RESPONDING TO CHALLENGING BEHAVIORS IN DEMENTIA: THE IA-ADAPT PROJECT*

PART 1: IDENTIFYING, ASSESSING & TREATING CONTRIBUTING FACTORS

This article is the first in a two-part series about treating behavioral symptoms in dementia. The information is based on the three-year project, *Improving Antipsychotic Appropriateness in Dementia Patients*, known as IA-ADAPT. The goal of this project is to disseminate information from the Agency for Healthcare Research and Quality (AHRQ) on evidence for off-label uses of atypical antipsychotics[1] in the context of a program that promotes best practices for managing behavioral and psychological symptoms in dementia. Antipsychotics are often used to manage behavioral symptoms, but they have limited effectiveness and serious risks including increased mortality.[2] A report from the Office of the Inspector General of the Department of Health and Human Services found that 22% of antipsychotics given to nursing home residents were used inappropriately.[3] To improve appropriate use antipsychotics and reduce unnecessary use, Dr. Carnahan assembled a team of experts and developed a variety of easy-to-use pocket cards, training videos, and other supportive materials that are available for free at https://www.healthcare.uiowa.edu/IGEC/IAAdapt/nurse. Dr. Smith led the development of resources to guide use of non-drug interventions to manage behavioral and psychological symptoms. Resources were reviewed by health care providers who provided helpful input. We invite readers to access and use the materials. After creating a login for the site, electronic copies can be found on the right sidebar, and laminated copies can be requested from a link on the sidebar. Free continuing education credit is also available.

Behavioral Problems in Dementia

The behavioral and psychological symptoms that accompany Alzheimer's disease and related dementias are called a lot of different names – agitated, aggressive, disruptive, problematic, catastrophic and resistive to name a few. Although labels sometimes help describe behaviors, they may also limit our focus and taint our views. Instead of thinking about the PERSON as experiencing a problem, we tend to think of the person as BEING the problem. We forget that dementia-related behaviors are symptoms of distress: the person is uncomfortable and it shows up in their behavior.

The very nature of dementia robs the person of the ability to describe sensations and feelings. They are no longer able to say, in words, what's bothering them: "That hurts" or "I'm afraid" or "The noise level is killing me!" Instead, their behavior "communicates" that something is wrong. And in turn, caregivers must "listen" with all their senses to understand what the behavior is telling them. This isn't really much different than the care provided to small children before they learn to talk. They too "communicate" their unmet needs – whether that is hunger, discomfort, loneliness, or boredom. Older adults with dementia ALSO have unmet needs, and ALSO communicate them through their behavior.

"Responding to Challenging Behaviors in Dementia"

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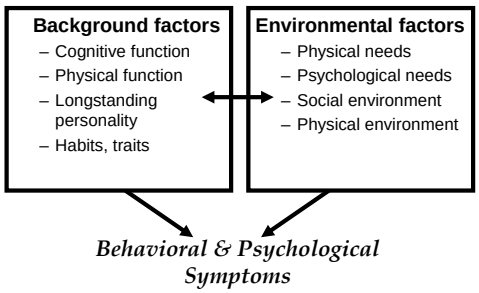
A big difference between caregiving approaches for little children and older adults with dementia is that the elder also has a long life history and many experiences that will help guide caregivers to understand what the behavior may represent. The Need-Driven, Dementia-Compromised, or NDB model[1] explains these differences. As shown in Figure 1, two main sets of factors contribute to problem behaviors. Background factors, like the person's stage of dementia, physical function, personality, and daily habits, tend to be stable and often influence how the person responds to their environment. For example, a person in the later stages of dementia responds much differently than one who is the early stages. Similarly, long-standing habits often "drive" behaviors, like trying to "leave" (labeled as eloping) to milk the cows, get the mail, or pick up the kids from school. Environmental factors are constantly changing – making them important targets for problem-solving and behavioral interventions.

Figure 1. Need-Driven Dementia-Compromised Behavior (NDB) Model



Adapted from Algase, et al. (1996)

IA-ADAPT: Three Steps

Problem-solving is an essential part of ALL dementia care models. As part of our project to reduce antipsychotic use in persons with dementia, we developed a problem-solving algorithm that builds on the NDB model and other approaches. The ideas are all grounded in dementia care research and theory, and are provided in a stream-lined format for daily care providers. We recommend a three-step approach. In Step 1, we focus on identifying and treating factors that contribute to problem behaviors. We recommend using the A-B-C approach[2] in this first step.

Start by describing the Behavior, focusing on just one behavior at a time. What is going on? Where? When? Ask yourself: Is the behavior really a problem for the resident? Or is it more upsetting to others around him/her? For example, when resident "Sally" wanders into another resident's room, and the occupant, "Mildred," becomes angry and starts yelling, whose problem is it?

Next, *look for Antecedents, or triggers* that may lead to the behavior. In our algorithm, four main groups of unmet needs may trigger problem behaviors: physical needs, psychological needs, environmental factors, and psychiatric factors. See Table 1 for examples of these factors. In the case of Sally and Mildred, Sally may just be getting some "exercise." She might also be looking for someone, or something like food, or possibly an interesting activity. Wandering into Mildred's room by itself isn't the problem. The problem is Mildred's reaction.

Table 1: Factors that Cause & Contribute to Dementia Behaviors

Unmet Physical Needs: Pain? Infection/illness? Hunger/thirst? Dehydration? Sleep disturbance? Medication side-effects? Sensory deficits? Constipation? Incontinence?
Unmet Psychological needs: Loneliness/boredom? Apprehension, worry, fear? Emotional discomfort? Lack of enjoyable activities? Lack of socialization? Loss of intimacy?
Environmental causes: Level/type of stimulation: noise, confusion, lighting? Caregiver approaches? Institutional routines and/or expectations? Lack of cues, prompts to function and way-find?
Psychiatric causes: Depression? Anxiety? Delirium? Psychosis? Other mental illness?

Source: Algorithm for Treating Behavioral and Psychological Symptoms of Dementia (aka Problem Behaviors), IA-ADAPT, http://www.healthcare.uiowa.edu/igec/

Also *look for Consequences, or reactions to the behavior*, including the reactions of both staff and other residents. The way we respond, or DON'T respond, can either increase OR decrease the behavior. In our case example, the "real" problem is when Mildred gets angry, yells at Sally, and orders her to get out of her room. Because Sally doesn't understand what she has done "wrong," Mildred's negative reaction is upsetting to her. If staff try to "help" by telling Sally "This isn't your room. Don't touch her things. You need to leave now!" – that's another reaction that Sally doesn't understand and risks making things worse.

The alternative approach is to reassure MILDRED that Sally means no harm, and then gently redirect SALLY to come with you. Try telling Sally you need her help, or have something to show her. Take her hand and smile, saying "Come with me." Calm, caring redirection using distraction is far better than giving "orders" the person doesn't understand. The tone of voice, facial expression, gestures and body language are all part of the "reaction," too. Sally doesn't understand Mildred's angry tone or grimacing face. And if staff are intent on "rescuing" Mildred from the "intruder" their approach is unlikely to engage Sally in a way that she will understand. Of equal importance, figuring out the trigger(s) to Sally's wandering can lead to approaches that reduce the risk of her "intrusions" in the first place. Offering her meaningful activities, food, company, or opportunities to exercise may all "solve" the problem.

The A-B-C (antecedents, behaviors, consequences) approach can be applied to all types of problem behaviors. Instead of "accepting" behaviors as being part of dementia, savvy caregivers look for UNMET NEEDS – things that cause and contribute to the behaviors. Paying attention to physical, psychological, environmental and psychiatric problems that overlap with dementia is critically important to reducing, resolving and preventing problem behaviors.

Our program recommends paying special attention to **delirium** as a possible cause of problem behaviors. Delirium is a psychiatric illness that is caused by physical health problems like chronic pain, medication side-effects and infections. Delirium shares many symptoms with dementia, but has a rapid onset and is reversible if the health problem is treated. See Table 2. People with dementia are at a very high risk of delirium because of the cognitive problems they already have, and reduced cognitive reserve to cope with stressors. The onset of acute confusion often causes additional behavioral and psychological symptoms that are NOT simply due to dementia. The person gets worse quickly, and often for no clear reason.

Table 2: Characteristics of Delirium

Acute onset: Is there evidence of an acute (rapid, sudden) change in the person's mental status? AND Inattention: Is the person having difficulty focusing their attention (e.g., distractable, isn't able to follow conversation) PLUS EITHER Disorganized thinking: Is the person's thinking disorganized or incoherent, as evidence by rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject? OR Altered Level of Consciousness: Is the person anything other than alert, calm and cooperative at the current time? This may include being **vigilant** (easily startled), **lethargic** (frequently dozing off when asked questions), or **stuperous** (very difficult to arouse and keep aroused), or **comatose** (could not be aroused). **Psychomotor retardation** (being sluggishness, staring into space, staying in one position, or moving slowly) also counts for this domain.

Source: Delirium Screening Tool, IA-ADAPT, http://www.healthcare.uiowa.edu/igec/

Assessing delirium symptoms using a standard scale like the Confusion Assessment Method or CAM (http://www.healthcare.uiowa.edu/igec/tools/cognitive/CAM.pdf) is valuable. Another effective approach is to ask **"Is the person more confused today than usual?"** If the answer is "yes," they likely have delirium overlapping on their dementia. Consistent staffing can help since caregivers who know a resident can more easily recognize changes. Identifying and treating the cause of delirium will reduce the resulting behavioral problems. Yes, the person will still have dementia, but the "new" behaviors should resolve. This may take time, since delirium may take longer to resolve than the underlying conditions that caused it.

In summary, successful caregivers reject the idea that dementia-related behaviors are an "understandable consequence" of dementia, OR that drug interventions are the way to "keep the peace" at home or in the facility. Instead, they STOP and question the behavior, and problem-solve to understand what the behavior "means" and what actions are needed to reduce or eliminate the behavior.

In Part 2 of this series, *Selecting and Applying Non-Drug Interventions and Monitoring Outcomes*, we'll talk about changing care approaches and the environment to reduce the risk that behaviors occur, tailoring non-drug interventions to treat persisting behaviors, and decision-making related to antipsychotic selection and use. Questions may be directed to Dr. Smith at marianne-smith@uiowa.edu or Dr. Carnahan at ryan-carnahan@uiowa.edu.

References

1. *Maglione M, Ruelaz Maher A, Hu J, Wang Z, Shanman R, Shekelle PG, Roth B, Hilton L, Suttorp MJ, Ewing BA, Motala A, Perry T. Off-Label Use of Atypical Antipsychotics: An Update. Comparative Effectiveness Review No. 43. (Prepared by the Southern California Evidence-based Practice Center under Contract No. HHSA290-2007-10062-1.) Rockville, MD: Agency for Healthcare Research and Quality. September 2011. Available at: www.effectivehealthcare.ahrq.gov/reports/final.cfm. Accessed May 5, 2012.*
2. *Jeste DV, Blazer D, Casey D, et al. ACNP white paper: update on use of antipsychotic drugs in elderly persons with dementia. Neuropsychopharmacology. 2008;33:957-70.*
3. *Department of Health and Human Services, Office of Inspector General. Medicare atypical antipsychotic drug claims for elderly nursing home residents. May 2011, OEI-07-08-00150. Available at: http://oig.hhs.gov/oei/reports/oei-07-08-00150.pdf. Accessed May 3, 2012.*
4. *Algase D, Beck C, Whall A, Berent S, Richards K, Beattie E. Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. American Journal of Alzheimer's Disease. 1996;11(2),10-19.*
5. *Teri L. Managing and Understanding Behavior Problems in Alzheimer's Disease and Related Disorders: A videotape training series for caregivers. 1990. Available at: http://depts.washington.edu/adrcweb/ManagingBehaviorProblems.shtml. Accessed April 12, 2012.*

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