Nonpharmacological Management of Alzheimer’s Disease

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DISCLOSURE OF FINANCIAL RELATIONSHIP

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I have no actual or potential conflict of interest in relation to this program/presentation

“Off-label” uses of medications
I will not be discussing any “off-label” uses of any medications

Unapproved/investigative use of a commercial device
I do not anticipate discussing unapproved/investigative use of commercial products/devices

Objectives
1. Understand behavioral issues of Alzheimer’s Disease
2. Learn strategies to help families manage behaviors
3. Support caregivers on the dementia journey

CASE

Elsie Larson is an 82-year-old, right-handed married Caucasian female with 16 years of education, retired from teaching 17 years ago. For the last 10 years, her husband Bob has noticed a gradual decline in memory.

Now Elsie stays home during the day and declines invitations to go out. Elsie does not think she has a problem and is angry that Bob is insisting that she see a doctor.

PREVALENCE: DEMENTIA TYPES

Types of Dementia
- Alzheimer’s Disease (63)
- AD & Vascular
- Lewy body
- AD & Lewy body
- Vascular
- Other

5% 8% 7% 10% 5% 5% 63%
COGNITIVE DISEASE
From Preclinical to MCI to Dementia

ALZHEIMER’S DISEASE PROGRESSION

WHY IS EARLY IDENTIFICATION KEY?
No disease modifying medications available yet.

• Behavior Management: Many neuropsychiatric symptoms are treatable (e.g., depression, sleep)

• Advance Care Planning: Helps families plan for the future, making living arrangements, take care of financial and legal matters, educate about behavior strategies and develop support networks—hopefully reducing caregiver burden. Powers of Attorney: Health, Finances

• Safety Issues:
  − forgetting to turn off stove or other appliances,
  − forgetting to pay bills,
  − getting lost when driving,
  − forgetting they are taking care of minor children/impaired adults,
  − forgetting emergency phone number 911.

ANXIETY IN DEMENTIA
Need more research!

• Starkstein (2007) suggested GAD in dementia as
  a) Excessive anxiety/worry that is difficult to control
  b) Three of the following
     • Restlessness
     • Irritability
     • Muscle tension
     • Respiratory symptoms
  c) Believed to be distinct from agitation
  d) Common with depression
  e) Difficult to appreciate in those with language deficits—somatic symptoms?

DEPRESSION IN DEMENTIA

• 15-27% of individuals ≥65 living in the community have depressive symptoms. Prevalence twice as high in women

• Look for crying, tearfulness, hopelessness, self-deprecating comments.

• Look for change in appetite, sleep and energy level.

• White males over 65 yrs old account for 83% of all suicides annually.

• Can amplify cognitive deficits
  − Executive dysfunction
  − Slowed processing of information
  − Retrieval memory problems

COMMON BEHAVIORAL SYMPTOMS OF DEMENTIA

• Anxiety/Depression

• Getting Lost / Wandering

• Apathy

• Psychosis

• Sleep

• Appetite

• Agitation/Aggression

• Disinhibition

Need more research!
GETTING LOST/WANDERING

- Wandering:
  - Stress or fear—trying to escape an overstimulating environment
  - Searching—for someone or some place (psychosis)
  - Boredom
  - Basic needs—looking for bathroom, food, go for a walk
  - Past Routines—try to go to work, do chores, buy groceries

- We do not know what part of the brain controls wandering

- No good medications for this

NONPHARMACOLOGICAL MANAGEMENT

- Getting Lost
  - GPS: Tile, Smart Phone
  - MedicAlert® + Alzheimer’s Association Safe Return®

- Wandering
  - Is there a pattern?
    - Same time of day? Provide activities
  - Searching for a loved one? Reassure will be visiting soon
  - Technology
    - Alarm, locks, video devices
    - Bookcase cover for a door; from www.alzstore.com

- Provide safe and controlled environment for wandering

APATHY IN DEMENTIA

“Doctor, he just sits in front of the TV all day!”

- Definition: It can be thought of involving simultaneous changes in 3 areas (Marin, 1991)
  - Behavior: initiating, sustaining, completing actions
  - Cognition: decrease in goal-related thought content
  - Emotion: diminished emotional responsivity

- Consequences
  - Daily functioning—lack of stimulation can hasten cognitive decline
  - Treatment adherence—medication, exercise
  - Quality of life—goal-directed behaviors that contribute much to the day-to-day quality of life
  - Caregivers distress—undermines emotional connection to the patient

PSYCHOsis IN DEMENTIA

- Delusions
  - Someone is stealing, spouse is having an affair
  - Misidentification syndrome
  - “You’re not my husband!”

- Hallucinations
  - Typically visual, most common in Dementia of the Lewy Body Type
  - Do not be overly concerned if they are not distressing to the patient

- Management
  - Optimize hearing and vision
  - These symptoms may need antipsychotic medications if bothersome
### PSYCHOSIS IN DEMENTIA

- AD
- FTD
- DLB
- PD

### SLEEP

- A sleep disorder may awaken patient at night (e.g., sleep apnea)
- Circadian rhythm:
  - Get at least one hour of sunlight within 30 minutes of your out-of-bed time.
  - Alcohol can have a rebound effect.
- Lack of activities and stimulation during the day may result in drowsiness and apathy during the day.
  - Regular exercise each day, preferable 40 minutes each day or an activity that causes sweating.
    - It is best to finish exercise at least six hours before bedtime.
  - Bed for sleep only
  - Keep regular bedtime hours
  - Have a bedtime ritual
  - Review medications

### MANAGEMENT OF APPETITE

- Loss of smell is common, making food less palatable
- Minimize medications that cause nausea or constipation
- Consider GERD symptoms
- Evaluate for depression

### WHAT IS AGITATION?

- Any inappropriate verbal, vocal, or motor activity
- Not an expression of obvious need or confusion
- May be aggressive:
  - Verbal (temper outburst, screaming, threats, name calling)
  - Physical (hitting, kicking, pushing, grabbing)
    - May be similar to aggressive premorbid behavior
  - May be non-aggressive
  - Verbal (complaining, repeating, constant talking)
  - Physical (checking, wandering, pacing, disrobing)

### MANAGEMENT OF AGITATION

- Define the target behavior and track the frequency
  - A-B-C program (Antecedent, Behavior, Consequence)

- Example: Every time the family takes Mrs. Larson out to dinner she has a lovely time, but when she comes back she is up all night yelling
  - A: Antecedent: dinner out
  - B: Behavior: yelling
  - C: Consequence: instruct the family that going out is "too much for her"; they should bring dinner in

### MANAGEMENT OF AGITATION

- Is it somatic?
  - Pain: arthritis, stiffness, undiagnosed fractures, inability to change posture.
  - Urinary or fecal impaction?
  - Hungry or thirsty?
  - Medication?

- Review premorbid psychiatric and psychosocial
  - History of depression, substance abuse, PTSD?
  - Was person an introvert or an extrovert?
MANAGEMENT OF AGITATION

• Is it environmental? Lighting, noise level, music, privacy, loneliness
  - Avoid outings to crowded places
  - Avoid glare from windows and mirrors
  - Use lighting to reduce confusion and restlessness at night

• Is it the caregiver’s approach? An unintentionally deficit-oriented approach can lead to the patient being continually confronted with the limitations caused by the dementia.

• Is it the situation? The patient suffering from dementia is in a difficult psychosocial situation (experience of loss, relocation to a nursing home) and lacks the cognitive resources to cope with it; (Katz 2017 p 448-449).

MANAGEMENT OF DISINHIBITION

• Define the target behavior and track the frequency
  - A-B-C program (Antecedent, Behavior, Consequence)
    - Identify the triggers or responses that maintain the behavior and modify or avoid them with the aim of lessening the behavior

• Ignoring the behavior if possible, redirecting or distracting
  - Arguing or talking does not help because the person cannot control the behavior and lacks insight that it is unusual or upsetting
  - If behavior is rather less dangerous, allow it to continue
  - If people’s reaction is a problem, have family carry a small card that reads “Please excuse my family member. He has a dementia that affects the way he acts.

• Behavior modification – substitute a more socially acceptable behavior

• Keep busy by engaging in games or other activities patient used to enjoy

KEY STEPS IN THE OFFICE SETTING

Memory Concerns in the office are a call for action

• Family/Caregiver Report
  - Anosognosia: Impaired self-awareness of deficits—patients typically have little or no insight into the disease
  - Have family members fill out a packet of questionnaires either mailed out to them before hand or while in the waiting room
  - Family/Caregiver Report of Cognition
  - Lawton Instrumental Activities of Daily Living
  - Katz Independence of Activities of Daily Living
  - Symptoms of Early Dementia Questionnaire (SED-11Q)
  - Neuropsychiatric Inventory Questionnaire
  - Zarit Caregiver Burden 21-40 mild to moderate: 41-60 moderate to severe: 61+ severe

• Review the above
  - This quickly identifies issues that need your attention (nurse can review)
  - You can scan into the Media tab of Epic or your electronic medical record (EMR) and can review yearly

FAMILY/CAREGIVER REPORT OF COGNITION

LAWTON IADLS AND KATZ ADLS
CASE: FAMILY/CAREGIVER REPORT

- Elsie Larson is demonstrating a gradual decline with no insight into her problems which include memory. Bob has had to take over all the cooking and household management. Elsie needs reminders to bathe.

- The Symptoms of Early Dementia-11 Questionnaire (SED-11Q) reveal she is repeating questions and reportedly she gets agitated when family members correct her.

- The Neuropsychiatric Inventory Questionnaire (NPI-Q) reveals agitation, anxiety, apathy, irritability, nighttime behaviors and appetite/eating.

- Mr. Larson is endorsing mild to moderate burden on the Zarit.

EVALUATION OF BEHAVIORS

Interpreting the family/caregiver reports/General Principles

- Let Bob know that he is doing a good job in a difficult situation

- Review items endorsed briefly and ask which is most concerning to him that we could discuss today – e.g., constantly asking the same question
  – Ensure the problem is really a problem (i.e. Is it the patient’s problem or the caregiver’s problem?)
  – Inquire about past successes/failure
  – Educate and Advise: memory centers in the brain are deteriorating. She cannot remember she has asked before. Answer and redirect.

- Let him know there is much information and support available to them

NONPHARMACOLOGICAL MANAGEMENT

Support Organizations – First Visit

- Alzheimer’s Association (https://www.alz.org/)
  - Help & Support in the purple banner at the top of the page
  - 24/7 Helpline 800-272-3900 (not just for emergencies)

- Alzheimer’s Society Canada (http://alzheimer.ca/en/home)
  - Brochures and publications in the blue banner at the bottom of the page
NONPHARMACOLOGICAL MANAGEMENT

Support Organizations – First Visit

- Dementia Australia (https://www.dementia.org.au/)

- Alzheimer’s Society (https://www.alzheimers.org.uk/)

UCSF’S TIPS FOR DAILY LIFE

https://memory.ucsf.edu/tips-daily-life

NONPHARMACOLOGICAL MANAGEMENT

Recommended Publications – First Visit

PRINCIPLES FOR NONPHARMACOLOGICAL MANAGEMENT OF ALZHEIMER’S

Insidious, neurodegenerative disease with no disease-modifying treatment, requiring monitoring over time

- Provide good primary care
  - Minimize medications
  - Optimize hearing and vision
  - Treat depression, pain, constipation, etc
  - Check annual CBC, CMP, TSH, B12, VitD

- Empower/educate the caregiver
  - Give them the available resources for managing the patient and keeping themselves healthy
  - Complete powers of attorney for health, finances

- Support the caregiver over time.

Who are the Caregivers?

- 65% of older adults rely exclusively on family and friends for assistance
- 66% of caregivers are women, average age 49, married, and employed.
- Women are nearly half of all workers, and mothers are the primary breadwinners or co-breadwinners in two-thirds of American families.
- Four out of ten caregivers say they had no choice in becoming caregivers.
- Women caregivers are almost 6X as likely to suffer from depression or anxiety
- Women’s physical health suffers
  - 2/3 don’t take advantage of preventive health services

Sources: Family Caregiver Alliance, The Shriver Report.
WHY IS IT SO HARD FOR PATIENTS TO RECEIVE CARE?
Perspective on what your loved one might be feeling

1. I don’t feel comfortable asking for help.
2. No one wants to be a burden on others.
3. It is hard to admit to needing care.
4. I’m afraid that I’ll ask and no one will be there, or I will be abandoned.
5. I don’t want to lose my privacy.
6. I don’t want to feel vulnerable.
7. I don’t want to lose my dignity.
8. I am the giver—not the other way around.

CAREGIVING: DIGNITY AND ROUTINE

• Waiting on the caregiver increases awareness of helplessness, along with the “tedium of anticipation.” Caregiver thinks “After all, she has all day and I have so much to do.” By the time the caregiver arrives, the patient may respond in anger. The caregiver thinks “This is what I get in return?”
• Instead give the patient a realistic predictable schedule

CAREGIVING: COMMUNICATION

• Limit choices
  - “Do want the red or the blue blouse?”
• Getting into the patient’s world: Base communication on what the patient believes is real, do not correct or try to orient. Validate what the patient believes, focus on feelings.
  - Active listening
    • “Are you missing your mother?”
  - Redirect the conversation to a new topic or activities
    • “While we are waiting, let’s make some tea.”

CAREGIVING: GOOD ENOUGH

• Moderation in help: In trying to help, caregivers often take over a patient’s life. The patient may respond with frustration and bitterness. Let the patient be as independent as possible.
• Honor the patient’s preferences: When independence is threatened (or lost), what may seem trivial or inconsequential, may take on great importance to the patient.
• Identify giving opportunities: Counter the patient’s feelings of indebtedness, passivity, and uselessness by accepting their offer to help (e.g. fold towels).

CAREGIVING: MAXIMIZE STRENGTHS

• It is important to maximize our patient’s strengths and minimize what is hard for the patient. Set up an environment where success is more likely and bumping up against memory problems is less likely.
• Day programs, if available, are great at doing that.

CAREGIVING: ACTIVITIES

Pet Therapy, Music Therapy, Art Therapy, Exercise, Sing-along
CAREGIVER: TAKING STOCK
Wellness is important not only for our patients but also for their families.

It is not possible for one person to perform all the duties required for their loved one.

• Determine the needs of the patient
  − i.e. personal care, daily activities, medical, supervision, organizing home care, organizing medical care, managing finances

• Decide what needs you can or would like to meet on your own

• Determine what needs can or must be met by others

• Identify family and friends to whom you can turn for help

• Establish the need for outside professional help

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SUPPORT GROUPS ARE KEY
Partner with local senior services, social worker, hospital

• Group Purpose
  − Emotional Support
  − Social and personal support and networking
  − Information
  − Education
  − Invited Speaker
  − Skills Acquisition

• Group Audience
  − Caregivers
  − Friends, family, other interested
  − Employed caregivers
  − Patients
  − Newly Diagnosed/Early Onset

CASE: BOB LARSON, CAREGIVER

• Mr. Larson is embarking on a long challenging journey of caregiving. He has some solace in having a diagnosis for his wife of dementia.

• Not correcting Mrs. Larson when she thinks her brother is alive or when she says she wants to go home is frustrating, but he is learning.

• He told Mrs. Larson that now that he is retired, he does not have enough to do and so he wants to drive her around. She has stopped driving.

• Mr. Larson meets for coffee at the local café every morning with three other men whose wives are having trouble remembering.

• Friday nights his daughter brings the grand kids over and Mr. Larson goes bowling with his buddies.

• He looks forward to Mrs. Larson’s visit with you every 3 months where he can give you a report of how she (and he) is doing.