
Setting Treatment Goals Using Cholinesterase Inhibitors in AD

Although people with Alzheimer's disease (AD) may experience successful treatment, it is important to recognize that such successes are not cures, and that patients and their families need to be advised about what they should expect from treatment. This article reviews Goal Attainment Scaling—a formal process of setting goals for patient care—and discusses some practical, less formal lessons that can be taken from this process. Most patients and caregivers will find it useful to set goals in the areas of cognition, function, behaviour, leisure and social activities. Maintenance of the patient's current state often is a reasonable goal of therapy.

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The treatment of Alzheimer's disease (AD) poses important challenges, including recognizing successful treatment. Current therapies rarely result in complete recovery of function, but often result in clinically important benefits. If recognizing success were simply a matter of repeating the Mini-Mental State Examination (MMSE) to look for a two-point improvement, tracking patients would be easy. But real clinical practice is more complicated than that; therefore, it is useful to consider how important treatment effects can be detected in practice.

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One way of detecting clinically important treatment effects is to see whether treatment meets the goals set by patients and their families. This paper will review a formal process of setting goals and measuring their attainment, and suggest a few high-yield symptoms that can be tracked in many patients with AD.

Goal Attainment Scaling

Goal Attainment Scaling (GAS) helps patients and families set goals for treatment and measure the extent to which these goals have been met. Developed in the United States for use in a community-based mental-health service,¹ GAS is a five-step process (Table 1):

Identify problem areas/goals. In AD, goals typically are set in the areas of cognition, function, behaviour, leisure activities and social interactions.²

Precisely describe patient's current level of function. Symptoms of a patient's illness should each be described in a sentence or

two, under one or more of the general domains mentioned above (*i.e.*, cognition, function, behaviour, leisure activities, social interactions). For example, consider John, an 80-year-old man who lives with his wife. John was recently diagnosed with mild AD (MMSE 21/30) and is about to start treatment with the cholinesterase inhibitor (ChEI) donepezil. He stopped driving (his own decision) about one year ago, after being involved in a minor "fender bender" for which he was at fault. Since then, a regular part of his day has been making the trip to the corner store "to pick up a few items." For the last few months, however, his wife has noticed that he has become more nervous about going to the store. His wife and friends also have noticed that he no longer calls anyone to go out, even though this has been a regular part of his life and something he has enjoyed.

Therefore, in this step of the GAS process, the symptoms of

Table 1

Goal Attainment Scaling in Dementia

Step	Description	Example
One	Choose goal areas	Function: going to the corner store
Two	Explain the present level of function, scored at “zero”	Can go to the corner store to pick up a few items (see Table 2)
Three	Weigh the symptoms (optional)	Use of telephone = 6
Four	Set “better” and “worse” outcomes than the present state	Much better = “Able to go to the store...” (Table 2)
Five	Score attainment at follow-up	Function scored as +1 (Table 2)

Table 2

Goal-attainment Follow-up Guide (sample)

	Use of Telephone	Going to the Corner Store
Much better (+2)	Uses the telephone to call friends to initiate social outings; reliably takes messages with only occasional mistakes.	Able to go to the store without any problems.
Somewhat better (+1)	Calls friends more often to chat. Sometimes takes messages.	Initiates going to the store (no fretting); can pick up several items; still uses a list; no confusion over the change.
Present state (0)	Less initiative in calling friends; only uses the telephone sporadically to look up well-known numbers; no mistakes; answers consistently, but reluctant to take a message.	Can go to the corner store to pick up a few items and does so 2-3 times per week, but needs a list; has started to fret about going; can make change but sometimes confused by the “new” coins; has not gotten lost.
Somewhat worse (-1)	No longer makes outgoing calls; sometimes will not answer; does not take messages.	Occasionally has gotten lost without serious consequence; is reluctant to go, needs much encouragement and checking at the store (e.g., a call home to say he has arrived and is coming back).
Much worse (-2)	No longer answers the telephone.	No longer wishes to go—with or without assistance; often gets lost.

John’s illness (*i.e.*, being nervous about going to the store and no longer using the telephone) could each be described under the domains of “function” and “social interaction.” Table 2 is a sample of a goal-attainment follow-up guide, where John’s symptoms are described in the “Present state” category.

Weigh the symptoms on a scale of one to 10 (one=least important, 10=most important). This step is optional. If symptoms

are not weighed, each symptom is given a weight of one by default.

Define better and worse treatment outcomes. This step involves defining how to measure whether a patient is somewhat better, much better, somewhat worse or much worse after treatment. This often requires judgment and negotiation.

Score effectiveness of treatment. Effectiveness of treatment should be observed, recorded and scored in the goal-attainment

follow-up guide on a quarterly basis. The goal-attainment follow-up guide has been adapted for use in AD, where deterioration can be expected just as often as improvement. Therefore, the baseline score is always at the “zero” level. In general, we advise setting goals for one year at a time.

Good Goals

Setting goals with respect to improving a patient’s current state, or determining whether a patient’s

Table 3

Attributes of Good Goals

- Relevant
- Observable
- Attainable
- Distinguishable from other levels of attainment
- Distinguishable from other goals

state might deteriorate, requires judgment on a number of factors. Determining what is reasonable to expect from treatment is one of the most important judgments (Table 3). An important factor to consider when making this judgment is the pattern by which a patient's state has changed. In the example of John, both the "somewhat better" and "much better" categories (see Table 2) describe states that were observed by John's wife, that were distinguishable from each other in her mind, and that were important to both her and John. Several of the attributes of good goals are therefore met in this case.

In addition, goals should be realistic. For example, improvements in both initiative and social engagement appear to be common after treatment with a ChEI. In John's case, even the "much better" state recognizes that mistakes might be made, and this is realistic too.

In terms of "worse" states, these are reasonable as they reflect the natural history of untreated AD (e.g., worsening apathy, apraxia, agnosia and aphasia). Thus, in the moderate stage of AD, using the telephone can become impossible, as can going out unaccompanied. In the experience of the authors, the intermediate (*i.e.*, "somewhat worse") state is regarded as worse than the present state, and includes the types of problems that occur in

untreated patients. The intermediate state also is regarded as the "not-too-distant" future of the patient if no treatment is undertaken. In this state, problems could be experienced in well over 12 months without treatment. In contrast, a "worse-than-anticipated" state (*e.g.*, nursing-home admission within the year) should not seem reasonable for the patient, even without treatment.

In John's case, no negotiation past step three of the GAS process is needed. However, this will obviously not always be the case (see "Practical Objections" section below).

Although goals generally are set for one year at a time, patients should be seen at the intervals when changes in their conditions might be expected to occur. Intervals should be no sooner than eight weeks apart, and physicians usually score between three to six goals per patient. At each follow-up, the goal-attainment follow-up guide can be scored again. Scoring is done according to a formula that adjusts for the weights (w_i) of the level of attainment of each goal. If goals are weighted equally, the goal-attainment score can be calculated using the formula $50 + C(\sum x_i)$, where x_i = score of the individual goal and C is a constant that varies with the number of goals set for that particular patient. For example, if one goal is set, C is calculated as $10(\sum w_i) / [0.7(\sum w_i^2) + 0.3(\sum w_i)]^{1/2}$ where w_i is equal to the weight of the "ith" goal; C adjusts to the fact that different patients have different numbers of goals and that some of the goals are interrelated.

If all goals are achieved in a particular patient, each x_i will be 0 and therefore $\sum x_i$ will equal 0. Therefore, the patient score will be

50 (*i.e.*, $50 + 0 = 50$). It is not necessary to use the formula every time the GAS score is calculated, as the formula can be obtained from a table.¹ A number higher than 50 means that goals are being met; a score lower than 50 means that deterioration is happening. In this way, although the items that make up the goals vary from one individual to the next, the average level of attainment of those goals can be calculated for a group of people. This is the strategy that was followed in the Atlantic Canada Alzheimer's Disease Investigation of Expectations (ACADIE) trial.³

In the ACADIE trial, 108 consecutive patients with mild-to-moderate AD were studied over one year. GAS was done two separate times: 1) by physicians with the patients and caregivers in the office, and 2) after one week, by patients and caregivers in their own home, with the help of a trained field-researcher. ACADIE found that patients and caregivers met their goals of treatment, and GAS scores indicated statistically significant improvements, on average, for nine months. The average score was not statistically significant from baseline (*e.g.*, no deterioration from baseline) at 12 months. The full results of the ACADIE study will be reviewed in a later issue of the *Canadian Alzheimer Disease Review*.

GAS has many attractive features for clinicians. It focuses on the given problems of a given patient, and thus, by employing clinical judgment, usually gives results that make sense to patients, caregivers and physicians. It also makes use of a physician's judgment and can be a valuable aid to counseling patients.

High-yield Items for Setting Goals

Most physicians who care for patients with dementia or AD will agree that there are definite treatment-effect patterns that have emerged since donepezil became available. There is not yet, however, a systematic account of what these patterns are. As part of the ACADIE study looking at patient/caregiver/physician expectations, the following target areas were analyzed: cognition, function, behaviour, social activities and leisure. While there are standard assessment tools that capture changes in many of these areas (*e.g.*, Disability Assessment for Dementia,⁴ Neuropsychiatric Inventory⁵), GAS is a more individualized means of assessing function in ways that may be particularly relevant to individual patients.

The authors have found that several symptomatic areas lend themselves to observable goals and demonstrate treatment effects (Table 4). For example, repetitive questioning and/or repetitive story telling often are noted by family members, but often not by patients, who usually have no idea to what extent they repeat themselves. Thus, an inquiry to a caregiver often reveals there is a problem—if it has not already been raised spontaneously.

As another example, a physician might note the following in a patient's medical record: "repeats same question over 10 times per day, most days, more before appointments; granddaughter says she is 'being driven crazy,' but patient has no insight." In this instance, no specific goal needs to be set, but the presence of the physician's note can be a precise guide for follow-up.

Table 4

Areas that Lead to Observable Goal Setting and Detectable Treatment Effects

- Repetitive questioning
- Ability to initiate and carry on a conversation
- Ability and interest with respect to interacting with family and friends
- Ability and interest with respect to hobbies and chores
- Less need for prompting in instrumental activities of daily living (especially telephone use and housework)

At follow-up, the treatment area can be revisited, and the patient's state can be judged as either better or worse than the pretreatment state. The authors recommend following up eight weeks after a patient has been taking the targeted dose of his/her medication (*e.g.*, donepezil 10 mg per day.)

Integrating Goal Setting into One Office Visit

Case example. A 78-year-old retired teacher, Helen, presents with worries that her memory is becoming worse. She now has to rely on a detailed list to go to the corner store, whereas previously she relied on memory alone. She is afraid that she repeats herself when she talks to her family on the telephone. Her mother was in a nursing home with advanced AD for 10 years before dying, and in her final stages, did not know her own daughter. Helen is terrified the same thing will happen to her.

Helen presents to her doctor's office over three subsequent visits to complete her assessment. The physician requests that Helen's daughter accompany her on one visit, for the purposes of gaining collateral information. The physician determines that Helen meets the criteria for early dementia. Helen is anxious to start medication, so the physi-

cian discusses what she should expect from the medication in terms of treatment effects and side effects.

Goal areas (present state of patient is described in each class):

1. **Function.** Able to go to the store to pick up one or two items without using a list.
2. **Memory.** Currently calls her daughter two or three times every night and tells her the same thing.
3. **Independence.** Able to live on her own and not go to a nursing home.
4. **Cognition.** Helen's MMSE score is 24/30.

Practical Objections to Goal Setting

In the constrained environment of a busy office practice, proposals to do things differently often are not regarded as well-intentioned, helpful measures, and may not be welcomed. Common objections to goal setting in clinical practice are listed below:

"It takes too long." Obviously, GAS can be a time-consuming process. To save time but maintain the purposes behind the process, the authors recommend simply noting the patient's present state and setting one goal for treatment. This often can be accomplished in a sentence or two (*e.g.*, "son says his mother never initiates conversation beyond the banal, and

wishes they could speak about meaningful things again”). As opposed to taking too long, this process actually can save time at subsequent visits. Over the long run, asking a few direct questions about meaningful issues to the patient and family will be more time-efficient than continually having unfocused interviews.

“It seems arbitrary.” At its heart, goal setting involves specific information about individual patients. Thus, while the process varies, that does not mean it is arbitrary. Indeed, standard tests can be more arbitrary, as they do not take into account individual circumstances and often their clinical relevance is not evident. Having an account of issues that are known to be meaningful can

ting goals becomes easier. Any physicians who have patients with AD will need to use their judgment at some point, and setting goals helps to “sharpen” that skill over time. The process may seem difficult at first, however we all have accomplished things that seemed harder at the outset.

Conclusions

Setting goals for treatment is an important way to enhance provision of care to patients with dementia; it also can be an important part of counseling, help make decisions, and is a less arbitrary, more useful way to sharpen clinical judgment about AD and its treatment. Treatment of AD with ChEIs often results in clinically meaningful treat-

Given that widespread use of ChEIs in AD is fairly recent, new observations still are being made clinically. And since there can never be an animal model of the human mind, ChEI therapy has the potential to provide researchers with an understanding of some fundamental aspects of mindfulness. By enhancing clinical observations, and being systematic about them, physicians can help contribute to this body of new knowledge.

As more experience is gained about the use of ChEI therapy in AD, a clearer picture of typical treatment-effect patterns will emerge. In consequence, we will be in a better position to give pragmatic advice about what to expect from treatment.

Treatment of AD with ChEIs often results in clinically meaningful treatment effects, even if patients are not cured. These effects can be detected formally, using the GAS process, but the essential feature of GAS can be done less formally, as part of routine care.

be less arbitrary than a process influenced by recent events (either good or bad), unrepresentative of how things are going and/or unimportant in the larger scheme.

“I’m not sure I know enough to be confident about my judgment of treatment ahead of time.” Chances are, if someone is reading this article, it is because he/she is interested, and if someone is interested, he/she has already won half the battle. Although the GAS process may not be as straightforward as following the inventory for other conditions (e.g., heart failure: “How many pillows? How far can you walk? How are your ankles?”), with time and practice, set-

ment effects, even if patients are not cured. These effects can be detected formally, using the GAS process, but the essential feature of GAS can be done less formally, as part of routine care. Good goals are observable, reliable, realistic and meaningful to patients and their caregivers, and each goal often can be summarized in a sentence or two.⁶ No more than three goals per patient are needed to understand whether treatment has been successful.

Good goal setting can help patients and their caregivers understand what lies ahead and, over time, can help sharpen the clinical judgment of physicians.

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