



## Preventing Excess Disability and Promoting Quality of Life

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## Overview



- Describe the University of Nevada, Reno **Nevada Caregiver Support Center** contextual model of dementia care
- Describe the concept of “excess” disability and how it applies to the quality of life of persons with dementia
- Briefly summarize recent research on factors that contribute to excess disability in older adults with dementia.
- Describe the “contextual” model for detecting, preventing, and reversing excess disability and promoting quality of life

## UNR Nevada Caregiver Support Center's contextual model of dementia care



- Treats caregiver/care recipient interactions as essential to caregiver and care recipient well-being (see Fisher et al, 2008)
- Assumes that a person who is experiencing progressive cognitive impairment will develop strategies to compensate for such impairment (Hussian, 1981)
  - “Doing the best they can”

## Contextual model of dementia care



- Affective and behavior changes can be understood within the biological, social, and personal historical context in which they occur.
- “Context” includes consideration of the:
  - degenerative brain disease,
  - person's current circumstances,
  - person's history

## UNR Nevada Caregiver Support Center: Priorities for promoting quality of life



- Persons with dementia:
  - Preserve functional repertoires
  - Prevent challenging behaviors that lead to negative outcomes for patients and their caregivers
  - Prevent excess disability
- Caregivers
  - Increase knowledge of neurocognitive disorders and their effects on behavior (make behavior predictable)
  - Promote ability to cope with emotional and practical challenges
  - Provide solution-focused support services
- Families
  - Preserve meaningful and rewarding qualities of relationships

## What is “excess” disability in persons with dementia?



- Excess disability: When impairment in functioning exceeds what is expected due to disease (Kahn, 1975)
- Excess disability in dementia: Premature reduction in behaviors that will inevitably be lost due to the disease process
  - Examples:
    - Corrective feedback from family and friends punishes verbal (Gentry & Fisher, 2007)
    - Misattributing behavior changes to neurodegenerative disease rather than a reversible condition

## Interpersonal context of behavioral decline



- Both person with dementia and their family experience slow fading of reinforcement in day to day interactions
  - Called “reinforcement erosion” in marital therapy literature (Jacobson & Christiansen, 1996)
- Caregivers – Usually experience slow extinction as painful and stressful
- Care recipient – Behavior is often inadvertently and unintentionally punished

## Interpersonal context of behavioral decline



- Communication problems
  - Leading cause of stress for family caregivers
  - Leading risk factor for lack of treatment for reversible conditions (e.g., pain, infection, depression)
- High rates of conflict:
  - Demand/request by caregiver:
  - Person with dementia agrees to complete task but is not capable
  - Caregiver escalates demands
- Behavior of person with dementia increasingly maintained by escape and avoidance

## Verbal deficits and risk of challenging behaviors in persons with dementia



- Loss of ability to understand and label internal (private) experiences and adverse events
  - Pain
  - Physical discomfort
  - Sensory impairment
  - Fear
  - Boredom
  - Sadness
- Changes in behavior that occur during adverse events often mimic declines due to dementia

## Common challenging behaviors in persons with dementia



- Challenging behaviors:
  - Resistance to care
  - Wandering or exit-seeking
  - Repetitive questions or statements
  - Disruptive vocalizations (e.g., repeated questions)
  - Paranoid allegations
  - Inappropriate sexual behavior

## Conflicting views of challenging behaviors



- Most common view: Challenging behaviors are “noncognitive psychiatric symptoms of dementia”
- Alternative view: Challenging behaviors are not “symptoms” of dementia
  - They are preventable and reversible
- Caregiver skills training and education in expected vs. abnormal behavior changes in dementia:
  - Improves detection and treatment of excess disability
  - Improves quality of life for persons with dementia and caregivers
  - Reduces healthcare costs due to unnecessary medication and hospitalizations
  - Prevents or delays need for costly and more restrictive residential long-term care placement

## Stigma of dementia label and risk of excess disability



- Adverse effects of stigma of dementia label:
  - Assumption that all behavior change is due to the degenerative dementia
  - Including behavior change due to adverse events and/or reversible physical and environmental conditions
    - Untreated pain
    - Infection
    - Medication side effects
    - Injury
    - Sensory impairment
    - Delirium
    - Excessive environmental demands
    - Under-stimulating environment

## Consequences of misattribution of behavioral and affective changes



- Lack of treatment for reversible conditions
- Use of treatments that suppress or prematurely eliminate behavior
  - Results in premature behavior loss or “excess” disability
- Health care proxies’ decisions may be based on judgments of person with dementia’s quality of life
  - Quality of life may be significantly lower than possible due to reversible excess disability
- Premature death

## Example: Pain management in persons with dementia



- Label “dementia” increases the risk of inadequate pain treatment when compared to persons with similar mental status scores and medical conditions
  - prescribed significantly less analgesic medication than patients with similar pain-related diagnoses but no cognitive impairment diagnosis
  - dosage prescribed to the patients with a cognitive impairment diagnosis significantly lower than to patients without the cognitive impairment diagnosis (Nygaard & Jarland, 2005)

## Pain management in persons with dementia



- If asked about pain, many persons with dementia are able to say if they are experiencing pain
- Experimental research has found persons with dementia do experience pain
  - Measured objectively by heart rate, blood pressure, muscle reflex, MRI scans
  - Measured subjectively by self-report
    - Benedetti, Vighetti, Ricco, Lagna, Bergamasco, Pinessi & Rainero (1999), Benedetti, Arduino, Vighetti, Asteggiano, Tarenzi, Rainero, (2004), Morrison, & Siu (2000); Nygaard & Jaarland (2005)

## Cognitive impairment and the experience and labeling of pain



- Belief that persons with dementia experience less pain than persons without dementia
  - Not supported by empirical research
  - What does change are expectations about the pain and memory about how long the pain has been occurring
- Verbal impairment may also affect the powerful placebo effect of medication and other pain treatments

## Common approaches to the treatment of challenging behaviors



- Most popular treatment approach: Reduce or eliminate the “symptom” (i.e., the challenging behavior)
- Dominant treatment approach: Psychotropic medication
  - atypical antipsychotics
  - conventional antipsychotics

## Symptoms of dementia vs. side effects of atypical antipsychotics



### Dementia

- Cognitive deficits
- Verbal impairment
- Impairment in judgment
- Impairment in new learning
- Declines in motor skills and coordination
- Behavioral disturbances

### Antipsychotics

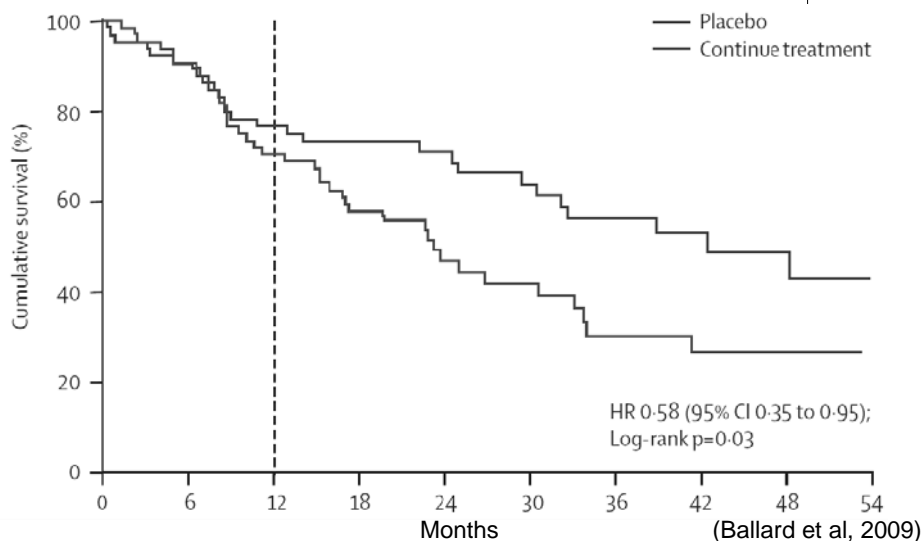
- Cognitive deficits due to sedation
- Premature loss of language
- Confusion
- Impairment in new learning
- Increased risk of falls
- Behavioral disturbances (Schneider et al, 2006; Sink, et al., 2005)

## Antipsychotic medication use in persons with dementia




- Food and Drug Administration Public Health Advisories (2005, 2008)
- Black box warnings: Higher death rate associated with use of conventional antipsychotic and atypical antipsychotics compared to patients receiving a placebo

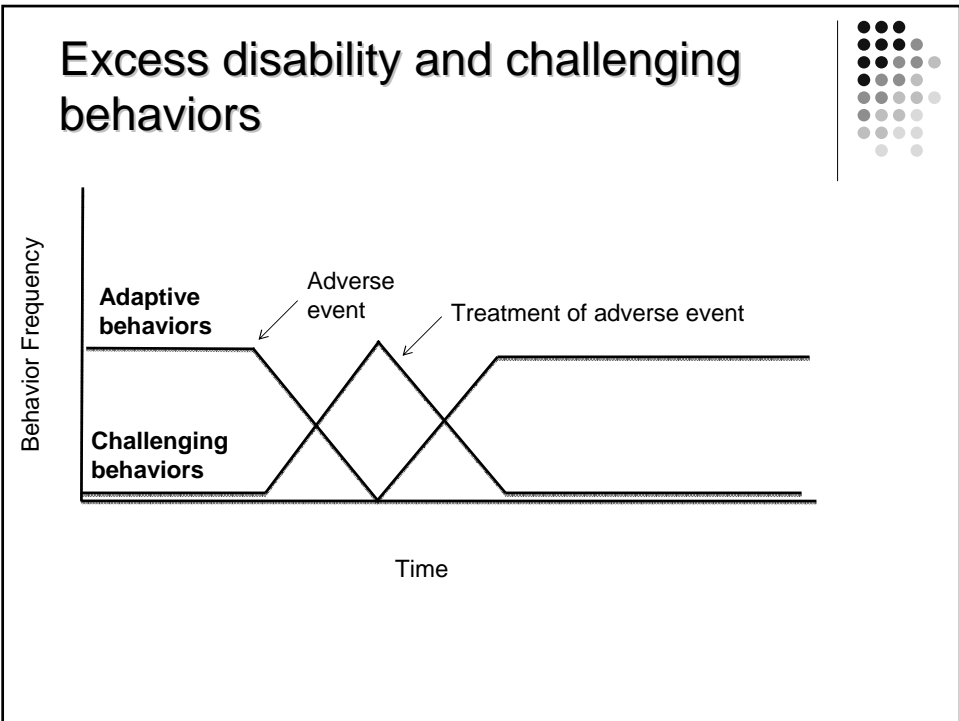
## Increased mortality in elderly receiving long term antipsychotic medication



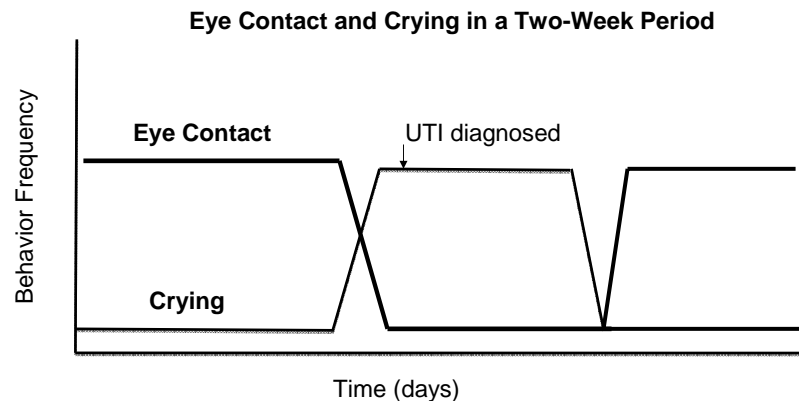
## UNR Study: Monitoring adaptive behavior to detect excess disability



- Goal: Improve detection, treatment, and reversal of excess disability
  - Distinguish expected vs. abnormal behavior changes
- Identify stable, frequent, long-standing behaviors for client
  - Smiling, joking
  - Eye contact and hand-shaking on greeting
  - Flirting
  - Tinkering
- Precipitous change in these adaptive behaviors is a signal to rule out an adverse event (Catlin & Fisher)



## Case example: Woman referred for behavior problem “crying”



## Assume precipitous behavior change is due to an adverse event



- Rule out reversible condition:
  - Medical (e.g., pain, medication side effect, infection, injury, delirium)
  - Age associated sensory impairment (e.g., uncorrected vision or hearing deficits)
  - Emotional distress (depression, fear, boredom)
  - Environmental (corrective feedback, verbal abuse, punishment, overly demanding environment)

## UNR Nevada Caregiver Support Center Caregiver Coaching Program



- Coach caregivers to collaborate with health care providers to reach and maintain optimal health of their family member
- Apply positive approaches for the prevention of challenging behaviors and maintenance of adaptive behavior
- Coach caregivers in skills that promote behavioral health and quality of life
  - Including caregivers' health and quality of life
    - Emotional coping skills
    - Solution focused skills for practical problem solving



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