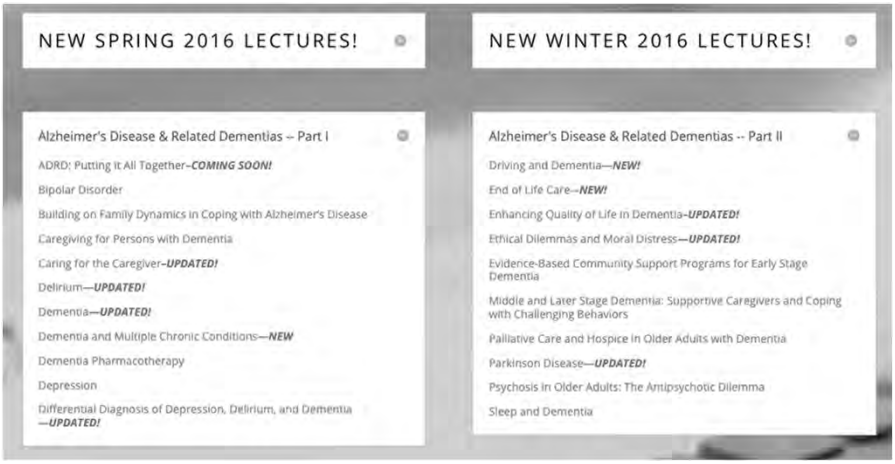
Putting It All Together: Challenges in Dementia

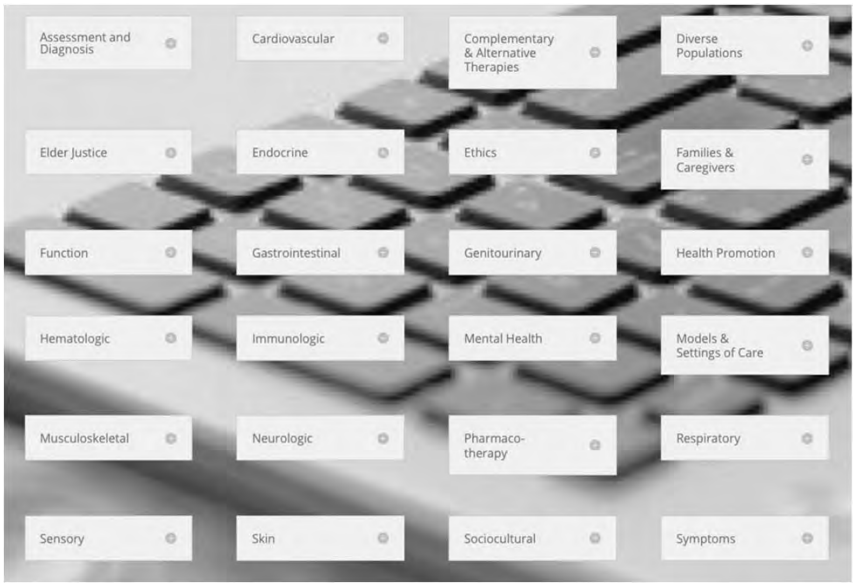
Stephen Thielke

I have no disclosures.

1. Dementia is not just a disease.
2. Dementia impacts far more than the individual.
3. Every case of dementia is different.
4. Dementia involves inherent ethical challenges.

Dementia Is Not Just Disease


NEW SPRING 2016 LECTURES!
NEW WINTER 2016 LECTURES!
Alzheimer's Disease & Related Dementias -- Part I
ADRD: Putting It All Together–COMING SOON!
Bipolar Disorder
Building on Family Dynamics in Coping with Alzheimer's Disease
Caregiving for Persons with Dementia
Caring for the Caregiver–UPDATED!
Delirium—UPDATED!
Dementia—UPDATED!
Dementia and Multiple Chronic Conditions—NEW
Dementia Pharmacotherapy
Depression
Differential Diagnosis of Depression, Delirium, and Dementia —UPDATED!
Alzheimer's Disease & Related Dementias -- Part II
Driving and Dementia—NEW!
End of Life Care—NEW!
Enhancing Quality of Life in Dementia–UPDATED!
Ethical Dilemmas and Moral Distress—UPDATED!
Evidence-Based Community Support Programs for Early Stage Dementia
Middle and Later Stage Dementia: Supportive Caregivers and Coping with Challenging Behaviors
Palliative Care and Hospice in Older Adults with Dementia
Parkinson Disease—UPDATED!
Psychosis in Older Adults: The Antipsychotic Dilemma
Sleep and Dementia


Assessment and Diagnosis
Cardiovascular
Complementary & Alternative Therapies
Diverse Populations
Elder Justice
Endocrine
Ethics
Families & Caregivers
Function
Gastrointestinal
Genitourinary
Health Promotion
Hematologic
Immunologic
Mental Health
Models & Settings of Care
Musculoskeletal
Neurologic
Pharmaco-therapy
Respiratory
Sensory
Skin
Sociocultural
Symptoms

A - B

- Alcohol Problems
- Anemia
- Arthritis
- Asian American Health
- Atrial Fibrillation & Anticoagulation
- Benign Prostatic Hyperplasia
- Bipolar Disorder

C - D

- Caregiving for Persons with Dementia
- Caring for the Caregiver
- Complementary & Alternative Medicine
- Complementary & Alternative Modalities
- Chronic Obstructive Pulmonary Disease (COPD)
- Coronary Artery Disease
- Delirium
- Dementia
- Dementia & Multiple Chronic Conditions
- Dementia Pharmacotherapy
- Depression
- Diabetes Mellitus Type 1
- Diabetes Mellitus, Type 2
- Driving & Dementia

E - F

- Early-Stage Dementia
- Elder Investment Fraud
- Elder Mistreatment
- End-of-Life Care
- Ethical Dilemmas with Cognitive Impairment
- Fall Prevention: A Nursing Perspective
- Fall Prevention: A Primary Care Perspective
- Family Dynamics & Alzheimer's Disease
- Frontline Tools for the Differential Diagnosis of Depression, Delirium, and Dementia
- Functional Assessment

G - H

- Gastrointestinal Health
- Grief & Loss
- Hearing Loss
- Heart Failure
- HIV
- Hoarding Disorder
- Older Adults who are Homeless & Low-Income
- Hospitalization Risks
- Hypertension

I - L

- Intellectual/Developmental Disabilities
- LGBT Health

M - O

- Medication Adherence
- Medications and Falls
- Medication Use
- Middle & Later Stage Dementia
- Nutrition
- Oral Health Care
- Osteoporosis

P - R

Pain Management

Palliative Care in Dementia

Parkinson's Disease

Physical Activity

Pneumonia

POLST: Practical Aspects

Pressure Ulcers

Preventive Services

Psychosis

Quality of Life & Behavior Changes in Dementia

Rheumatology Update

S - T

Sexuality

Shingles

Skin Lesions

Sleep Disorders

Sleep & Dementia

Stroke

Substance Abuse & Addiction

Suicide

Thyroid Disorders in Older Adults

U - Z

Urinary Incontinence

Urinary Tract Infections

Vision Loss

Vitamins & Supplements

Women's Health

A - B

Alcohol Problems … in dementia

Anemia … in dementia

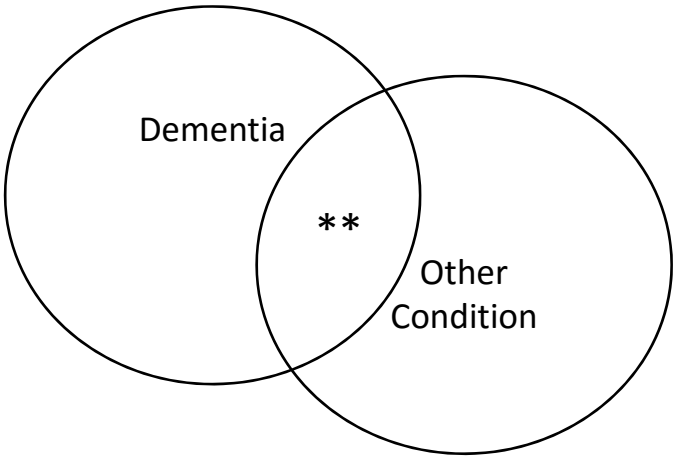
Arthritis … in dementia

Asian American Health … in dementia

Atrial Fibrillation & Anticoagulation … in dementia

Benign Prostatic Hyperplasia … in dementia

Bipolar Disorder … in dementia



Chronic Conditions & Geriatric Syndromes

Chronic Conditions (CC)

- Asthma
- Arthritis
- Bone Diseases (e.g., Osteoporosis)
- Cancer
- Cardiovascular Diseases (e.g., CAD, Hypertension, Hyperlipidemias)
- Cerebrovascular Diseases (e.g., Stroke)
- Chronic kidney disease
- Chronic pain
- Dental problems
- Depression and other chronic mental illness (PTSD, schizophrenia, bipolar)
- Diabetes
- Emphysema/COPD
- Neurological conditions (Parkinson's, epilepsy, multiple sclerosis)
- Sleep disorders
- Substance abuse
- Risk factors IF CC is present (e.g., obesity, smoking, gait)

Geriatric Syndromes

- Falls, fractures & other injuries
- Frailty
- Functional impairments
- Polypharmacy / High-risk medications
- Urinary incontinence

What difference does it make if depression occurs more frequently in patients with dementia?

Guide to Preventive Services– The Community Guide
What works to Promote Health

Mental Health & Mental Illness

Task Force Recommendations & Findings
This table lists interventions reviewed by the Community Guide, with Task Force findings for each. Click on an underlined intervention title for a summary of the review.

Interventions to Reduce Depression Among Older Adults	
Home-Based Depression Care Management	Recommended
Clinic-Based Depression Care Management	Recommended
Community-Based Exercise Interventions	Insufficient Evidence

Quality of Life for Individuals with Dementia

- Sense of well-being
  - Absence of clinical depression and excessive anxiety
  - Freedom from physical pain
  - Safety and security
- Satisfaction with life
  - Preferred living arrangements
  - Engagement in meaningful and pleasant activities
  - Participation in family and social activities
- Self-esteem
  - Recognition of contributions
  - Respect from others

Non-motor features of early PD

- May precede cardinal motor features by several years
- Rapid Eye Movement (REM) Sleep Behavior disorder
- Hyposmia (reduced sense of smell)
- Depression, anxiety, and mild cognitive problems
- Dysautonomia:
  - constipation
  - reduced heart rate variability
  - sexual dysfunction
  - bladder urgency

Park A and Stacy M. J Neurol. 2009;256 (Suppl 3):293-8

Dementia Impacts…

Diagnosis
Prevention
Symptom tracking
The patient experience
The meaning of the disease or symptom
Interactions with health care
Adherence to treatments
Goals of care
Risks and benefits of specific treatments

Dementia Impacts Far More Than the Patient

Burdens of Dementia Caregiving

* Demands, negative impacts generally higher than in non-dementia caregiving
  * More hours/week providing care
  * 20% give care for >5 years
  * More disruptive to family life
  * More negative mental health impact on caregiver
  * Reduced time for leisure, other social/family activity
  * Greater strain assoc w/behavioral problems, unpredictable disease course
* Caregiver depression/function often improves after death of care recipient (but not after NHP)

Neurol Clin 18:993, 2000
Schulz R et al. NEJM 349:1936, 2003

* YOU are a caregiver, too!
* Be aware of your own grief (and be able to distinguish it from burnout)
* Grief can be worked on, burnout is more complicated
* We are here to help "serve" not "fix"
* Recognize that you are doing an amazing job and providing services that your patients would otherwise not have

How Providers Can Help

* Understand purpose of assessment , communicate this to caregiver
* Engage with caregivers, even when not asking for help
* Listen and reflect
* Acknowledge emotions
* **Normalize**

Clinical situations leading to distress

- Unclear goals of care
- Disregard of patient wishes
- Continued life support – futile care
- False hope given to patients/families
- Hastening death
- Inadequate symptom relief for patients
- Inadequate staffing or training
- Inappropriate use of scarce resources

Corley, *Nursing Ethics*, 2002
Hamric, *AJOB*, 2012

Caring for the Whole Patient, the Family, and the Environment

Listen

Don't make assumptions about what is easy or difficult

Screen caregivers and family members for depression

Focus on aggregate quality of life for the whole family unit

Recommend the Alzheimer's Association, County Senior Services, private social workers

Every Case of Dementia is Different

"When you've seen one case of Alzheimer's, you've seen one case of Alzheimer's."

What you might hear in clinic

- I can't focus
- She's not interested in her usual activities
- I can't come up with the word I want
- My energy is low
- My husband's "selective attention" is worse – he doesn't listen to me
- My short-term memory is shot
- I couldn't find my car in the parking lot
- You didn't tell me to increase my atenolol and stop taking HCTZ

Could it be . .
Depression?
Delirium?
Dementia?

Dementia, Delirium, and Depression

	Common Features	Hallmarks
Dementia	Subjective confusion Difficulty performing tasks	Problems with memory plus problems with speech, actions, recognition, or executive functioning Chronic and progressive, slow onset Functional decline
Delirium	"Not right" on interview	Trouble with attention and concentration Rapid onset; waxing and waning Due to a medical cause
Depression	Loved ones are worried	Decreased concentration and interest Sensorium is clear

Psychosocial Treatment Implications

- Maximize **social and ADL functioning**
- Treat **depressive symp**toms and encourage **pleasant activities**
- Improve or maintain **physical mobility**
- **Support caregivers** to reduce burden and depression

Dementia Care Involves Ethical Challenges

Early Diagnosis

"I must be truthful."

"I would want to know."

"My parents would want to know."

"A reasonable person would want to know."

"Knowing can help patients and families plan."

"Knowing doesn't really help anyone."

"People who have known have regretted it."

"Ignorance may be bliss."

"The harm from being wrong is huge."

"I wish I didn't know."

Pharmacotherapy

- Some believe that treatment should start at the onset of diagnosis, while others suggest treatment when "functional impairment" is present

Driving and Dementia

Counseling

- Validate the difficulty
  - But don't dwell on it
  - Privilege, not a right
    - Careful with this one
- Recommendations are not all or nothing
  - Identify as needing tracking and re-evaluation
  - Restrictions/limitations
  - Consultation/evaluation from other providers
  - Behavioral interventions
    - Disabling the car
    - Changing the keys

Driving Cessation and Depression

Driving Cessation and Health Outcomes in Older Adults

Stanford Chihuri, MPH,[*†] *Thelma J. Mielenz, PhD, MS,*[*‡] *Charles J. DiMaggio, PhD,*[§] *Marian E. Betz, MD, MPH,*[¶] *Carolyn DiGuiseppi, MD, PhD,*[**] *Vanya C. Jones, PhD,*[††] *and Guohua Li, MD, DrPH*[*†‡]

CONCLUSION: Driving cessation in older adults appears to contribute to a variety of health problems, particularly depression. These adverse health consequences should be considered in making the decision to cease driving. Inter-

Patients need capacity to…

- Accept or refuse medical treatment
- Return to independent living
- Leave hospital AMA
- Participate in research
- Complete an advance directive
- Request meds to end their lives
  - Death with Dignity – WA, OR

More about decision-making capacity

- Dementia or other psychiatric diagnoses don't automatically mean someone is incapacitated.
- "Age, eccentricity, poverty, or medical diagnosis alone shall not be sufficient to justify a finding of incapacity."

  Revised Codes of Washington (RCW) 11.88.010

No teaching choir to sing: We all know…

70% say they want to die at home—BUT
70% die in a hospital, nursing home, or long-term care facility

80% say that, if seriously ill, they would want to discuss EOL care—BUT
7% said they actually got to converse with their doctors

82% say it is important to put their wishes in writing BUT
23% have done it (fewest in ethnic communities)

60% say it is important not to burden their families with tough decision BUT
56% have not communicated their EOL wishes

Basically a good death preserves personal dignity, is free of excessive pain, avoids futile or harmful treatments that delay death at high personal, social, and economic cost, permits spiritual and emotional peace of mind, allows families to avoid unnecessary stress

Fundamental Ethical/Legal Tenet

"Every human being of adult years and sound mind has the right to determine what shall be done with his own body." Justice Cardozo

Schloendorff v. Society of New York Hosp., 211 N.Y. 125 (1914)

What Is Your Role?

Fix ?
Decide ?
Explain ?
Advise ?
Listen ?
Understand ?
Feel ?
Connect ?
Give permission ?