Dementia: Late Stage

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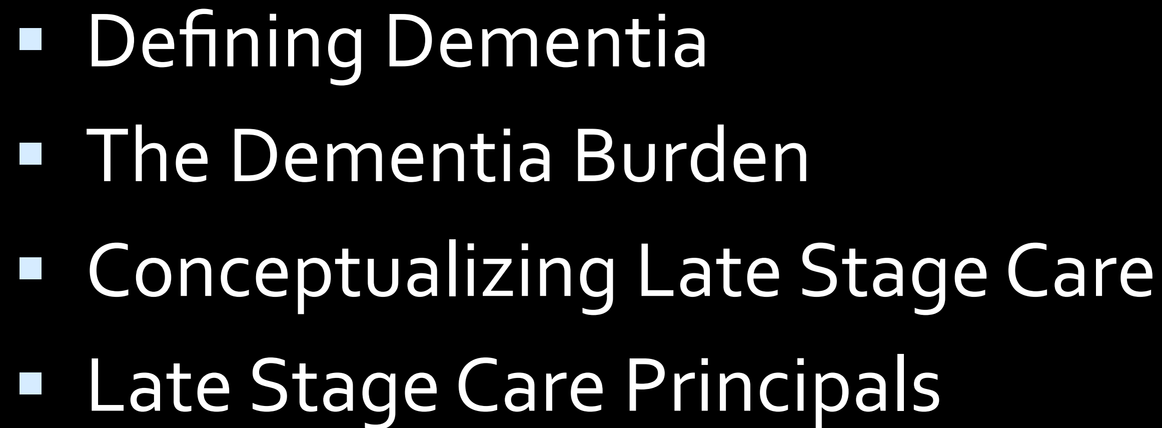
Outline


Defining Dementia
The Dementia Burden
Conceptualizing Late Stage Care
Late Stage Care Principals

Defining Dementia

Defining Dementia

- Acquired neurological condition
- Progressive brain failure
- Most common cause is Alzheimer's dementia (about 65%)
- Only 1% or less is reversible

Defining Dementia

- Cognitive deterioration interferes with day to day function
- Typically starts with memory impairment and impairment in other brain function

Dementia

- Aphasia (impaired language abilities)
- Apraxia (impaired ability to complete motor tasks despite intact motor system)
- Agnosia (impaired ability to recognize or identify objects, despite intact sensory abilities)
- Executive dysfunction: judgment, planning, organizing or carrying out tasks in proper sequence

Other Diagnoses

- Delirium
- Depression
- Drugs

- Aphasia
- Hearing

History

- Onset
  - gradual
- Memory
  - repetitive questions, head-turning sign
- Language
  - Word-finding
- Personality change
  - Social skills preserved early (that's why Dx may be missed), maybe irritability, apathy

Some Dementias

- Alzheimer Dementia (AD)
- Lewy Body Dementia (LBD)
- Vascular Dementia (VaD)
- Frontotemporal Dementia (FTD)
- Mixed (features of AD & VaD)
- Primary Progressive Aphasia (PPA)
- Cog impairment assoc w Parkinsons Disease

Alzheimer’ s Dementia

- Neurodegenerative
- Abnormal protein (amyloid) accumulates in brain cells
- Plaques and tangles are formed
- Important neurochemical-acetylcholineo-supply diminishes
- Brain cells die

Table 2.

Table 2: Types of dementia seen in patients referred to dementia clinics in Canada

Type of dementia	% of patients
Alzheimer disease	47.2
Mixed Alzheimer disease	27.5
Mixed others	6.3
Vascular dementia	8.7
Frontotemporal dementia	5.4
Dementia associated with Parkinson disease or with Lewy bodies	2.5
Unclassifiable	1.8
Other	0.7

Source: Feldman et al.[34]

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

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CMAJ·JAMC

Function: IADLs

- Cooking
- Shopping
- Medications
- Driving
- Finances

Phone
TV remote
Cards
Hobbies
Volunteer Work

Function: ADL's

- Repetitive Dressing
- Impaired basic ADLs

  Walk, toilet, dress, bathe, groom, eat

FUNCTIONAL ASSESSMENT STAGING (FAST)- Axis 5

IADLS
Repetitive dressing
ADLS: a) Difficulty dressing
b) Bathing
c) Toileting
d) Incontinence
No speech, no ambulation

Mild
Moderate
Severe

Very severe

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

Function

IRAN

Mild	I	IADLs
Moderate	R	Repetitive dressing
Severe	A	ADLs
Very Severe	N	Non-ambulatory
		Non-verbal

RECENT MEMORY (BCRS)

Mnemonic = CURE

4	**C**	Current events	**mild**
		Television shows	
		Evening meal	
		Recent events	
5	**U**	US Pres/PM	**mod.**
6	**R**	Relatives	**severe**
7	**E**	Everything	**very severe**

Dementia as Diagnosis

- Dementia is not just a “memory problem” but rather progressive brain failure
- As the disease progresses, more and more fundamental brain functions will be compromised: language, walking, swallowing, speech

Dementia as Diagnosis

- Dementia is a terminal condition with individuals often succumbing to sequelae of the disease

- Grief reaction from the diagnosis and progression is felt throughout the slope of decline

The Dementia Burden

The Dementia Burden

- The aging of the Canadian population is occurring in a steadfast manner
- By 2030, one in five adults will be over 65
- Current Canadian dementia prevalence
  - 8% at age 65 and 30% by age 80

The Dementia Burden

- Prevalence rates will triple by 2031, to epidemic levels

Rising Tide Study

- Health Burden of Dementia for Canada: 2008-2038
- Incidence of Alzheimer's disease and related dementias in Canada:
- 2008 - 103,700 new cases per year (1 every 5 minutes)
- 2038 - 257,800 new cases per year (1 every 2 minutes)

Rising Tide Study

- Prevalence of Alzheimer's disease and related dementias in Canada:2008
- 480,600 people with dementia (1.5% of Canada's population)
- 2038 - 1,125,200 people with dementia (2.8% of Canada's population)

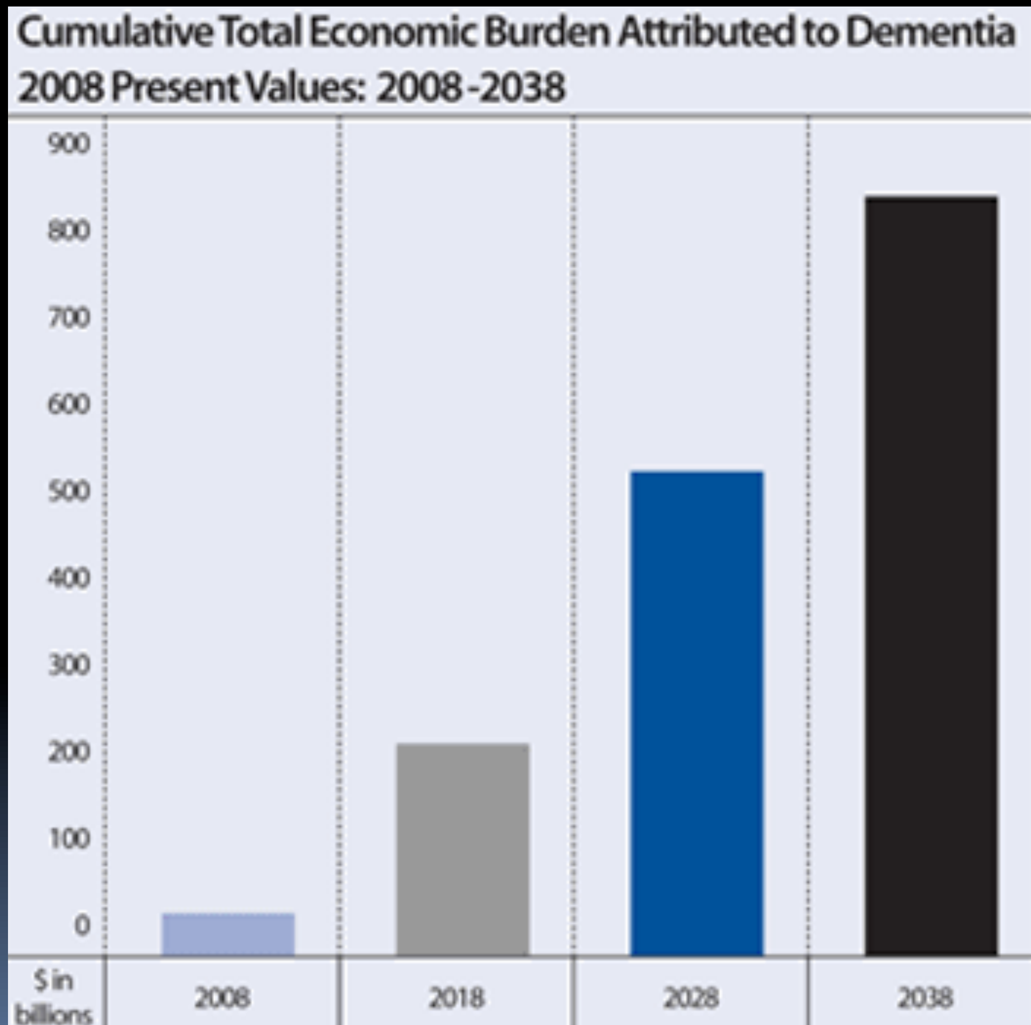
Economic Burden of Dementia (future dollars)

2008 - $15 billion

2018 - $37 billion

2028 - $75 billion

2038 - $153 billion

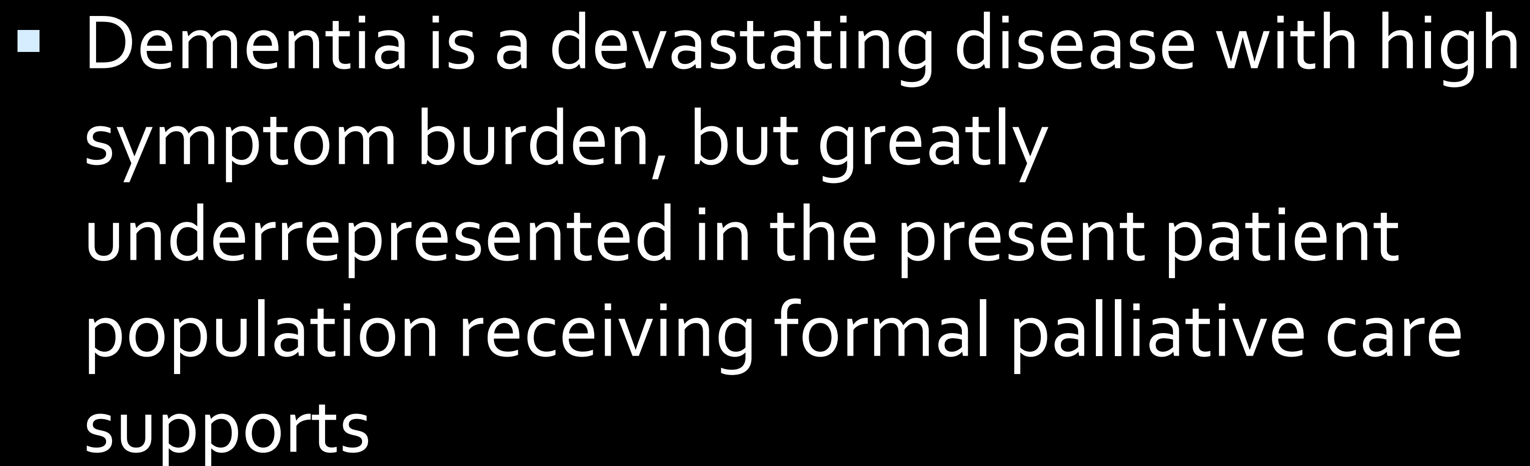


Rising Tide: The Impact of Dementia in Canada 2008 to 2038. RiskAnalytica, 2009.)

The Dementia Burden

- Cost of dementia in Canada annually is 3.9 billion: $ 14,000 per patient per year
- Dementia is a devastating disease with high symptom burden, but greatly underrepresented in the present patient population receiving formal palliative care supports

The Dementia Burden



- Dementia is a devastating disease with high symptom burden, but greatly underrepresented in the present patient population receiving formal palliative care supports

The Dementia Burden

- In the US, Medicare beneficiaries must have an estimated life expectancy of less than 6 months to be eligible for hospice services
- Palliative care as a construct was developed primarily to care for patients with noncurable cancer entering its terminal stages

The Dementia Burden

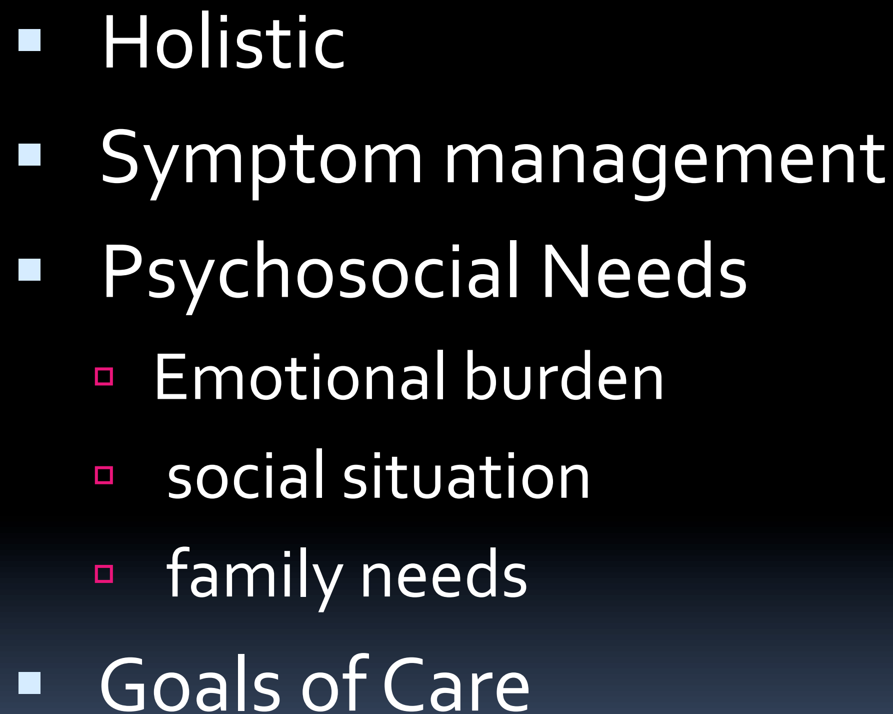
- Approx. 1.8 million people in the US have end stage dementia- by description at "FAST 7C"- fully dependant and immobile
- Dementia pts have accounted for ~1.5% of US Medicare hospice patients

The Dementia Burden

- Survey of 600 family members of patients with Alzheimer's Dementia: 71% would choose hospice approach for their loved one with end stage dementia

Conceptualizing Late Stage Care

Conceptualizing Late Stage Care



- Holistic
- Symptom management
- Psychosocial Needs
  - Emotional burden
  - social situation
  - family needs
- Goals of Care

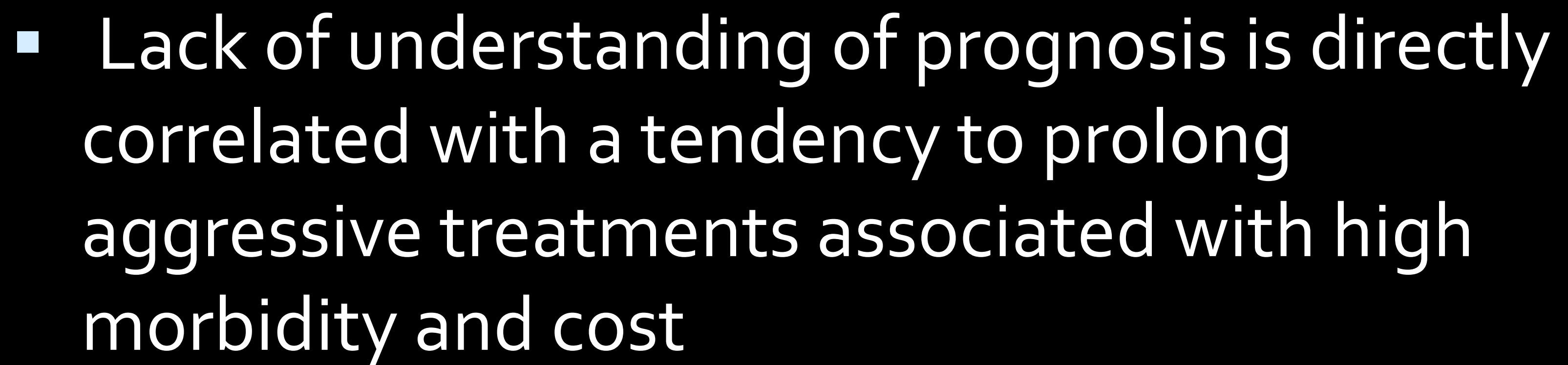
Conceptualizing Late Stage Care

- Individuals with life-limiting progressive diseases
- Classic model is cancer
- Chronic diseases need holistic care

Recognizing Dying

- Mitchell et al compared 1609 pts with advanced dementia cared in NH with pts with terminal cancer
- Non- palliative interventions were much higher in adv. Dementia group
- Only 1.1% of NH pts with adv. Dementia were perceived as having a life expectancy of 6 months or less while 71% died in that time

Recognizing Dying


Lack of understanding of prognosis is directly correlated with a tendency to prolong aggressive treatments associated with high morbidity and cost

The Frailty Burden

- With population aging, more and more individuals will suffer from chronic, life-threatening illnesses, amplifying the need to focus on care of frail elderly patients in a palliative framework

Palliative Care for Frail Elderly Individuals

1. Greater potential for complexity
   - co-presentation of geriatric syndromes (eg. incontinence, falls, polypharmacy)
   - impact on QOL and can make medication adjustments difficult
   - age-related changes alter pharmacokinetics of drugs and liver/renal dysfunction common

Palliative Care for Frail Elderly Individuals

2. "Atypical" Presentations

- acute illness symptoms can lack classic signs and symptoms (eg. Chest pain and dyspnea for ACS)
- Falls and worsened cognitive or functional impairment may be the only clue to an acute problem

Palliative Care for Frail Elderly Individuals

3. High risk of social isolation and economic difficulty

   Psychosocial needs often great and shared with partner/caregiver

4. Multiple medical conditions

   Prognostication and resource allocation is more difficult and underutilization of supports is more likely

Frailty and Death

- Age itself is not a predictor of outcomes
- Frailty is a very good predictor of outcomes
  - Functional decline and cognitive impairment are known predictors of mortality
  - Unintended weight loss is a negative prognostic factor
  - Frailty burden correlates directly with prolonged hospitalization, institutionalization and death

Frailty and Death

- Common dilemma: knowing a pt is dying but not sure what of…
- Often leads to the need to intervene with more investigations and treatment to find out the "why" and correct the problems
- This can interfere with the need to attend to patient's symptoms acutely and the families' distress….. And increases burden on pt

Frailty and Death

- We need to get over the need to find and correct all the variables of what is going wrong
- It is enough that someone has reached the limit of frailty to know it is the right time to talk about symptom management and quality of life
- This can be difficult to realize but is often a huge relief to pt and family who already know

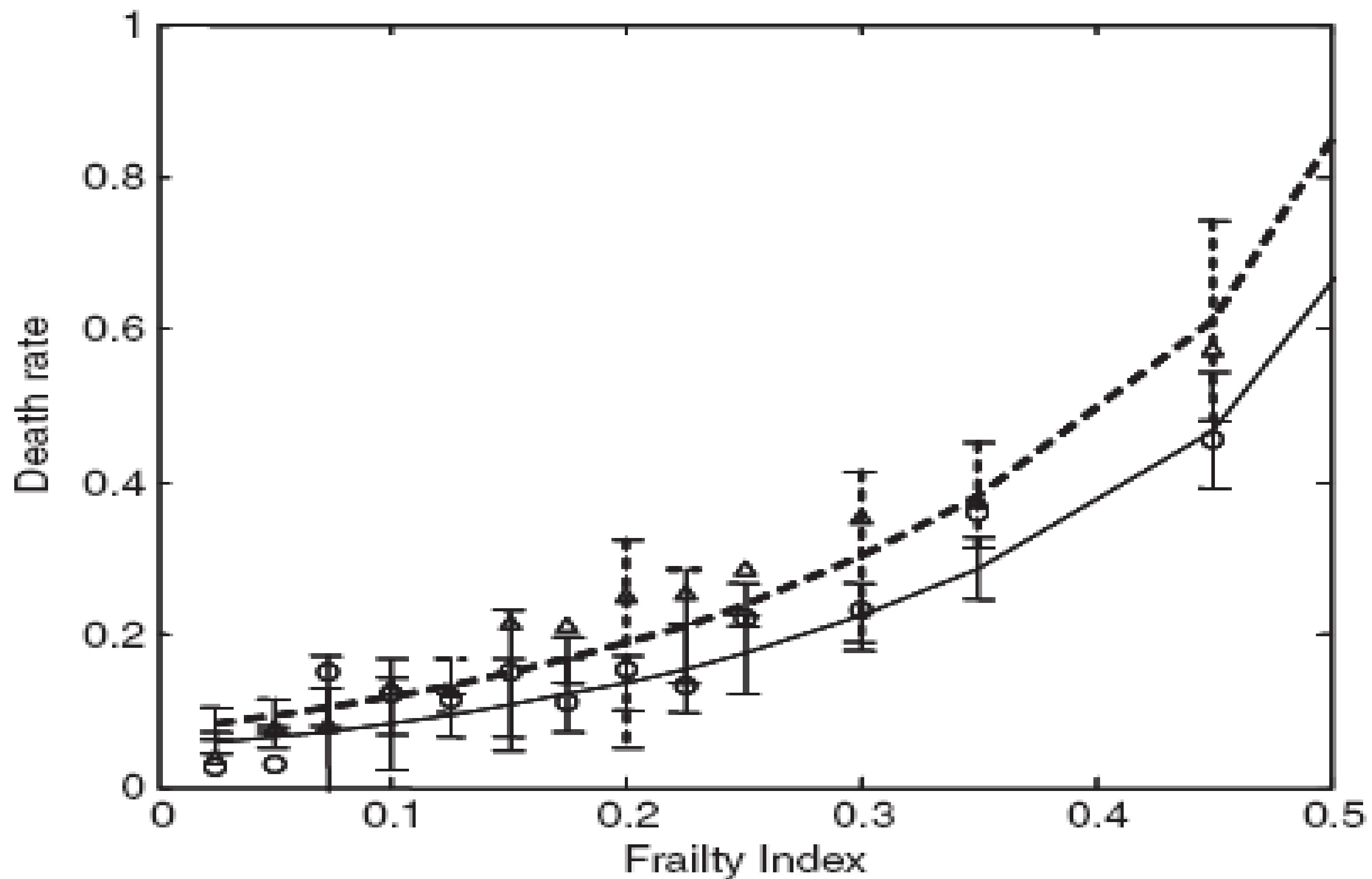


Figure 3. Sex differences in the relationship between the frailty index and mortality. Near-term death rates (3 years) by the frailty index. Circles (women, solid) and triangles (men, dashed)

Challenges with Dementia

1. Dementia is a heterogeneous disease in itself: it is **progressive and ultimately terminal** but the decline can vary
2. Acute illnesses punctuate the downhill slope but may not be recognized as part of disease progression and further decline

Challenges with Dementia

3. Multiple co-morbidities often co-exist which increase the physical and psychological symptom burden
4. Failure to recognize dementia as a terminal illness reduces the opportunities to discuss treatment decisions and define goals of care

Challenges with Dementia

5. With acute illness episodes, families often struggle with declining "standard" treatments and physicians struggle not prescribe antibiotics for "curative" intent
6. Advancing disease brings loss of direct patient centered care… we rely on loved ones or further collateral to make essential treatment decisions and goals

Challenges with Dementia

7. Behaviour and mood symptoms of advanced dementia can cause significant symptom burden for both patient and loved ones
8. Symptom management is hindered by increasing communication barriers/ assessment barriers when verbal skills decline

Challenges with Dementia

9. Caregiver issues are significant
   - bereavement can begin with diagnosis
   - often they too are increasingly frail
   - burnout associated with placement

Late Stage Care Principals

Dementia Related Conditions

Delusions/Hallucinations

- Behavioural: aggression, withdrawal, disinhibation, wandering…
- Mood symptoms: GDS
- Dysphagia, aspiration pneumonia, incontience, pressure ulcers etc

Functional Assessment

- Mobility Review
  - Falls history
  - Aids used
  - Orthostasis/Parkinsonian symptoms
  - Sensory Impairment

Functional Assessment

- IADL'S and ADL's:
  - Trajectory of functional decline
  - Home functional support assessment
  - Important predictor of location of care/placement issues

Medication Rationalization

- Aligning treatments with goals
- Disease Modifying
- Symptom support
- "Beer's List" drugs to rationalize
- Cost/benefit analysis

The Medication Appropriateness Index

1. **Is there an indication for the drug?**
2. **Is the medication effective for the condition?**
3. **Is the dosage correct?**
4. **Are the directions correct?**
5. **Are the directions practical?**
6. **Are there clinically significant drug-drug interactions?**
7. **Are there clinically significant drug-disease/ condition interactions?**
8. **Is there unnecessary duplication with other drugs?**
9. **Is the duration of therapy acceptable?**
10. **Is this drug the least expensive alternative compared with others of equal usefulness?**

:**Holmes et al. 2006**

Medication Rationalization

Orthostasis: diuretics, BP meds, BZD's, Anticholinergics

GI upset: ASA, Fe, Ca, digoxin, CholeI, SSRI's

Akathisia: antipsychotics, antidepressants

- Look at the temporal association with behaviours/psychiatric Sx to see if med could have been related

Symptom Burden

Edmonton Symptom Assessment Scale

- Collateral information is key: caregiver, nursing home representative…
- Novel pain scales for advancing dementia need to be explored

Symptom Burden

Considerations:

- Abbey Pain Scale
- Behavioural Analysis (proxy)
  - Restlessness
  - Grimacing
  - Moaning
  - guarding
  - unexplained changes in activity

Symptom Burden

- Non-verbal pain indicator checklist
  - completed by interviewer directly after the patient encounter
  - used in the PEACE program
- Need to be cognisent of the fact that patients with AdvD can't express their symptoms verbally – may experience adverse drug effects impeeding symptom control

Symptom Burden

- Palliative symptom review should include pain history by records and with caregivers… can help to formulate "anticipated sources of pain" and "what worked/didn't"
- R/A meds that caused patient symptoms before or weren't necessarily helpful in achieving meaningful outcome

Symptom Burden

Anticipatory Sx monitoring:

- Ensuring basic comfort needs have been met: toileting, hunger, fear, lonliness, sensory impairment
- Empirical trials of analgesic when search does not yield source for possible pain behaviours

Psychosocial Support

Assessing current supports in place, formal and informal

- Gathering an understanding of the caregivers health state
- Dementia Education: on progression and symptom burden is crucial: for patient (if possible) and caregiver

Goals of Care Planning

- Providing patients (whenever possible, depending on decision capacity) the framework for making medical decisions in the context of their frailty burden is KEY
- This is the basis for the conceptualization of the PATH clinic….

Case Discussions

Case Reflections

- Were these outcomes unexpected?
- Might the treatment decisions and outcomes been different had there been more discussions prior about what to expect?

PATH Clinic

New Approach: PATH

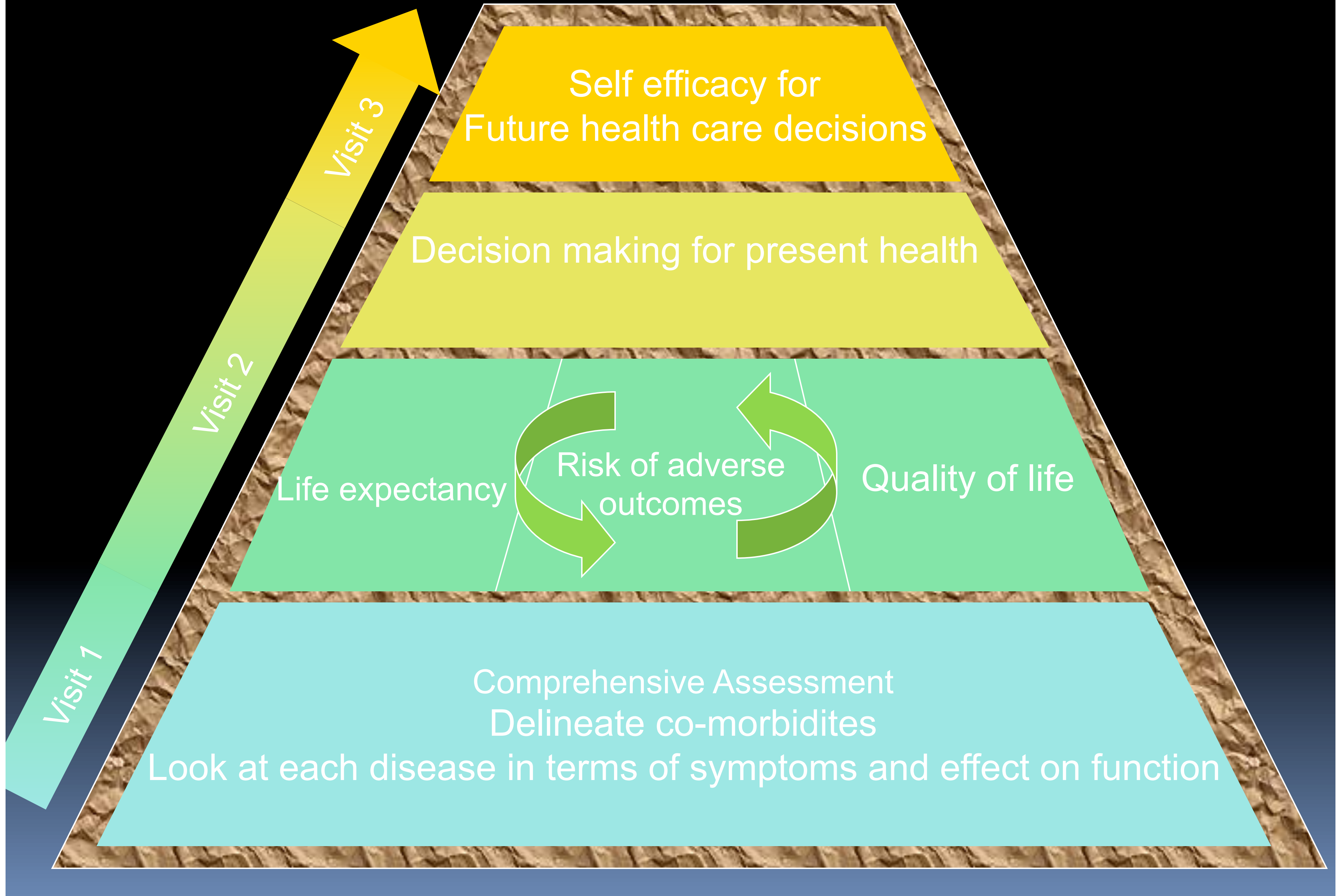
Palliative and Therapeutic Harmonization (PATH) Clinic

- For frail older adults with
  - advanced medical conditions,
  - many recent hospitalizations,
  - unmanaged symptoms
- Where the impact of interventional procedures (surgery, etc) on quality of life may be questioned

New Approach: PATH

Principles of PATH

1. People want information about their medical conditions
2. Physicians and patients do not always recognize how common health conditions affect overall health and survival
3. Patients are often unaware about the seriousness of their health conditions
4. Health care decisions are often made without full disclosure of the risks and benefits
5. Counseling can help individuals make the better decisions


Conceptual Framework for the PATH
Self efficacy for
Future health care decisions
Decision making for present health
Life expectancy
Risk of adverse
outcomes
Quality of life
Comprehensive Assessment
Delineate co-morbidites
Look at each disease in terms of symptoms and effect on function
Visit 1
Visit 2
Visit 3

In Summary

- Dementia is a devastating disease with a relentless decline
- Any little change or intervention for someone with dementia can have major ramifications esp. when delirium occurs
- Optimization of quality of life is always an appropriate and patient centered goal

In Summary

- Aligning treatment options with the stage of the dementia is essential
- People with dementia should be entitled to the same palliative services and principles as people with other terminal conditions such as non-curable cancer
- Goals of care with open, informed discussions need to be addressed early and often

THANK YOU

artwork by Edith Dunn

cannington house gallery