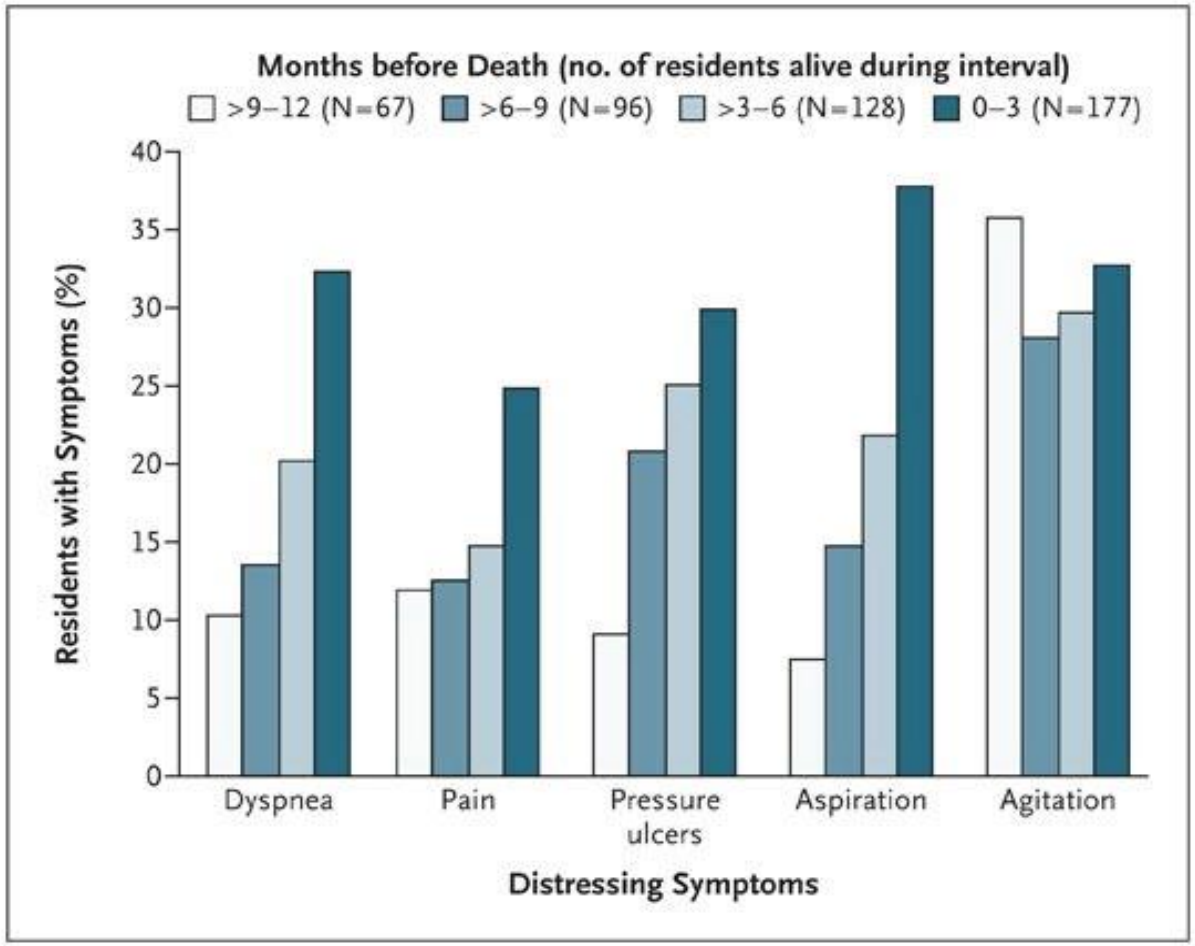
Stage	Deficits in cognition and function	Usual care setting
1	**Subjectively and objectively normal**	Independent
2	Subjective complaints of mild memory loss. Objectively normal on testing. No functional deficit	Independent
3	**Mild Cognitive Impairment (MCI)** Earliest clear-cut deficits. Functionally normal but co-workers may be aware of declining work performance. Objective deficits on testing. Denial may appear.	Independent
4	**Early dementia** Clear-cut deficits on careful clinical interview. Difficulty performing complex tasks, e.g. handling finances, travelling. Denial is common. Withdrawal from challenging situations.	Might live independently – perhaps with assistance from family or caregivers.
5	**Moderate dementia** Can no longer survive without some assistance. Unable to recall major relevant aspects of their current lives, e.g. an address or telephone number of many years, names of grandchildren, etc. Some disorientation to date, day of week, season, or to place. They require no assistance with toileting, eating, or dressing but may need help choosing appropriate clothing.	At home with live-in family member. In seniors' residence with home support. Possibly in facility care, especially if behavioural problems or comorbid physical disabilities.
6	**Moderately severe dementia** May occasionally forget name of spouse. Largely unaware of recent experiences and events in their lives. Will require assistance with basic ADLs. May be incontinent of urine. Behavioural and psychological symptoms of dementia (BPSD) are common, e.g. delusions, repetitive behaviours, agitation.	Most often in Complex Care facility.
7	**Severe dementia** Verbal abilities will be lost over the course of this stage. Incontinent. Needs assistance with feeding. Lose ability to walk.	Complex Care

Adapted by Dr. Doug Drummond from Reisberg B, Ferris SH, Leon MJ, et al. The global deterioration scale for assessment of primary degenerative dementia. American Journal of Psychiatry 1982;139:1136-1139.

Stages of Dementia

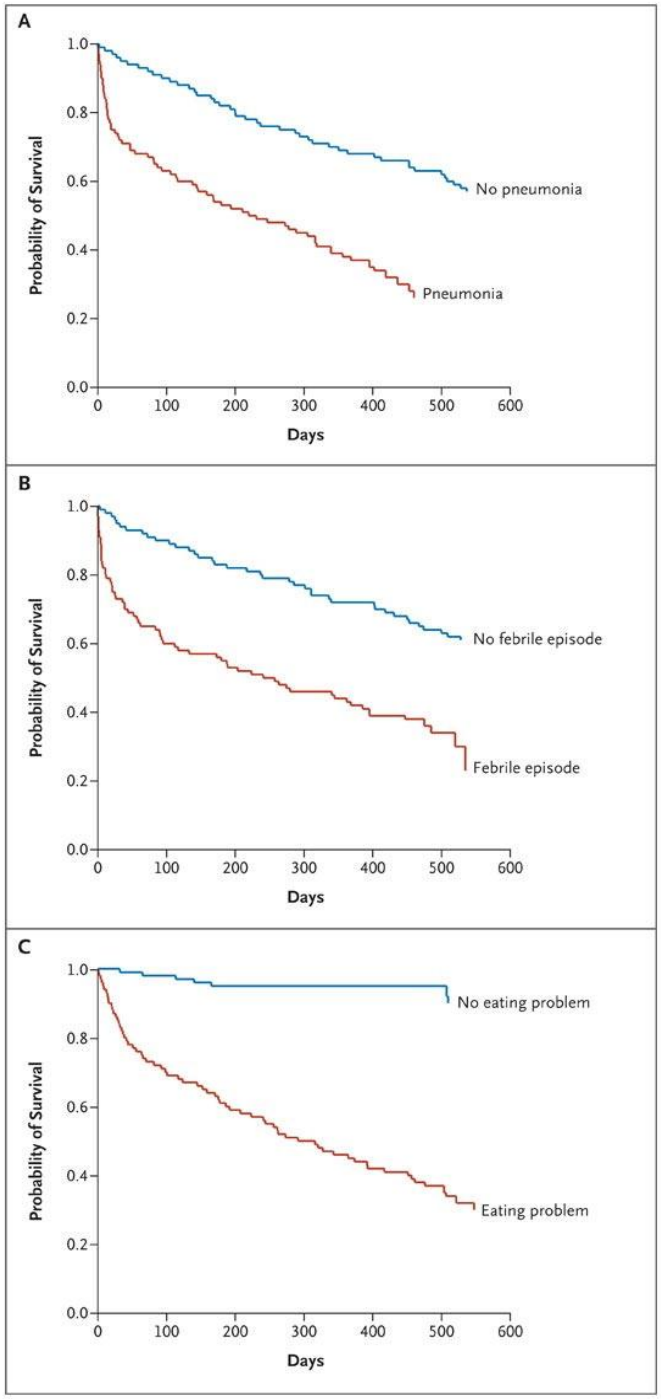
- End stage dementia
  - 6 month mortality rate of 25%
  - Median survival 1.3 years
  - Similar to metastatic breast cancer or Stage IV heart failure
  - A study of dementia in US nursing homes found that staff thought only 1% of their dementia residents had a life expectancy of <6 months, yet 71% of these residents died within that timeframe. (Mitchell 2004)

Proportion of Nursing Home Residents Who Had Distressing Symptoms at Various Intervals before Death.



Mitchell SL et al. N Engl J Med 2009;361:1529-1538.

The NEW ENGLAND JOURNAL of MEDICINE

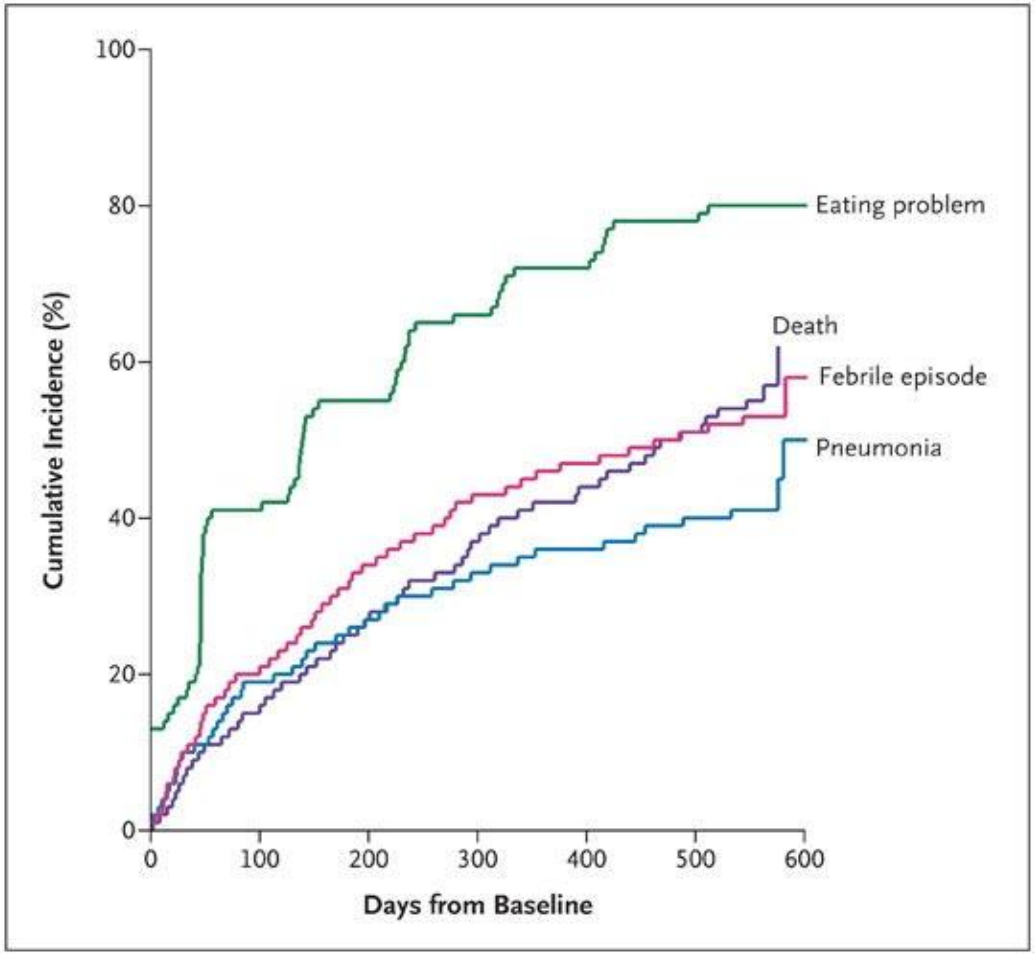


Survival after the First Episode of Pneumonia, the First Febrile Episode, and the Development of an Eating Problem.

Mitchell SL et al. N Engl J Med 2009;361:1529-1538.

The NEW ENGLAND JOURNAL of MEDICINE

Overall Mortality and the Cumulative Incidences of Pneumonia, Febrile Episodes, and Eating Problems among Nursing Home Residents with Advanced Dementia.



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Dying with Dementia

Burdensome Intervention (Died)	%
Parenteral therapy	34.4 (29.4)
Hospitalization	16.7(12.4)
ER visit	9.6(2.8)
Tube fed	8.0 (7.3)
Any intervention	(40)

The residents' median age was 86 years, and the median duration of dementia was 6 years; 85.4% of residents were women. Followed for 18 months

Mitchell SL et al. N Engl J Med 2009;361:1529-1538.

Dying with Dementia

- Most common reason for hospitalizations
  - pneumonia, (68.2%)
  - other infections, (13.6%)
  - heart failure, (9.1%)
  - hip fracture, (4.5%)
  - dehydration, (4.5%)
- Only 22% went to hospice

Mitchell SL et al. N Engl J Med 2009;361:1529-1538.

Burdensome Interventions in Nursing Home Residents during Their Last 3 Months of Life According to Health Care Proxies' Understanding of Prognosis and Expected Clinical Complications.

Table 2. Burdensome Interventions in Nursing Home Residents during Their Last 3 Months of Life According to Health Care Proxies' Understanding of Prognosis and Expected Clinical Complications.*

Proxy's Understanding of Prognosis and Expected Complications	Residents Who Died during 18-Mo Study Period (N=177)	Residents Who Underwent Any Burdensome Intervention during Last 3 Mo of Life	Odds Ratio for Burdensome Intervention during Last 3 Mo of Life (95% CI)†	
			Unadjusted	Adjusted
	no. (%)	*no./total no. (%)*		
Believed resident had <6 mo to live				
Yes	46 (26.0)	14/46 (30.4)	0.45 (0.19–1.04)	0.34 (0.14–0.81)
No	131 (74.0)	58/131 (44.3)	Reference category	Reference category
Understood expected clinical complications				
Yes	146 (82.5)	52/146 (35.6)	0.30 (0.15–0.62)	0.33 (0.17–0.63)
No	31 (17.5)	20/31 (64.5)	Reference category	Reference category
Believed resident had <6 mo to live and understood expected clinical complications	37 (20.9)	10/37 (27.0)	0.13 (0.04–0.44)	0.12 (0.04–0.37)
Either believed resident had <6 mo to live or understood expected clinical complications, but not both	118 (66.7)	46/118 (39.0)	0.23 (0.10–0.57)	0.25 (0.13–0.49)
Neither believed resident had <6 mo to live nor understood expected clinical complications	22 (12.4)	16/22 (72.7)	Reference category	Reference category

* Burdensome interventions included any hospitalization or emergency room visit, parenteral therapy (administration of intravenous or subcutaneous hydration, intravenous antimicrobial agents, or intramuscular antimicrobial agents), and tube feeding. Of the 177 residents who died during the 18-month study period, 72 (40.7%) underwent at least one burdensome intervention in the last 3 months of life. CI denotes confidence interval.

† Both the unadjusted and adjusted odds ratios were calculated with the use of generalized estimating equations to account for clustering at the facility level. The adjusted odds ratios were also adjusted for pneumonia (in 66 of the 177 residents [37.3%]), febrile episode (57 [32.2%]), and other sentinel events, such as hip fracture (8 [4.5%]) in the last 3 months of life.

Mitchell SL et al. N Engl J Med 2009;361:1529-1538.

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Dying with Dementia

- DEOLD (Dutch End of Life with Dementia) study
- Symptoms during last week of life of 330 Dutch NH residents:
  - Pain 52%
  - Agitation 35%
  - Shortness of Breath 35%
- Most common causes of death:
  - dehydration/cachexia 38%
  - cardiovascular disorders 19%
  - respiratory infection 18% (82% pneumonia)

http://dx.doi.org/10.1016/j.jpainsymman.2013.05.015

Challenges

- Communication of symptoms
- Proxy understanding of patient's prognosis
- Risk of undertreatment
- Risks of polypharmacy
- Risks of anticholinergic burden
- Applicability of guidelines

Assessment of Symptoms

Pain Assessment in Advanced Dementia Scale (PAINAD)

Instructions: Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

Behavior	0	1	2	Score
Breathing Independent of vocalization	• Normal	• Occasional labored breathing • Short period of hyperventilation	• Noisy labored breathing • Long period of hyperventilation • Cheyne-Stokes respirations	
Negative vocalization	• None	• Occasional moan or groan • Low-level speech with a negative or disapproving quality	• Repeated troubled calling out • Loud moaning or groaning • Crying	
Facial expression	• Smiling or inexpressive	• Sad • Frightened • Frown	• Facial grimacing	
Body language	• Relaxed	• Tense • Distressed pacing • Fidgeting	• Rigid • Fists clenched • Knees pulled up • Pulling or pushing away • Striking out	
Consolability	• No need to console	• Distracted or reassured by voice or touch	• Unable to console, distract, or reassure	
			TOTAL SCORE	

(Warden et al., 2003)

Scoring:

The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

Source:

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc*. 2003;4(1):9-15.

Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)

Indicate with a checkmark, which of the items on the PACSLAC occurred during the period of interest. Scoring the sub-scales is derived by counting the checkmarks in each column. To generate a total pain sum all sub-scale totals.

Facial Expression	Present
Grimacing	
Sad look	
Tighter Face	
Dirty Look	
Change in Eyes (Squinting, dull, bright, increased eye movements)	
Frowning	
Pain Expression	
Grim Face	
Clenching Teeth	
Wincing	
Open Mouth	
Creasing Forehead	
Screwing Up Nose	

Activity/Body Movement	Present
Fidgeting	
Pulling Away	
Flinching	
Restless	
Pacing	
Wandering	
Trying to Leave	
Refusing to Move	
Thrashing	
Decreased Activity	
Refusing Medications	
Moving Slow	
Impulsive Behaviours (Repeat Movements)	
Uncooperative/Resistance to care	
Guarding Sore Area	
Touching/Holding Sore Area	
Limping	
Clenching Fist	
Going into Fetal Position	
Stiff/Rigid	

Social/Personality/Mood	Present
Physical Aggression (e.g. pushing people and/or objects, scratching others, hitting others, striking, kicking).	
Verbal Aggression	
Not Wanting to be Touched	
Not Allowing People Near	
Angry/Mad	
Throwing Things	
Increased Confusion	
Anxious	
Upset	
Agitated	
Cranky/Irritable	
Frustrated	

Other (Physiological changes/Eating Sleeping Changes/Vocal Behaviors)	Present
Pale Face	
Flushed, Red Face	
Teary Eyed	
Sweating	
Shaking/Trembling	
Cold Clammy	
Changes in Sleep Routine (Please circle 1 or 2) 1) Decreased Sleep --- 2) Increased Sleep During the Day	
Changes in Appetite (Please circle 1 or 2) 1) Decreased Appetite --- 2) Increased Appetite	
Screaming/Yelling	
Calling Out (i.e. for help)	
Crying	
A Specific Sound of Vocalization For pain “ow,” “ouch”	
Moaning and groaning	
Mumbling	
Grunting	
Total Checklist Score	

Confusion Assessment Method

1. Acute onset and fluctuating course
2. Inattention
3. Disorganized thinking
4. Altered consciousness

For delirium: 1 **and** 2 plus 3 **or** 4

Principles of Geriatric Pharmacotherapy

Clinical Practice Guidelines

- *DISEASE-SPECIFIC not PATIENT-CENTERED*
- Conflicting or additive recommendations
- 79 yo woman with OP, OA, COPD, HTN and T2DM, all of moderate severity:
  - 12 medications
  - 19 daily doses
  - 5 times a day
  - As well as prn

Sergi, Drugs Aging 2011

American Geriatrics Society Updated Beers Criteria for Potentially Inappropriate Medication Use in Older Adults

- JAGS 2012
- The Context:
- 27% of ADEs in primary care and 42% in LTC are preventable.
- ADEs cost millions annually
  - Wasteful use of resources
  - Hospitalizations

Updated Beers Criteria for Potentially Inappropriate Medication Use in Older Adults

- 34 potentially inappropriate medications and classes to avoid in older adults.
  - New additions include megestrol, glyburide, and sliding-scale insulin.
- 14 potentially inappropriate medications and classes to avoid in older adults with certain diseases and syndromes that the drugs listed can exacerbate.
  - New inclusions are thiazolidinediones or glitazones with CHF, CI's with history of syncope, and SSRIs with falls and fractures

STOPP and START criteria

- (Gallagher et.al. 2008)
- STOPP: Screening Tool of Older People's potentially inappropriate Prescriptions (65 criteria)
- START: Screening Tool to Alert doctors to Right, i.e. appropriate, indicated but often omitted Treatments (22 indications)
- In Irish primary care population, identified more potentially inappropriate medication issues than Beers' list

STOPP and START criteria

- STOPP and START criteria in an RCT of hospitalized patients (Gallagher et.al. 2011)
- The intervention reduced:
  - (i) the use of unnecessary drugs (absence of indication, lack of effectiveness, or therapeutic duplication);
  - (ii) the risk of drug–drug and drug–disease interactions;
  - (iii) the prescription of drugs at incorrect doses, frequency, and duration, and
  - (iv) underprescribing for common conditions such as cardiovascular system disorders, diabetes, and osteoporosis.

Tool for identifying and discontinuing potentially inappropriate drugs.

Scott I A et al. Evid Based Med 2013;18:121-124

Scott I A et al. Evid Based Med 2013;18:121-124

EBM

1. Accurately ascertain all current drug use

- 'brown paper bag' medication reconciliation

2. Identify patients at risk of, or suffering, ADR

- at risk: ≥8 medications
  advanced age (>75 years)
  high-risk medications
- assess for current, past or highly likely future toxicity

→ All three at-risk criteria – aim for ≤ 5 drugs
Discontinue drugs for which there is unequivoval evidence of past, current or future toxicity
(eg triple whammy of NSAID, diuretic, ACE inhibitor)

3. Estimate life expectancy

- clinical prognostication tools or lifespan calculators

4. Define overall care goals

- consider current functional status and quality of life with reference to estimated life expectancy

→ If life expectancy less than 2 years, preservation of function and quality of life predominate over prolonging life and avoiding future complications as goals of care

5. Verify current indications for ongoing treatments

- perform diagnosis-medication reconciliation
- confirm diagnostic labels against formal diagnostic criteria
- ascertain, for each confirmed diagnosis, drug appropriateness

→ Discontinue drugs for which the diagnosis is wrong or totally unsubstantiated or where, for a confirmed diagnosis, the drug is ineffective

6. Determine need for disease-specific preventive medications

- estimate clinical impact and time to future treatment benefit
- compare this estimate with expected lifespan

→ Discontinue preventive drugs whose time until benefit exceeds expected lifespan

7. Determine absolute benefit-harm thresholds of medications

- reconcile estimates of absolute benefit and harm using prediction tools (see http://www.mdcalc.com)

→ Discontinue drugs whose absolute level of harm exceeds absolute level of benefit; in 'line-ball' cases elicit patient preferences

8. Review the relative utility of individual drugs

- rank drugs according to the relative utility from high to low based on predicted benefit, harm, administration and monitoring burden

→ Discontinue drugs of low utility

9. Identify drugs to be discontinued and seek patient consent

- reconcile drugs for discontinuation with patient preferences

→ Discontinue drugs patients are not in favour of taking

10. Devise and implement drug discontinuation plan with close monitoring

Scott I A et al. Evid Based Med 2013;18:121-124

PAIN

Dying with Dementia

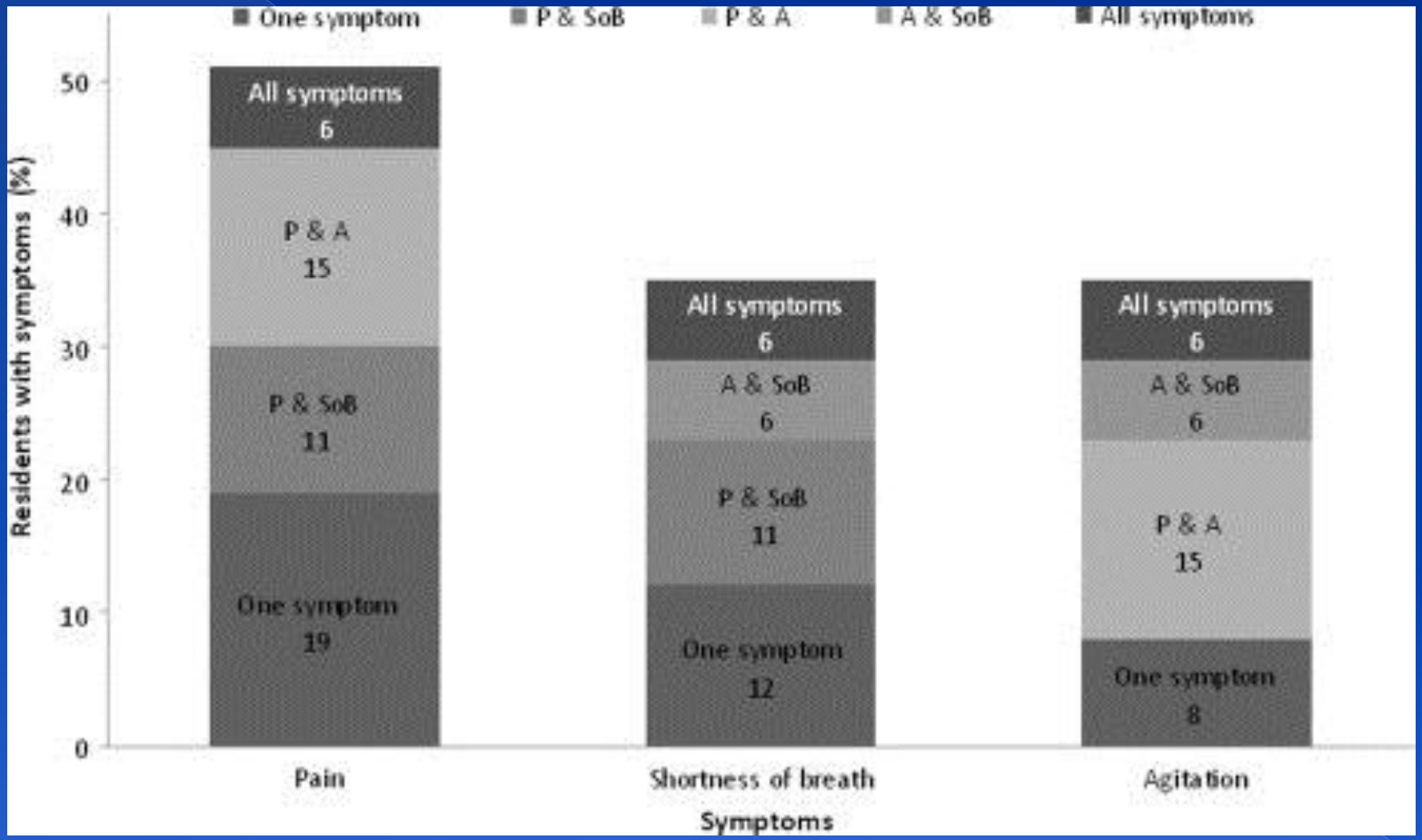

Fig. 1 Nursing home residents with symptoms of P, SoB, and A in the last week of life. P = pain; SoB = shortness of breath; A = agitation.

http://dx.doi.org/10.1016/j.jpainsymman.2013.05.015

Symptom	Treatment	%
Pain	Opioid	73
	Acetaminophen	87
	Nonphramacological (in combination)	99
Shortness of Breath	Opioids	71
	Oxygen	43
	Bronchodilators	20
	Diuretic	15
	Scopolamine	13
Agitation	Non-pharmacologic	62
	Anxiolytic/Hypnotic	57
	Antipsychotic	50
	Limb Restraints	5
	No therapy	3

http://dx.doi.org/10.1016/j.jpainsymman.2013.05.015

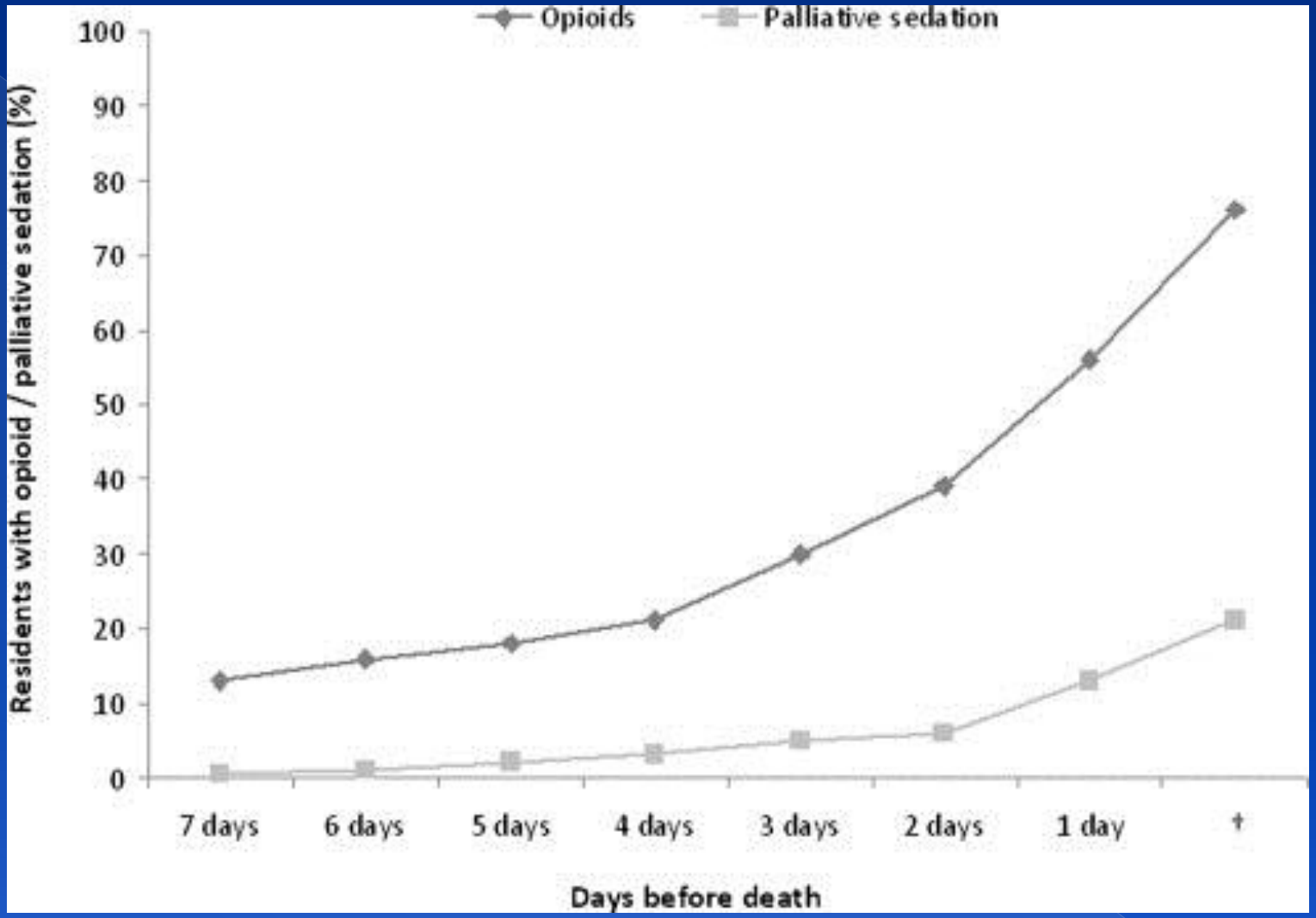

Fig. 2 Proportions of residents receiving opioids and palliative sedation over the days before death.

http://dx.doi.org/10.1016/j.jpainsymman.2013.05.015

Recommendations from American Geriatrics Society (2002)

- Use the least invasive route for medication;
- Where possible, choose sustained release formulations;
- Introduce 1 agent at a time, at a low dose, followed by slow dose-titration;
- Allow a sufficiently large interval between introducing drugs to allow assessment of the effect;
- Treatment should be constantly monitored and adjusted if required to improve efficacy and limit adverse events;
- It may be necessary to switch opioids

Opioids

- Opioid Suggested Starting Dose
  - Morphine 2.5–5 mg PO or SL
  - Oxycodone 2.5–5 mg PO or SL
  - Hydromorphone 0.5–1 mg PO or SC

Effect of Reduced Hepatic Function On Pharmacokinetics of Opioids

Opioid	$T_{1/2}$	Plasma Concentration of Metabolites	Recommendations	Evidence Level
Morphine	↑	↓	Dosage ↓	IIb
Oxycodone	↑	↑	Dosage ↓	IIb
Hydromorphone	?	?	Dosage ↓	IV
Fentanyl TD	↑	?	Dosage ↓	III
Buprenorphine TD	↑	↓	Dosage ↓	IIb
Methadone	↑	?	No dosage change	IIb

Opioids and the Management of Chronic Severe Pain in the Elderly: Consensus Statement of an International Expert Panel with Focus on the Six Clinically Most Often Used World Health Organization step III Opioids, Pain Practice 2008, Pergolizziet.al.

Effect of Reduced Renal Function On Pharmacokinetics of Opioids

Opioid	$T_{1/2}$	$T_{1/2}$ Metabolites	Recommendations	Evidence Level
Morphine	↑	↑↑	Dosage ↓	IIa
Oxycodone	↑	↑↑	Dosage ↓	IIb
Hydromorphone	↑	↑↑	Dosage ↓	IIb
Fentanyl TD	↑	↑	Dosage ↓	IIb
Buprenorphine TD	=	=	Adjust±	IIa
Methadone	↑	↑	Dosage ↓	IV

Opioids and the Management of Chronic Severe Pain in the Elderly: Consensus Statement of an International Expert Panel with Focus on the Six Clinically Most Often Used World Health Organization step III Opioids, Pain Practice 2008, Pergolizziet.al.

MALNUTRITION

Artficial feeding

- Up to 30% of PEG feeding tubes placed in patients with dementia (1996)
- Prolonged tube feeding does not prevent ongoing weight loss, micronutrient deficiencies and muscle loss

Li I.. Am Fam Phys. 2002

Artficial feeding

- No improvement in pressure sores
- No decrease in aspiration risk
- No change in comfort scores
- No improved functional status
- No prolonged survival

Li l.. Am Fam Phys. 2002

Risks of feeding tube

CATEGORY	COMPLICATIONS
Local	Local pain
	Suture breakage
	Cellulitis of the abdominal wall
	Abscess of the abdominal wall
	Stomal inflammation
	Skin excoriation
	Bleeding from the site
	Closure or stenosis of stoma
	Hematoma
Mechanical	Erosion of bumper into abdominal wall
	Tube leakage
	Tube blockage
	Tube migration or loose fixation plate
	Tube malfunction
	Fractured tube
	Kinked tube

Li I.. Am Fam Phys. 2002

CATEGORY	COMPLICATIONS
Pleuropulmonary	Erosion of tube into pleural cavity
	Aspiration pneumonia
Gastrointestinal	Flatulence
	Nausea
	Vomiting
	Diarrhea
	Ileus
	Gastroesophageal reflux
	Bowel obstruction (requiring laparotomy)
	Intra-abdominal leak
	Intra-abdominal peritonitis
	Intra-abdominal bleeding
	Gastric mucosal erosion
	Gastric perforation
	Upper gastrointestinal bleed
	Necrotizing fasciitis
Other	Anorexia
	Fluid overload
	Increased skin moisture
	Agitation, self-extubation
	Use of restraints
	Metabolic disturbances
	Loss of social aspects of feeding
	Altered cosmesis
	Fever
	Sepsis

Li I.. Am Fam Phys. 2002

Preventing aspiration pneumonia for those patients at risk

- Sit the patient upright (45 degrees) while eating
- Bolus size of less than one teaspoon
- Restrict clear liquids
- Place food well into the mouth
- Encourage gentle coughs after each swallow
- Remind to swallow multiple times after each mouthful of food to clear the pharynx

Li l.. Am Fam Phys. 2002

Strategies to improve food intake

Basic tenet: Alter flavors, amounts, consistency, and availability of food.

Use strong flavors	Hot or cold (not tepid) Gravy, Juices, Enrichers (cream, spices), Sweets
Use varying amounts of food	Try finger foods Use preferred foods in large quantities
Adapt food consistency to suit the individual	Try liquid supplements (Give 1.5-2 hrs before the next meal; should never with meal as can promote satiety) Try slightly thickened food (e.g., puddings, milkshakes) Try blending foods
Make food available to the patient	Lengthen mealtimes Allow patients to keep their supplements at the bedside
Modify environmental factors	Capitalize on the midday meal If resistive or combative at mealtime, try holding hands or reassuring touches on the arms, or try cheerful conversations or singing softly

Li l.. Am Fam Phys. 2002

DELIRIUM

Principles of delirium care

- Prevention – Hospital Elder Life Program (HELP)
- Treat underlying cause
- Hypoactive
- Hyperactive: small doses of neuroleptics
  - Haldol 0.5-1 mg q6h
  - Quetiapine 12.5-25 mg BID and prn
  - Risperidone 0.25-0.5mg BID and prn
  - …or BDZ

Conclusions

- Dementia is a terminal illness with an end stage
- Pain and symptom management is important in end stage of dementia
- Important to be patient centered rather than disease specific in making treatment decisions
- Advance care planning

Resources

- Mitchell S, et.al. The Clinical Course of Advanced Dementia N Engl J Med 2009; 361:1529
- Hendriks S, et.al. Dying With Dementia: Symptoms, Treatment, and Quality of Life in the Last Week of Life J Pain Sym Man 2013
- Casey DA, et.al. Dementia and Palliative Care. Annals of Long-Term Care: Clinical Care and Aging. 2012;20(1):21-26
- Li I. Feeding tubes in patients with severe dementia. Am Fam Phys. 2002;65(8): 1605-1610, 1515.