
Assessment and Approach of Patients with Severe Dementia

In the past five years, a number of instruments have been made available for the treatment of moderate to advanced Alzheimer's disease (AD). The second installment of this two-part article focuses on 12 principles for treating advanced AD.

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The first part of this article,¹ expertly written by Dr. Serge Gauthier, updated us on new instruments and evaluation scales that allow us to better study the advanced stages of Alzheimer's disease (AD), as well as the clinical benefits of cholinergic agents and memantine.

For the second part of this article, I could have written about the benefits of neurotropics (antidepressants, neuroleptics, etc.), especially for behavioral problems commonly

associated with the advanced stages, but I chose not to. First of all, several articles on the subject have already been published in past issues of the *Review*.^{2,3} Second, as the disease progresses, behavioral problems that do not respond—or respond poorly—to neurotropics also increase. Such is the case, for example, observed in disinhibition, and screaming and wailing.^{4,5}

What can we do when our routine tools—medications—give us disappointing results? We need to get back to basics, back to square one, to a better understanding of the very nature of this terrible disease.

Retrogenesis

No one understood the nature of AD better nor described it as well as Reisberg when he introduced the concept of retrogenesis.⁶⁻⁸ Retrogenesis, already described in the *Review*,^{9,10} demonstrates that people suffering from AD lose their cognitive skills and abilities virtually in the reverse order in which they learned them. This explains the fact that, in the early stages of the dis-

ease, patients lose skills acquired during adolescence (planning, judgment, social skills, etc.) at the same time or perhaps even before their cognitive skills deteriorate. In the later stages of this disease, patients regress, feeling and behaving like two- to five-year-old children (stage 6) and zero- to two-year-olds (stage 7), with emotional needs, fears and anxieties.

Stage 6

During this stage, which lasts approximately two and a half years and is typically characterized by behavioral disorders, patients quickly go from an MMSE score of 10 to a score of zero. When we try to classify them, we quickly find evidence to this effect.¹¹ Some of the dysfunctional behavior is the result of psychiatric problems that have a good chance of responding to a pharmacologic approach (Table 1). Many more behavioral disorders, however, will not respond or will respond poorly because they are the result of retrogenesis. In many cases, behavioral disorders are reactions to



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this regressive or even normal state, given the context (Table 2). If we think of an agitated two- or three-year-old child in an unfamiliar environment with strangers taking care of them, some of this behavior (intrusive behavior, disinhibition, obstinacy, hoarding items, getting dressed or undressed inappropriately, asking repetitive questions, hiding objects, trying to remove any restraints, etc.) is certainly not atypical or incomprehensible.

Stage 7

Many patients, I would almost say happily, do not make it to stage 7. Many die at the end of stage 6, often due to pneumonia, a disease Mark Twain referred to as the elderly's "best friend." Patients who progress until the final stage of AD will regress to a mental age of two to zero years. At the beginning of this stage, they are able to walk, but they will eventually lose that ability. They will only be able to sit down and will become bedridden, lying in increasingly fetal positions due to muscle contraction.

Assessment

In stages 6 and 7, understanding what the patient is experiencing, making astute observations and having a good imagination will help alleviate patients' mental pain and resolve their behavioral problems. Is there an internal cause for their agitation? Is the patient hungry or thirsty and unable to express his or

Table 1

Dysfunctional Behaviors in the Elderly with Dementia which may be Amenable to Pharmacotherapeutic Management

1. *Anxiousness*: restlessness (hand-wringing, pressured pacing, etc.), fidgeting, agitation, sometimes self-mutilation
2. *Sadness*: crying, anorexia, insomnia (particularly terminal awakening), nihilism, guilty/paranoid thinking, morbid preoccupation with death
3. *Withdrawn*: apathy, quiet negativity, anorexia, sullenness, uncooperation, frequent mutedness, stuporous
4. *Markedly bizarre or regressed behavior from previous standards* (including personal appearance and lifetime moral standards)
5. *Over-eloquence*: insomnia, psychomotor hyperactivity, rapid/pressured speech, often disorganized thinking
6. *Overly boisterous*: verbal hostility, aggressiveness, argumentativeness, belligerence, physically assaultive
7. *Delusions*: ideas of influence and reference, jealousy, paranoia, fear, persecution, grandiosity, and/or tactile (formication)
8. *Hallucinations*: primarily auditory, visual, and/or tactile (formication)

her needs because he or she has lost the ability to speak? Is the patient constipated? Is he or she suffering from a urinary infection or any other hidden medical problem? Above all, is the patient in pain and, again, incapable of expressing himself or herself verbally?

Does the patient respond to an external cause, meaning the patient's setting or environment? Is the environment too complex? Does the patient have too many elements to cope with? Do the physical, psychological, architectural or other (environmental) demands exceed their abilities? Is the environment overstimulating? Understimulating? More important, is the environment hostile? Are the interventions or interactions from caregivers not consistent enough, given that patients see three different groups of caregivers on the same day?

It is clear that, in the advanced stages of AD, the most therapeutic approach is based on understanding retrogenesis: constantly adjusting to patients (and not the other way around), understanding what they are feeling as they are undergoing this inevitable regression. This approach will result in interventions that meet the real needs of patients, delivered in a professional and, it must be stated, compassionate manner.

Therapeutic Approach

Allow me to refer to some principles⁹ that are useful in providing healthcare interventions to patients in the advanced stages of AD who are agitated or in mental pain.

Determine who is agitated. Ask yourself who is really agitated in a specific situation. Is it the patient, a member of the family or

Table 2

Dysfunctional Behaviors in the Elderly with Dementia Usually Not Amenable to Pharmacotherapeutic Management

1. Wandering without aim, pacing	11. Spitting
2. Inappropriate ambulation into others' rooms, toilets, beds	12. Inappropriate undressing/dressing
3. Inappropriate, insulting, hostile or obnoxious verbalizing (including perseveration, echolalia, incoherence, calling out, cursing, strange noises, yelling or screaming)	13. Constant requests, comments, or questions
4. Annoying activities (touching, hugging, unreasonable requests, invading personal space, banging a walker, repetitive tapping, rocking, etc.)	14. Prolonged, frequent repetition of words/sentences
5. Hypersexuality (verbal or physical)	15. Hiding things
6. Inappropriate sexual activities (including public masturbation, exposing oneself)	16. Pushing a wheelchair-bound patient
7. Willfulness or other difficult personality traits (including refusing treatments, medications, care or food)	17. Tearing things; flushing items down the toilet
8. Hoarding materials (pencils, straws, cups, toiletries, clothes, etc. from other patients, nursing stations, med carts, etc.)	18. Inadvertently putting oneself or someone else in a hazardous situation/place
9. Appropriating ("stealing") items from other patients and staff (glasses, teeth, etc.)	19. Eating inedible objects (including feces)
10. Inappropriate urination/defecation (including smearing feces)	20. Bumping into objects, tripping over someone or something
	21. Tugging at/removal of restraints
	22. Physical self-abuse (e.g., scratching or picking at oneself, banging head, removing catheter)
	23. Inappropriate isolation (e.g., refusal to leave room or socialize)
	24. Physically disruptive (dumping or throwing food trays, eating from another's tray, lying on the floor)

a healthcare provider who is concerned with the patient's behavior?

Ensure that the physical environment meets the patient's needs. Organizing the patient's environment should be the first therapeutic measure taken. The patient's room should be well lit and adapted to the elderly (calendars, schedules, a clock and familiar objects from the patient's home should also be placed within view). The patient must be able to have contact with family mem-

bers and have enough room to move around.

Particular attention should be paid to the attitude of caregivers. They must reassure patients, treat them with respect, help them become aware of their environment and orient them every time they interact with them. The patient's functional capacity must be re-assessed on a regular basis so caregivers can modify their interactions accordingly. Personality conflicts

between patients and healthcare providers must be resolved quickly.

Speak to your patients. It is easy for us to forget to speak to patients with advanced AD, especially if they are aphasic and unresponsive. There is nothing better to reassure AD patients and calm them than speaking to them in a natural manner. Telling them what is going on in the care unit, speaking to them about their past interests or giving them news about their family creates a normal environment, not to mention that talking to them has therapeutic value and helps to strengthen the bond between healthcare professionals and patients.

Resist the natural temptation to probe AD patients for information.

It may be difficult for them to answer simple questions, such as "What is wrong?" or "Why are you angry?" which will only make them more confused. Connect with them instead by saying, for example, "I know that you are angry" or "You are not feeling well, but I will help you"—messages that are much more positive.

Develop efficient communication strategies. In Table 3, you will find the acronym "FOCUSED" which reminds us of the major principles of efficient communication with patients with advanced AD.¹²

Avoid construing a patient's agitation, aggressiveness or violence as a personal attack. Caregivers should never think that such behavior is directed at them

personally or that their patient is angry with them.

Never underestimate the benefits of physical activity. Regular physical activity channels patients' energy, helps them sleep better, and increases their general well-being.

Never underestimate the benefits of distracting patients during a crisis. Bring the patient into another room or suggest another activity, such as eating, which may help diffuse aggressive outbursts.

Provide consistent interventions. Regardless of the type of care plan or strategies that have been adopted for the patient, make sure the plan is applied on a regular basis by the staff of all three work shifts.

The patient's family members are the professional caregiver's best allies. When patients are agitated, the presence of their loved ones reassures them.

Finally, if the patient is agitated, determine the cause. If the behavioral problem is a new one, assess the patient's gestures and try to find out what causes it. If the disruptive behavior is something the patient has done before,

Table 3

FOCUSED Communication Strategies in Dementia

F ace to face:	- face the patient directly - attract the patient's attention - maintain eye contact
O rientation:	- orient the patient by repeating key words several times - repeat sentences exactly - give the patient time to comprehend
C ontinuity:	- continue the same topic of conversation for as long as possible - prepare the patient if a new topic must be introduced
U nsticking:	- help the patient become "unstuck" if he uses a word incorrectly by suggesting the word he's looking for - repeat the patient's sentence using the correct word
S tructure:	- structure your questions to give the patient a simple choice to respond with - provide only two options at a time - provide options the patient would like
E xchange:	- keep up normal exchange of ideas found in conversation - begin conversations with pleasant, normal topics - ask easy questions the patient can answer - give the patient clues as to how to answer
D irect:	- keep sentences short, simple and direct - use and repeat nouns rather than pronouns - use hand signals, pictures and facial expressions

find out what caused it in the past and, more important, find out what helped resolve the problem.

Conclusion

AD, especially in the advanced stages, seems to be the most horrible disease. Nonetheless, when we think of the last 15 years and the next 25, hope reigns. With two dif-

ferent classes of medication now available, there is every reason to hope for major therapeutic breakthroughs with pharmacologic research and, perhaps, stem cells.

With a better understanding of the real needs of AD patients, clinicians and caregivers will be able to provide a level of healthcare that is increasingly human and compassionate.

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