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Living With Dementia and Making Each Day Count

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  - Chair, Disease Management & Mental Health Subcommittee, Clinical Roundtable, San Diego County's Alzheimer's Project

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Lecture Outline

- Introduction including Background and Key Points
- Maintaining Wellness
- Successful Communication
- Structure and Stimulation
- Progression of dementia
- Summary

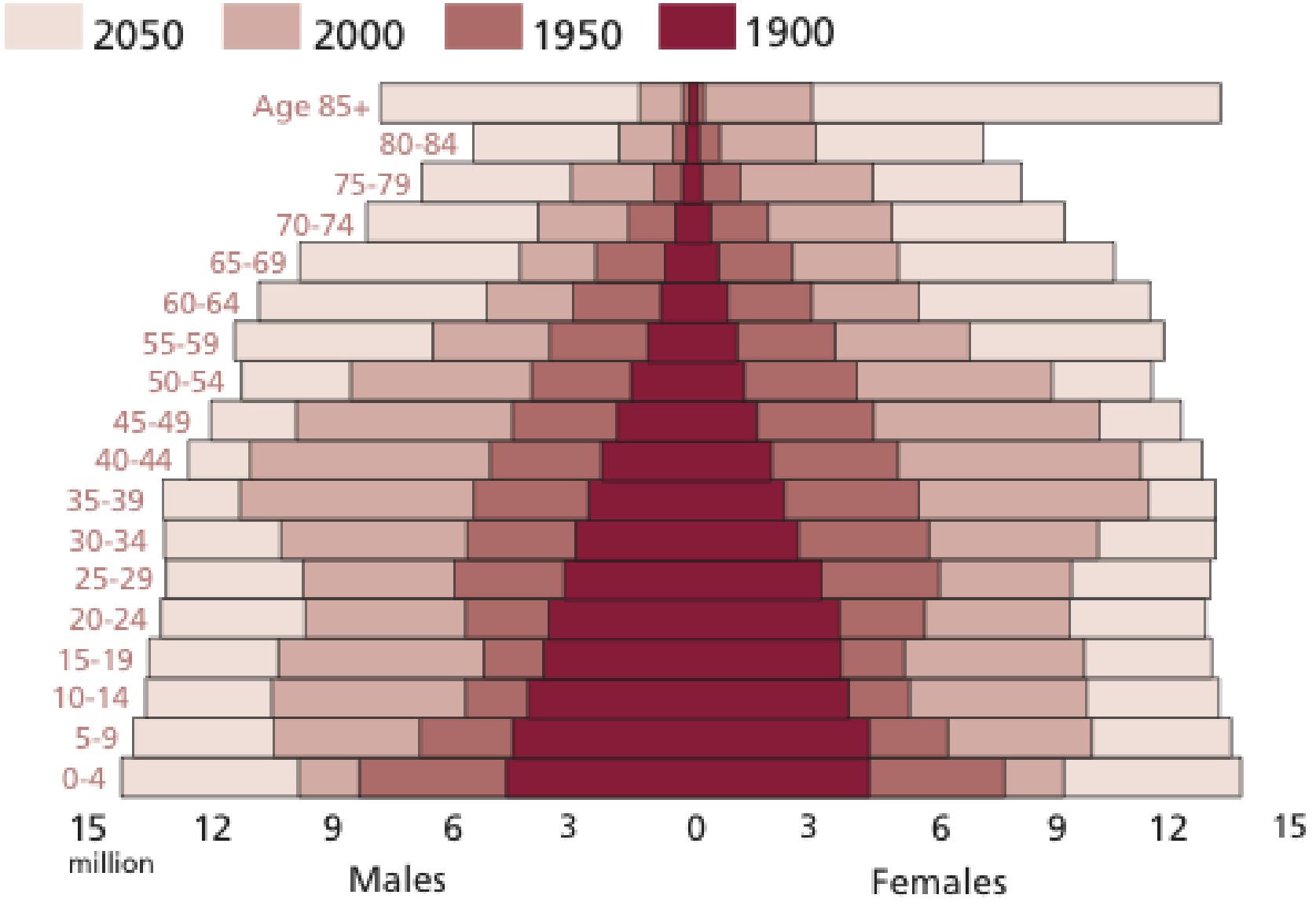
Background

- Both the absolute number of older individuals and the proportion of older individuals relative to other age brackets are rapidly increasing
- The most important risk factor for a dementia illness is increasing age
- The most common problem for someone living with dementia and those caring for someone living with dementia is the development of challenging behavioral symptoms
- Behavioral symptoms in patients living with dementia: a) erode the quality of life of the individual living with dementia and those connected to the individual; b) are the most common reason for hospital admission; c) greatly increase the costs of care
- Maintaining the overall health/wellness of an individual living with dementia helps prevent and resolve behavioral symptoms
- Providing structure and an optimal amount of stimulation for an individual living with dementia also helps prevent and resolve behavioral symptoms

Five Key Points

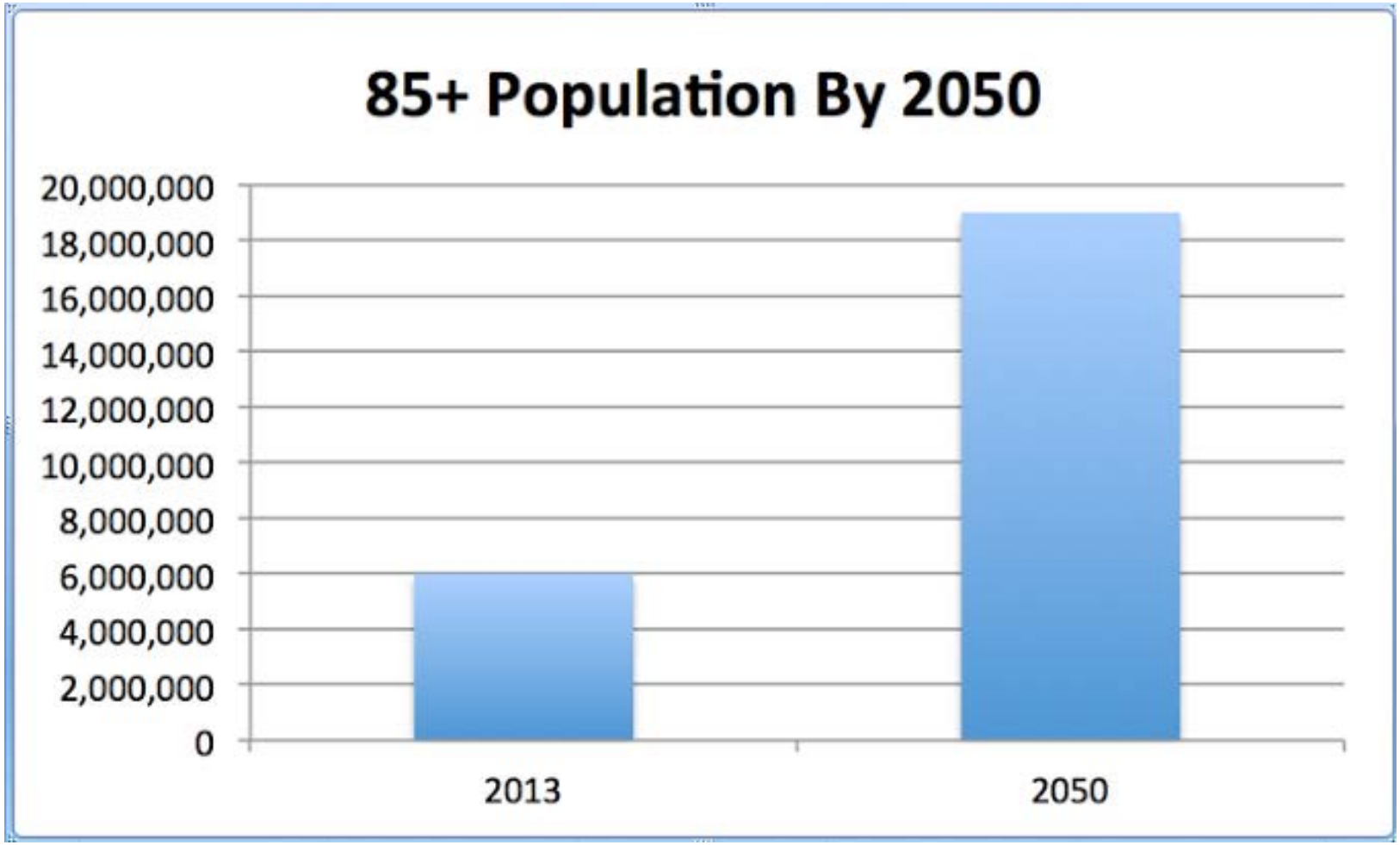
1) Factors which may trigger behavioral changes in patients with dementia can be separated into two categories which are not mutually exclusive: patient-related (e.g. medical illness/lack of wellness) and environment-related (e.g. suboptimal caregiver communication or suboptimal environments).
2) New or rapidly worsening behavioral symptoms in an older patient should be considered a sign of an underlying medical illness until proven otherwise.
3) The first step in the evaluation is to assess whether underlying medical factors may be involved.
4) Sometimes addressing environment-related triggers is all that is needed.
5) Remember that most dementias are progressive and, as a result, behavioral symptoms may evolve or disappear over time.

U.S. age pyramid



Source: http://www.ctmt.com/pdfs%5CemergingDirections%5Cdemographicsasdestiny.pdf

The Silver Tsunami AKA The Golden Wave



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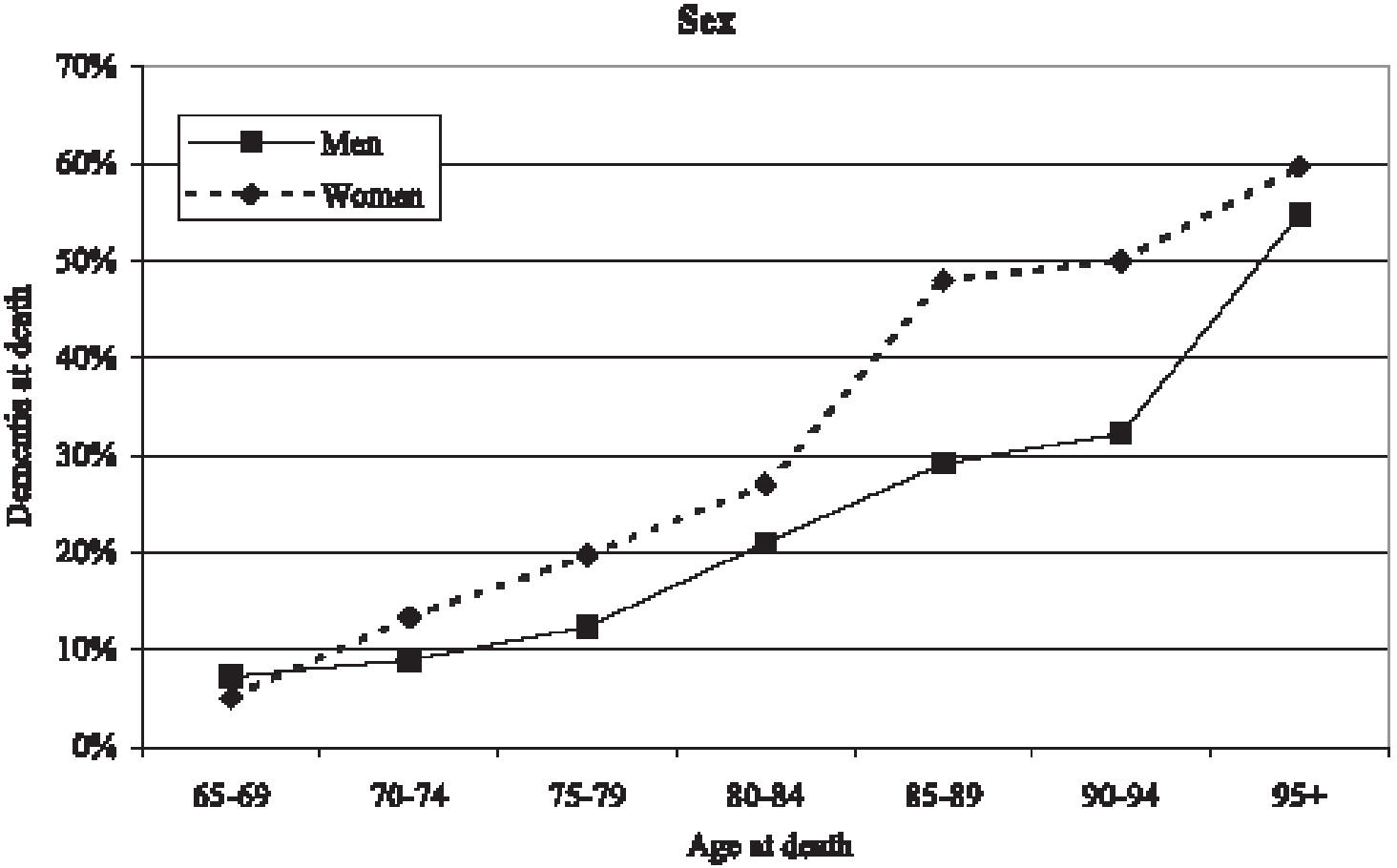
Aging and Frequency of Dementia



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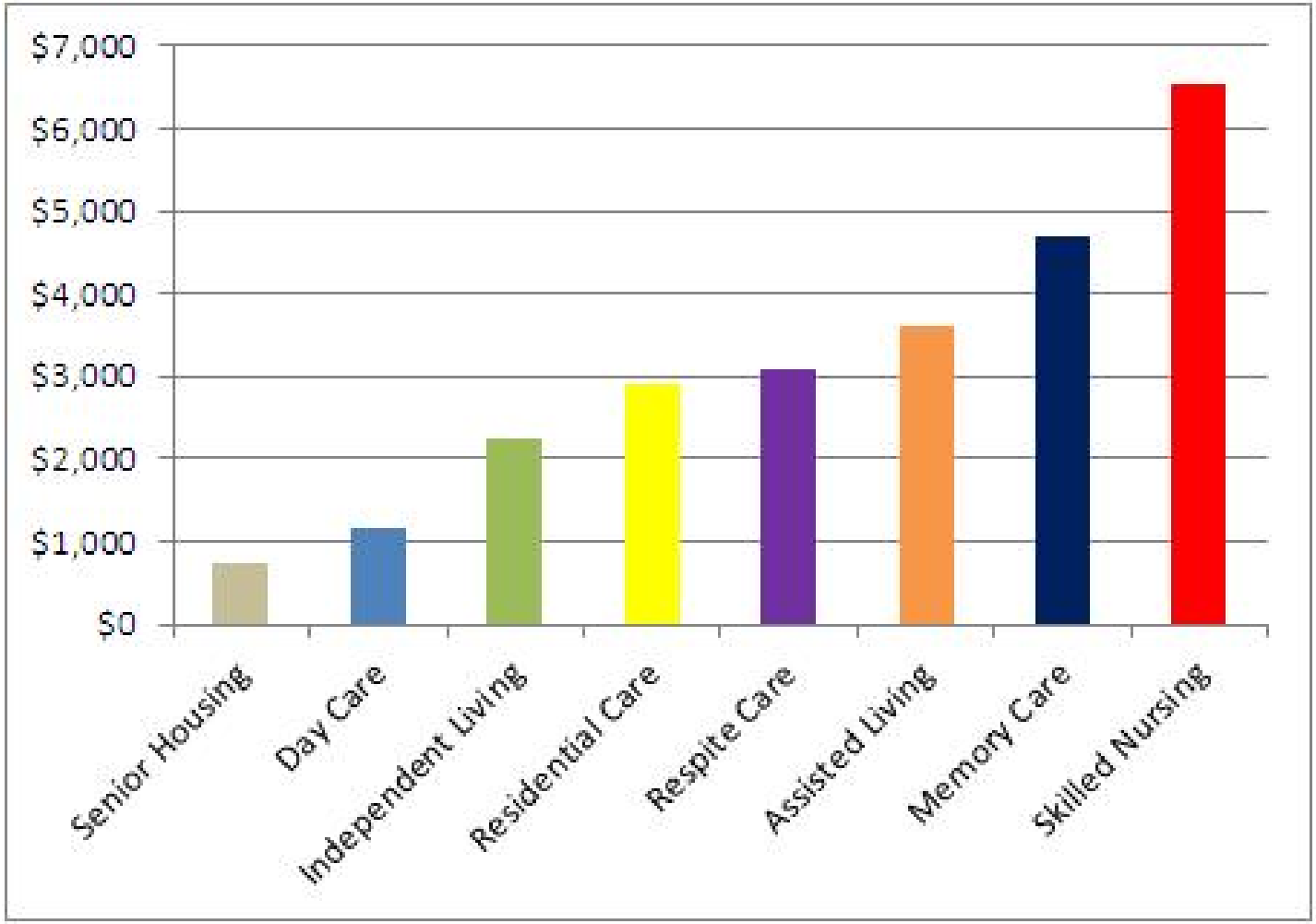
RAND Study Results

- Alzheimer's (AD) is the most expensive malady in the U.S. and costs families and society between $157 and $215 billion a year
- The biggest cost of AD: the care needed to get mentally impaired people through daily life
- Comparison data of direct costs (from medicines to nursing homes)
  - Dementia $109 billion
  - Heart disease $102 billion
  - Cancer $77 billion

New England Journal of Medicine, April 4, 2013

The Costs of Dementia Care



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Classifying the Triggers of Behavioral Symptoms in Individuals Living with Dementia

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Causes Related to the Patient

- Causes related to the patient may be divided into the following categories:
  - **Medical** including uncorrected sensory deficits, hypoglycemia and pain
  - **Psychiatric** including depression, anxiety, and paranoia
  - **Psychological** including frustration, boredom, TV violence and loneliness
  - **Other** causes such as thirst, hunger, fatigue, noise and movement restriction

Causes Related to the Caregiver

- Ineffective communication due to:
  - Making more than one request at a time
  - Speaking too fast with poor diction
  - Not allowing time for the patient to respond
  - Not using more than one sensory modality
  - Not maintaining eye contact
  - Not assuming a comfortable, relaxed posture
  - Not identifying and verbalizing the patient's affect
  - Not using simple direct statements

Causes Related to the Environment

- An unfamiliar environment
- The absence of a place to exercise
- The absence of a secure area in which to roam safely without cul-de-sacs and dead-ends which create agitation because patients may not know what to do when stuck
- Lack of access to wandering paths which include places to sit, socialize, or engage in activity
- Noise/Overstimulation
- Uncomfortable ambient temperature

Maintaining Wellness

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Possible "Medical" Causes of Behavioral Symptoms in a Patient with Dementia

- Delirium
- Exacerbation of pre-existing medical illness
- Onset of new medical problem
- Medication toxicity (e.g. polypharmacy or suboptimal prescribing)
- Drug or alcohol intoxication
- Drug or alcohol withdrawal
- Exacerbation of pre-existing psychiatric illness
- Onset of a new psychiatric illness

The Optimal Evaluation

“True genius resides in the capacity for evaluation of uncertain, hazardous, and conflicting information.”

--Winston Churchill

The Optimal Evaluation

- Behavioral symptoms should be viewed as a signal of an underlying medical problem **until proven otherwise** and should trigger a careful medical evaluation which includes:
  - History gathering including careful review of medication list
  - Physical examination including a Mental Status Examination
  - Lab tests (including TSH and serum drug levels)
  - Brain imaging (especially if never previously done, new focal neurologic deficits or a history of a recent fall)
  - Other tests

Unrecognized Medical Illness Associated with Problem Behaviors

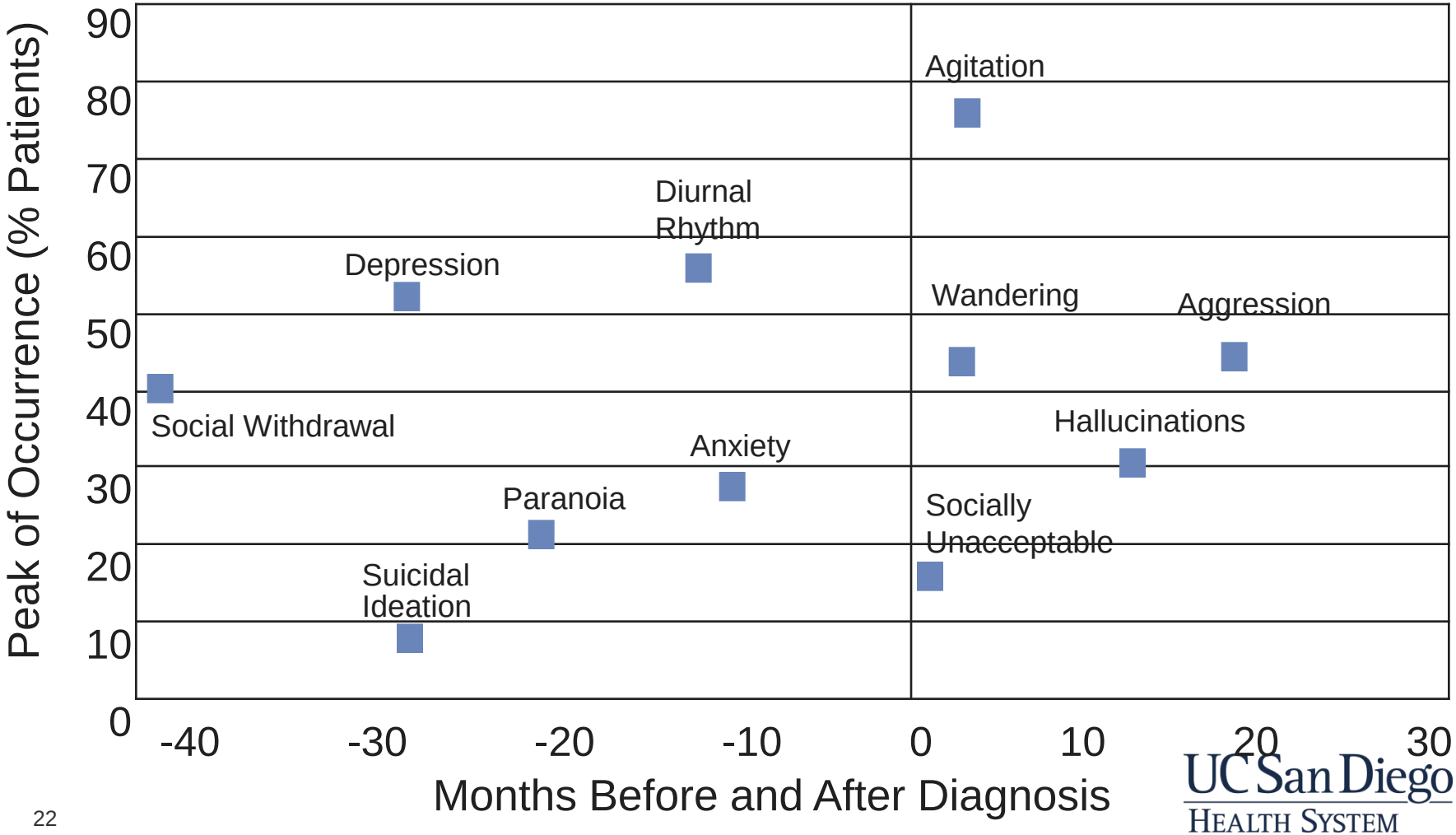
- Study Population (N=79)
  - Consecutively admitted from 5/99 – 10/99
  - Mean age = 78 years
  - 92% Caucasian
  - 51 female and 28 male
- Results: 34% had unrecognized medical illness
- Diagnosis (N)
  - Obstipation (7)
  - Urinary Infection (7)
  - Hypothyroidism (5)
  - Pneumonia (3)
  - Other (12)

Woo BKP et al. *J Geriatr Psychiatry and Neurol* 16:121-125, 2003

Suboptimal Prescribing

- Polypharmacy (too many medications) and the prescribing cascade
- Prescribing a medication from an essential category of medication that is not senior friendly
- Prescribing a dose an essential medication that is larger than needed
- Prescribing a medication to be taken at a time of day that is not optimal (e.g. diuretics at bedtime)
- Not prescribing a needed medication (e.g. a pain medication)

Peak Frequency of Behavioral Symptoms in Alzheimer's Dementia



Jost BC, et al. *J Am Geriatr Soc*. 1996;44:1078-1081.

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Successful Communication

“The most important thing in communication is hearing what isn't said.“

--Peter Drucker, an Austrian-born American management consultant (November 19, 1909 – November 11, 2005)

Recognizing and Responding Appropriately to Behavior Changes

- Behavior changes are a form of communication
- When a person with dementia experiences a change in behavior the first goal is to determine the meaning or message being communicated
- Sometimes the meaning or message will be simple or obvious but sometimes it may take a while to understand

Effective Communication

- Make one request at a time
- Speak clearly and slowly
- Allow time for the patient to respond
- Maintain eye contact
- Assume a comfortable posture with arms and hands relaxed
- Identify the patient's affect and verbalize this for him/her
- Time communications optimally based on circumstances (e.g. hunger, fatigue, background noise, etc.)
- Remember that even when words may no longer convey meaning volume, prosody and melody of speech may still convey information

Validation Therapy

- The need to be seen, heard and understood is a part of human nature and does not disappear simply because someone is living with dementia.
- Individuals living with dementia may have problems with expressive and receptive aphasia.
- Putting a thought, need or emotion into words for can sometimes be powerfully helpful
- Someone living with dementia may have preserved emotional intelligence
- When interacting with someone who is living with dementia strive to avoid triggering feelings of shame.

Redirection

- Represents an intentional thwarting of goal directed thought or behavior
- Goal is to help patient refocus in order to be more:
  - calm
  - cooperative
  - content
  - safe
- May trigger frustration or agitation
- Has two forms: simple and complex

Simple Redirection

- **Simple redirection**
  - **Presentation of options**: “This door is closed but this door is open.”
  - **A compliment**: e.g. “My that’s a beautiful sweater!”
  - **A request for help**: e.g. “Please help me fold these towels.”
  - e.g. other possibly helpful distractions include: food, drink, music, humor.

Complex Redirection

- **Complex redirection**: 4 steps
  - **Validate**: “You look worried.”
  - **Join**: “You’re looking for [fill in the appropriate item]. I’m trying to find [fill in an item]. Let’s look together…”
  - **Distract**: “Let’s look over there…”
  - **Redirect**: “That coffee smells good. Do you want a cup?”

Complex Redirection

- Enter the agitated patient's reality
- Approach in a calm manner
- Communicate your desire to help

Complex Redirection

- Example: A patient is trying to get out the door to see his wife.
- Don't say "You're wasting your time. Don't you remember that your wife died a long time ago?"
- Do say:
  - "You seem upset because you can not find your wife. (**Validate**)
  - I haven't seen her but I will help you look. (**Join**)
  - This door is broken. I need to get it fixed. (**Distract**)
  - In the mean time, Let's take a walk and try to find her. (**Redirection #1)**)
  - Look, the Padres are on the TV. Are you a Padres fan?" (**Redirection #2**)

Structure and Stimulation

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Structure and Stimulation

- In the scientific literature, these are described as “Nonpharmacological interventions.”
- In general, nonpharmacological interventions provide benefits to both patients and caregivers.
- Nonpharmacological interventions work best when individualized.

Rationale & Benefits of Nonpharmacological Interventions

- Address unmet physical, emotional, and psychosocial needs
- Provide opportunities for physical and intellectual exercise and maintaining function based on the concept of “Use it or lose it”
- Allow for the application of behavior modification principles
- Ease adjustment problems associated with enrollment in daycare or a move to residential care facility
- Avoid the side effects from psychiatric medications such as sedation, falls, and metabolic changes
- Alleviate boredom

Rationale & Benefits of Nonpharmacological Interventions

- Preserve relationships
- Foster hope through action
- Prevent wandering: structured activities prevent the boredom and uncertainty that may lead to wandering
- Routines can be learned and then may reduce anxiety
- A majority of studies report at least modest improvement (>91% of studies)

Types of Activities

- Types of activities:
  - Physical fitness
  - Intellectual exercise
  - Emotional health
  - Spiritual needs
  - Enjoyment
- Note: Some activities may fit in more than one category

Specific Activities

- Arts and crafts
- Baking
- Current events
- Exercise
- Gardening
- Grooming
- Music
- Pets
- Reminiscing

Progression of Alzheimer's Disease

Mild - MMSE >20

- Forgetfulness
- Problems with shopping, driving, and hobbies
- Depression

Moderate - MMSE 10-20

- Impairment of recent memory
- Require help with ADLs
- Wandering
- Insomnia
- Delusions

Severe - MMSE <10

- Very limited language
- Loss of basic ADLs
- Agitation
- Incontinence

Galasko. *Eur J Neurol.* 1998;5:S9-S17.

Summary

"We don't stop playing because we grow old. We grow old because we stop playing."

--George Bernard Shaw

Key Points Take Two

1) Factors which may trigger behavioral changes in patients with dementia can be separated into two categories which are not mutually exclusive: patient-related (e.g. medical illness/lack of wellness) and environment-related (e.g. suboptimal caregiver communication or suboptimal environments).

2) New or rapidly worsening behavioral symptoms in an older patient should be considered a sign of an underlying medical illness until proven otherwise.

3) The first step in the evaluation is to assess whether underlying medical factors may be involved. In other words: **ensuring wellness**

4) Sometimes addressing caregiver or environment-related triggers is all that is needed.

5) Remember that most dementias are progressive and, as a result, behavioral symptoms may evolve or disappear over time.

Questions and Answers

Thank You!

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