Managing Challenging Behaviors

Kimiko Domoto-Reilly, MD
Assistant Professor of Neurology
Memory and Brain Wellness Center
University of Washington

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High Prevalence and Cost of Behavioral Symptoms

- almost all persons with dementia will exhibit at least 1 behavioral symptom over the disease course
  - 5 year Cache County Study: 97% experienced at least one neuropsychiatric symptom
- high consequences and costs
  - increased utilization of services (health care, ancillary care)
  - direct care costs: clinic and hospital visits, transportation, medication, paid care, respite stay, nursing home placement
  - indirect care costs: lost income for family members, replacement cost of hiring ancillary help (e.g., housekeeper, bookkeeper, handyperson)
  - accelerated functional decline if significant symptoms are untreated
  - carepartner, family distress

Beeri et al, 2002; Gitlin et al, 2012; Kales et al, 2014; Steinberg et al, 2008

Wide Range of Potential Behavioral Changes

- repetitive questions
- difficulty falling asleep
- difficulty staying asleep
- “shadowing”
- sadness
- lack of empathy
- decreased motivation
- delusional thoughts
- resistance to assistance
- restlessness

- many manifestations of “agitation”: hit, pace, scream, mutter, stare, grind teeth, tap foot

refer to: Rhoads ECHO talk Jan 14 2022; Ramirez ECHO talk, Dec 10 2021

Considerations when Screening for Symptoms

- information source: how and from whom is symptomatology obtained?
  - no universal standard
- assessment tools
  - *multidomain* (e.g., Neuropsychiatric Inventory, Brief Psychiatric Rating Scale, Behavioral Pathology in AD Rating Scale [BEHAVE-AD])
  - *agitation* specific (e.g., Cohen-Mansfield Agitation Inventory)
  - *depression* specific (e.g., Geriatric Depression Scale, Cornell Scale for Depression in Dementia)
  - most commonly cited in literature: NPI-Q
    - 12 symptom domains with severity ratings; self-administered
- terminology
  - how person with dementia, caregivers label symptoms and associated distress

Burley et al, 2021; Harper et al, 2022; Kaufer et al, 2000

Behavioral Symptoms Vary by Dementia Type and Stage

- Alzheimer's disease
  - depression, anxiety in MCI / early stage dementia
- Vascular cognitive impairment
  - depression
- Lewy Body disease
  - early hallucinations, delusions; depression with disease progression
- Frontotemporal dementia
  - repetitive sayings and motor activities, lack of empathy, loss of social graces

- behaviors often change as disease progresses
- patient insight is variable, and may contribute to distress

Gitlin et al, 2012

Efficacy of Non-Pharmacologic Interventions

- hard to gauge given variability of care settings, methodology, etc
- interventions which involve the caregiver may be most beneficial, especially for dyad
- as with all treatments, best approach is individualized
- in-the-moment benefit can be helpful, even without long term measurable changes
- low (but not zero) risk of side effects
- likely not helpful to consider pharmacologic and non-pharmacologic approaches as exclusive interventions

Abraha et al, 2017; Brodaty & Arasaratnam, 2012;
Cohen-Mansfield 2001; Gitlin et al, 2012; Kales et al 2015

Types of Non-Pharmacologic Interventions

- sensory stimulation
  - acupressure
  - aromatherapy
  - massage therapy
  - light therapy
  - sensory garden, horticulture
  - music and/or dance
  - white noise
  - Snoezelen multisensory stimulation therapy

Snoezelen

Abraha et al, 2017; Brodaty & Arasaratnam, 2012; Cohen-Mansfield 2001

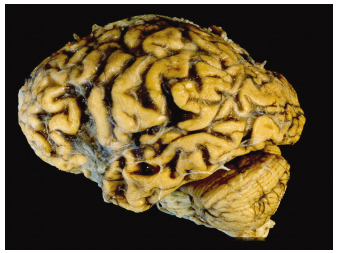
Types of Non-Pharmacologic Interventions

- person-centered activities
  - cognitive stimulation
  - reminiscence therapy
  - simulated presence therapy
  - exercise therapy
  - animal-assisted therapy (live, toy, robotic)

Sun Sentinel

Abraha et al, 2017; Brodaty & Arasaratnam, 2012; Cohen-Mansfield 2001

Factors Influencing Manifestation of Behaviors



JNNP

vulnerable brain

Behavioral and Psychological Symptoms of Dementia (BPSD)

Patient factors
- premorbid personality
- concurrent medical issues
- medication interactions, side effects
- autonomy, vulnerability
- engagement in daily activities
- basic needs: voiding, pain, temperature, sleep, thirst, hunger, socialization

Caregiver factors
- relationship history
- understanding of dementia
- appreciation of current abilities
- detection and interpretation of symptoms
- communication strategies
- safety / welfare concerns

Environmental factors
- over-stimulation
- under-stimulation
- routine, structure
- daily tasks
- activity transitions, cues
- objects, furniture, room layout
- social interactions
- cultural values / expectations

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refer to: Carlson ECHO talk May 28 2021

Approach to Detection and Treatment: DICE

- Step 1: **D**escribe
  - elicit thorough, accurate description of symptoms and context
  - understand what is distressing, and to whom
- Step 2: **I**nvestigate
  - evaluate both causes and consequences, for modifiable factors: e.g., medication changes, medical co-morbidities, sensory deficits, sleep hygiene, bathing routine, caregiver stress
- Step 3: **C**reate
  - collaborative treatment plan including modeling / concrete examples
- Step 4: **E**valuate
  - feasibility and efficacy of implementation, unintended consequences, future modifications as behaviors change

Kales et al, 2014; Kales et al, 2015

refer to: Godfried ECHO talk June 25 2021; Rhoads ECHO talk Mar 10 2022

Education and Support can Bolster Care Alliance

- strategies for mitigation and prevention
  - establish “brain healthy habits” early
  - describe some symptoms which can be seen in dementia, and which to bring to attention
  - early identification and intervention to reduce escalation
  - establish appropriate expectations, and adjust accordingly
    - determine whether a behavior is truly problematic
    - diffuse perception of intentional antagonism
  - even incremental improvements can be crucial
- support
  - acknowledge potential grief, guilt
  - importance of medical and mental self-care, respite
- SLP, OT, psychologists, therapists, social workers can help provide individualized interventions

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QUESTIONS?