THE HIDDEN CAREGIVERS OF DEMENTIA: IDENTIFYING & ASSISTING

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GOALS AND OBJECTIVES

- Identifying the caregiver and personal biases
- Caregiver centric care
- DICE
- Soliciting and addressing caregiver concerns
- Healthcare provider concerns
- Interventions for caregivers

A

B

C

IDENTIFYING A CAREGIVER AND PERSONAL BIASES

Wheelchair vs. able body

Talking vs. non-expressive

Amnestic vs dysexecutive

Young vs. old

Galli, G., Lenggenhager, B., Scivoletto, G., Molinari, M., & Pazzaglia, M. (2015).

DO YOU VIEW YOURSELF AS A CAREGIVER?

- Caregivers have their own cognitive biases (O'rourke, et al. 1996)
  - Enhance the value of marriage as it becomes threatened by disease (dementia)
  - Older women show this bias
  - Caregivers who show more socially desirable responses to marriage questionnaires report less burden.
- Zarit Burden Inventory - 22 item self report (Zarit, Orr, & Zarit, 1985),
  - 1. Role strain
  - 2. Guilt
- Assess caregiver expectations of self
  - "It's my duty"
  - "I've always been a caregiver" – long list of tragic family caregiving
  - "We care for family no matter what"

IDENTIFY CAREGIVER NEEDS AND ABILITIES – WHERE ARE THEY IN THE DISEASE?

A

B

The DICE Approach

Describe

- Caregiver **describes** problematic behavior
  - Context (who, what, when and where)
  - Social and physical environment
  - Patient perspective
  - Degree of distress to patient and caregiver

Investigate

- Provider **investigates** possible causes of problem behavior
  - Patient
    - Medication side effects
    - Pain
    - Functional limitations
    - Medical conditions
    - Psychiatric comorbidity
    - Severity of cognitive impairment, executive dysfunction
    - Poor sleep hygiene
    - Sensory changes
    - Fear, sense of loss of control, boredom
  - Caregiver effects/expectations
  - Social and physical environment
  - Cultural factors

Kales et al, JAGS, 2014

Create

- Provider, caregiver and team **collaborate to create** and implement treatment plan
  - Respond to physical problems
  - Strategize behavioral interventions
    - Providing caregiver education and support
    - Enhancing communication with the patient
    - Creating meaningful activities for the patient
    - Simplifying tasks
    - Ensuring the environment is safe
    - Increasing or decreasing stimulation in the environment

Evaluate

- Provider **evaluates** whether "CREATE" interventions have been implemented by caregiver and are safe and effective

Consideration of Psychotropic Use (Acuity/Safety)

1. WHAT ARE YOUR THREE BIGGEST STRUGGLES AS A CAREGIVER TO MR. SMITH?

CAREGIVER CENTERED CARE

- The mismatch of the provider's primary concern (safety-related) with the caregiver's biggest concern (acute problem of the day)
- "Will you just tell him he has dementia, he doesn't believe me"
- "He won't stop talking about the past and repeats the same question over and over"
- "He keeps lying to me, saying he doesn't remember cutting down the bushes … should I take pictures?"

VS

- Driving; Weapons; Home Safety; Wandering; Medication Management

2. LISTEN AND VALIDATE

- Using motivational interviewing – Pick the flower in the weeds
- Regardless of risk and public safety concerns
- Find something they are doing well
- Let them talk

Because….

- This opens the door to help them
- Without a relationship, education is less effective
- Think about your experience at a service provider (car being fixed)

3. RE-LEARNING COMMUNICATION

- Validate how difficult it is to change communication
- Decrease reasoning
  - They are not in denial, lack of insight is part of the disease
- Therapeutic lying
  - "He says things that are just wrong and is sad when I correct him"
  - "I guess someone broke the computer"
- Join their reality - "You go the AZ group?"
- Repeated Question:
  - Simplify answer
  - Structure (calendar, clocks, routine)
  - BREAKS! ADHC, family visiting

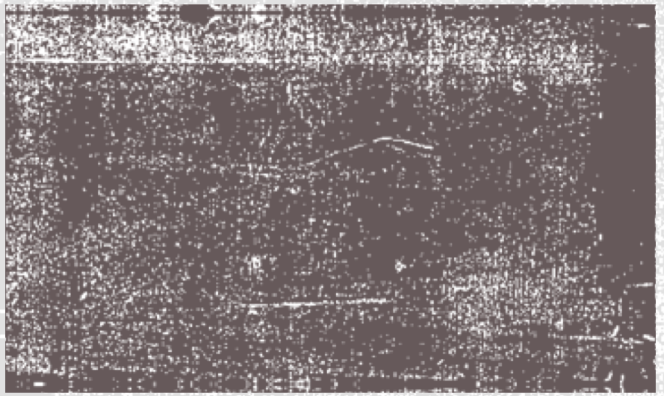
3. RE-LEARNING COMMUNICATION

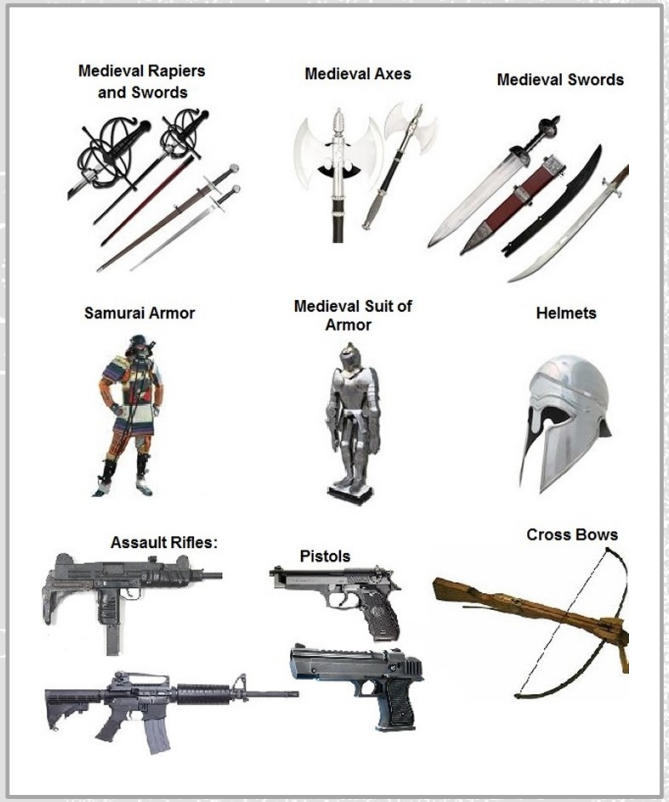
Example: Need to leave for appointment, spend 15 minutes picking out clothes

- Allow extra time and be intentional about timing of outings
- Slow down (speed of talking and approaching) to match slowed processing speed
- One direction at a time
- Respond to the emotion not the verbal content ("Well why don't you just throw me in a nursing home")
- Non-verbal language matters – attempt to not show negative emotions, respond calmly
- May forget the argument, but the emotion will stay
- This is tough: tired, sick, patience has been tested, running late

4. PUBLIC SAFETY AND PERSONAL SAFETY

- Driving
- Weapons
- Hallucinations





DELIVERY OF INFORMATION TO CAREGIVER

- Invite caregiver to call with further questions re: Driving/Weapons
- If possible meet with caregiver without patient in the room (waiting room with magazines)
- Caregiver/memory group
- 36 Hour Day (Mace & Rabins, 2011)
- REACH VA for Dementia
  - TMS training quarterly
  - Caregiver Book and Instructor manual

DRIVING

- Patient and caregiver insight into safe driving:
  - Persons with dementia are unreliable sources of information for safe driving
    - Most patients who have failed driving evaluations have considered themselves "safe drivers"
  - Caregiver
    - Most caregivers overrate safe driving of patients with dementia
    - Those who voice concerns are reliable sources
    - For those who deny concerns, report should not be weighted heavily
- Crash history/citations in last 5 years is predictive of a future crash
- Self-imposed driving restrictions may indicate higher risk for accident in MCI population
- Aggressive or impulsive behaviors + dementia put someone at a greater risk

Iverson et al (2010)

HOW TO PUT THIS INFORMATION INTO PRACTICE

- 1st: Patient – any accidents in the last 5 years? Near misses?
- 2nd: May I ask your loved one about your driving?
  - Tell me concerns you have about your loved one's driving.
  - Pay attention to non-verbals of caregiver

TALKING TO A PATIENT ABOUT SAFE DRIVING

- Those who can prepare/plan for future of not driving tend to do the best.
- Start the conversation early
- Discuss your evidence using simple language
- Involve family

1) "I recommend that you retire from driving as you are at risk of an accident"
2) Allow time to discuss patient's response, address concerns
3) Some caregivers appreciate a prescription of no driving
4) Utilize team – social work and psychology

WEAPONS & UNINTENTIONAL INJURY

- What do you consider a weapon?
- Patient/caregiver is unlikely to initiate this conversation
- In Veteran population, query if they keep a loaded rifle bedside or in a 4WW
- Similar to driving, reassure that VA cannot take your weapons
- If early in cognitive impairment, plan for the future, similar to an advance directive
- "What do you want to do with your weapons to avoid the risk of unintentional injury?"
- Encourage caregiver to find someone who can
  - Disarm the firearm
  - Check if firearms are loaded
  - Remove ammunition
  - Put in locked area
  - Consider taking to gun shop/local police station

HALLUCINATIONS/DELUSIONS

- Hallucinations – Is it bothersome or like a nice drug?
  - If bothersome - increase sensory experience
  - Gently touch patient to focus on you
  - Distract – take a walk, music, photos, move rooms, turn on lights
  - Scared of reflection – cover mirror
- Delusions – infidelity of the spouse, neighbors are harmful, stealing money
  - Arguing will likely only upset the patient and not make it go away
  - Distract, redirect
  - Remember this is the disease, not your loved one
- Consider medication if behavioral approaches are not effective and patient is distressed

QUESTIONS?

- Contact: Joleen.sussman2@va.gov

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