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ON THE COVER

The Caregiver, Paper collage by Jonah Samson

I wanted to find some hope in Alzheimer's disease. I wanted to produce an artwork that would reassure those confronted with this terrible and discouraging disease. What struck me most in my search for inspiration was not the efforts of science and medicine, but the unwaivering support provided by those family members who care for Alzheimer's patients everyday. I felt inspired by the effort and commitment they showed. I wanted to express this commitment in the greenery of the background, the clear skies, the embrace of the two figures, and in the fruit and eggs I placed on the table to express life, renewal and expectation. When it came time to create the faces, however, I was forced to recognize the distress that accompanies Alzheimer's disease. And so, despite my intent to convey hope, this picture remains touched by sadness.

We'd Like to Hear From You!

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Unique Perspectives

by Peter N. McCracken, MD, FRCPC

This issue of the *Canadian Alzheimer Disease Review* offers some refreshing viewpoints and commentaries on otherwise traditional concepts. Among them is the description by Drs. Mary Gorman and Kenneth Rockwood on the formal process of setting goals for patient care—Goal Attainment Scaling—particularly with respect to evaluating patient response to cholinesterase-inhibitor treatment. The article (page 4) contains a step-by-step account on how to establish practical, relevant, and attainable goals for each individual patient that embarks on treatment with a drug of this class. Rather than using outcome measures designed by a researcher who may be geographically and culturally remote from any individual patient, why not place this process in the joint hands of the healthcare team, patient, and caregiver? The key to the process is determining what is reasonable to expect from treatment. Such goals are set in the areas of cognition, function, behavior, leisure and social activities. Goals are then weighted according to the categories "somewhat better" versus "much better," or "somewhat worse" versus "much worse." The mathematical formula for calculating whether a patient improved or deteriorated from baseline status is also revealed. To impart fairness to the viewpoint offered, practical objections to goal attainment scaling, as well as hurdles in the process, are outlined clearly.

Dr. Chris MacKnight tackles the complex question of the incidence and prevalence of dementia in the extremely elderly (*i.e.*, those aged 90 years and older; page 10). It is lamented that most epidemiologic studies of dementia include very few individuals older than the age of 95 years. It is suggested that studies specifically aimed at demented individuals of advanced age would circumvent the non-response bias and improve the appropriateness of any cognitive examinations used. Dr. MacKnight also focuses on the growing discrepancy, with increasing age, of the extent of neuropathologic changes in the autopsied brain and the degree of cognitive impairment immediately prior to death. The curious decline in the incidence of Alzheimer's disease (AD) in centenarians also is noted, even though the prevalence of other types of dementia continue to increase. A further variation is the reduced impact of the apolipoprotein E epsilon 4 allele upon the expression of AD in extremely elderly subjects.

Dr. Timothy Epp presents the concept of person-centered dementia care (PCC; page 14). The central principle of PCC is that an individual's life experience, unique personality and network of relationships should be valued and taken into account by staff in care settings. The maintenance of a positive, supportive, social environment for persons with dementia is described thoroughly, and the barriers to this goal also are well articulated. The lack of strategies with which to address variation in individuals with dementia at different stages is put forward.

Also included in this issue is the first chapter in a series articulating the unique reflections of an AD caregiver named Roberta Bedard (page 20). This opening chapter sets the stage for what is to follow in an individual's crusade to battle and cope with the progression of AD in her husband.

Finally, this issue's contribution from the Alzheimer Society (page 22) reveals the unique evolution of the Society's focus in its 25 years of existence. Its journey is chronicled from the provision of support programs and educational information for family members and caregivers of people with AD to the establishment of focus groups involving individuals with early AD. These focus groups occur while early-stage individuals still have significant insight into their own changes as well as the language skills to express these changes. This new partnership with the patients themselves has added extremely valuable information to the wealth of knowledge the Society provides to caregivers and patients.

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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.

by Mary Gorman, MD, CCFP, and Kenneth Rockwood, MD, MPA, FRCPC

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 "i^{th}" 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 Inventory[5]), 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 physician 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 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, setting 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 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. 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.

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.

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Is Dementia Inevitable?

Does the incidence of dementia steadily increase as we grow older? Or is there a decrease or plateau in risk? To answer these questions, this article reviews the epidemiology of dementia in extremely old age and examines the distribution of specific causes of dementia. Important risk factors for and possible mechanisms of dementia also are discussed.

by Chris MacKnight, MD, MSc, FRCPC

Many diseases are either age-related or aging-related. An age-related disease is a disease that typically occurs around a specific age (*e.g.*, Hodgkin's disease, rheumatoid arthritis). An aging-related disease is a disease that typically occurs with increasing age, and often is considered to be caused, at least in part, by degeneration of and/or "wear and tear" on the body's cells and tissues (*e.g.*, osteoarthritis, atherosclerosis). Aging-related diseases are diseases that many of us can expect to develop, if we live long enough. Into which category does dementia—specifically Alzheimer's disease (AD)—fall?

The prevalence and incidence of AD increase exponentially with age, and some studies have reported a prevalence of dementia close to 100% in people around 100 years of age (centenarians).[1] Most of these types of epidemiologic studies, however, have included very few people older than 90 years of age.

This review will briefly discuss studies that have evaluated the eldest of the elderly population, and also will review explanations for some of the conflicting findings.

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Epidemiology of Dementia in Late Life

Early epidemiologic studies of dementia included very few subjects older than 95 years of age. For example, the EURODEM-prevalence-research-group analyses, which included close to 16,000 subjects, had only 69 subjects older than 95 years of age.[2] An early systematic review did not attempt to draw conclusions about the extremely elderly, because of their under-representation in the 47 studies reviewed.[3]

Several large, recent epidemiologic studies have reported the prevalence of dementia in their eldest participants:

- ***The Kungsholmen study.***[4] Investigators from this study found a 30% prevalence of dementia in men and a 50% prevalence of dementia in women ≥ 95 years of age, with another 12% of subjects having questionable dementia.
- ***Canadian Study of Health and Aging (CSHA).***[5] This study reported a 59% prevalence of dementia in those aged 95 years and older, with 86% of those aged 100 years and older having dementia.
- ***The Kame project.***[6] This study evaluated Japanese-Americans in Washington State and found a steady increase in the prevalence of dementia with increasing age, with over 70% of men and women aged 95 years and older having dementia.
- ***The MRC-ALPHA project.***[7,8] This study took place in Liverpool, England and found only a 47% prevalence of dementia in centenarians.
- ***Ritchie and Kildea.***[9] This 1995 meta-analysis concentrated on the extremely elderly and analyzed data from 1,388 subjects aged 90-94 years and 317 subjects aged 95-99 years. The prevalence of dementia did not increase exponentially compared to younger ages; rather, the rate of increase in dementia prevalence was found to fall in the age range 80-84 years; around the age of 95 years, prevalence was seen to level off. The prevalence of dementia at age 95-99 years was 44.8%.

Unfortunately these cross-sectional studies are plagued with biases. Sample sizes often are very small and non-response rates are very high. For example, the Kungsholmen study had a 40% non-response rate in the ≥ 95-year age group. And in the CSHA study, the

extremely elderly were almost all nursing-home residents. Subjects with dementia are more likely to refuse participation in such studies,[10,11] and since dementia increases mortality,[12-14] cross-sectional studies may underestimate the true burden of disease, through both non-response bias and selective mortality.

A more useful approach may be to conduct studies specifically aimed at the extremely elderly. This may decrease the non-response bias and improve the appropriateness of any cognitive examinations used.

A number of centenarian studies have investigated cognition in detail. Table 1 summarizes the results of population-based centenarian studies.[15-23] The prevalence of dementia in these studies is most often between 30% to 60%, with women generally having a higher prevalence than men. When causes of dementia are reported, AD emerges as the most common, with over 75% of cases in Italy, Finland and Japan having that diagnosis.[16-18] The exception is Denmark, where 50% of dementia cases are classified under vascular dementia.[22] Many of the studies also include a cognitive impairment—not dementia—category; 20% to 30% of cases are classified under this diagnosis.

Some centenarian studies include neuropathologic examinations. A small series of studies evaluating cognitively normal Japanese centenarians found that 92% had incurred at least one infarct, but few had any changes associated with AD, such as plaques or tangles.[24] Furthermore, a small French study found no relationship between the density of senile plaques and the degree of cognitive impairment.[25]

Table 1

Population-based Centenarian Studies

Place	Complete Examinations	Non-response Rate	Prevalence
Leiden[15]	34	—	41%
Finland[16]	185	32%	36% male/17% female
Japan[17]	47	6%	70%
Italy[18]	92	60%	70% male/50% female
Netherlands[19]	15	12%	87% male/100% female
Sweden[20]	100	39%	30% male/16% female
Tokyo[20]	218	67%	71% male/43% female
Denmark[21,22]	207	19%	51%
New England[23]	34	21%	64%

Several studies suggest that the extent of neuropathologic changes and degree of cognitive impairment are poorly correlated in the extremely elderly.[26,27] In the New England Centenarian Study,[28,29] infarcts were common, but few patients met neuropathologic criteria for AD (even among those with a clinical diagnosis of AD). Several patients had no cognitive impairment, despite extensive neuropathologic abnormalities, and conversely, several patients with significant cognitive impairment had no identified neuropathologic abnormality.

Even the centenarian studies have significant non-response and cannot account for any mortality bias. Additionally, surveys of particular age groups, at particular points in time, are vulnerable to cohort effects, where the findings may be due to something common to that cohort of subjects, rather than reflecting some biological property of aging. Longitudinal studies can overcome some of these weaknesses by accounting for mortality and, perhaps, comparing multiple cohorts. Unfortunately, even longitudinal studies are vulnerable to non-response, as drop-outs from these studies are more likely to be cognitively impaired.[30]

The longitudinal studies that have reported results in extremely old age generally show a decline in incidence of dementia for men, with the decline in women, if present, occurring later.[31-37] However, several studies have shown no decline in incidence.[7,38-40] When examining subtypes, most studies showed a decrease in the incidence of AD, particularly in men, even when the incidence of all dementias continued to increase.[32,33,36,37,39,40]

The investigators from the Cache County study[37] performed a particularly thorough analysis. This study included a largely Mormon and rural population with AD and other forms of dementia. The investigators found a decrease in the incidence of all dementias in men and women in the oldest age group

When causes of dementia are reported, AD emerges as the most common, with over 75% of cases in Italy, Finland and Japan having that diagnosis.[16-18]

(≥ 93 years). Careful examination suggested that this decline was not a methodologic artifact. Possible explanations for the results include: unusual aspects of the population; heterogeneity, such that an "early-" onset group disappears, leaving an impervious group; or the interaction of vascular and dementia risk factors (*i.e.*, those at highest risk die younger).

Apolipoprotein E and Dementia in Late Life

The presence of an apolipoprotein E (ApoE) epsilon 4 allele may increase one's risk of AD, however its effect in late life is controversial. Several centenarian studies have demonstrated no increased risk of AD with an ApoE epsilon 4 allele,[16,17,41] but results from other studies conflict.[42] Studies also have shown that the epsilon 4 allele may not impair cognition in very old people who are not demented,[42,43] but again, results from other studies suggest otherwise.[44] Interesting results from a Finnish study[45] found that ApoE status did not correlate with clinical dementia, but did correlate with neuropathologic AD (*i.e.*, 42% of participants carrying the epsilon 4 allele, who were not demented, had neuropathologic AD). Investigators also have found that, although the epsilon 4 allele predicts early onset of dementia, there is a peak after which both the incidence and prevalence of dementia decrease, even in the presence of the epsilon 4 allele.[46,47] Investigators from the Adult Changes in Thought study found similar results.[40]

Is There a Primary Dementia of Aging?

Terry and Katzman[48] argue that there is a primary dementia of aging. They believe that with ongoing neuronal and, most importantly, synaptic losses, we all will develop dementia. Their hypothesis suggests that humans gain synapses in early life (a process accelerated by education) and then, after adolescence, inexorably lose synapses. Any negative effects of these synapse losses are not seen until a critical threshold is reached—a threshold that is far past most people's expected life span. People with less education and/or neuronal loss due to other factors (*e.g.*, alcohol abuse, head injury, hypertension) may exhibit this primary dementia of aging at a younger age.

Although this is an interesting hypothesis, there is little hard evidence to support it at this time. However, sophisticated magnetic-resonance-imaging (MRI) studies suggest that "connectivity" is lower in older, healthy subjects compared to younger, healthy subjects.[49] Terry and Katzman's hypothesis certainly is one method to explain the apparent "disconnection" between neuropathologic changes and cognition in extremely late life.

Conclusions

This review, in effect, raises more questions than answers:

1) Is the decline in incidence of AD in men a true finding, or is it due to the frequency of coexisting stroke and the difficulty operationalizing standard criteria in the extremely elderly?
2) How can the disconnection between neuropathologic findings and dementia be explained?
3) How appropriate are neuropsychologic examinations in these subjects, who often have severe vision and hearing impairment, and functional impairment unrelated to their cognition?
4) Does the effect of ApoE truly disappear?
5) Are cholinesterase inhibitors safe and effective in the extremely elderly—an age group which is typically excluded from clinical trials?
6) Can lifestyle changes and chronic-disease management prevent dementia even in extremely old age?

Despite the need for further investigations to answer these questions, the results of this review are hopeful in the sense that there is definitely a substantial minority of centenarians who remain cognitively intact. Therefore, there is one final question we can answer:

Is dementia inevitable? No.

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Person-centred Dementia Care: A Vision to be Refined

Healthcare professionals have increasingly been moving away from a task-oriented, professional-driven model of healthcare, towards a more holistic model of care which emphasizes patients' perspectives and their subjectively defined experiences and needs. In the field of dementia care, this shift has been described most often as a move towards "person-centred care." Despite a wealth of literature describing the philosophy of person-centred care, we know very little about the current definition and implementation of this philosophy in dementia-care settings. This article will provide an overview of the literature to date.

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The concept of the "person" is at the centre of current debates on the beginning and end of life,[1] the assessment of competency,[2,3] and human suffering.[4] Promoted as a shift in the "culture" of care, holistic dementia care is referred to most often as "person-centred" (although terms such as "individualized," "resident-focused," and "patient-centred" also are utilized), and is based on various sources, including the social psychology of professor Tom Kitwood.[5]

Person-centred dementia care (PCC) has emerged as a response to an old culture of care[6,7] which: 1) reduced dementia to a strictly biomedical phenomenon;[8] 2) was task-driven; 3) relied on control techniques including chemical and physical restraints,[9] warehousing and unnecessary medication; and 4) devalued the agency and individuality of persons with dementia. In contrast, PCC is value-driven, focuses on independence, well-being and empowerment of individuals and families,[10] and "enables the person to feel supported, valued and socially confident."[11] Promotion of PCC also is a response to the lack of attention in dementia research, and to the agency and subjectivity of persons with dementia.[12]

Personhood

According to Kitwood,[5] personhood is "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being... impl[ying] recognition, respect and trust." The aim of good dementia care is "to maintain personhood in the face of the failing of mental powers."[5] Attention to personhood includes recognition of "the centrality of relationship, the uniqueness of persons, [and] the fact of our embodiment."[5] Dementia care which focuses only on the disease and its treatment does not attend to a patient's personhood, treats the patient as a passive object, and is damaging to the patient.

PCC is founded on the ethic that all human beings are of absolute value and worthy of respect, no matter their disability, and on a conviction that people with dementia can live fulfilling lives[8] (Table 1). Central to PCC is the principle that an individual's life experience, unique personality and network of relationships should be valued and taken into account by staff in care settings. This perspective is founded on the observation that the presentation of dementia cannot be reduced to the effects of neuropathologic damage, but is instead a combination of factors, including personality, biography, physical health, neurologic impairment and social psychology. In contrast, focusing on a patient's losses or deterioration may reinforce negative perceptions and treatment of individuals with dementia, and also may have a significant impact on the progression of dementia.

Several studies have identified the importance of self-esteem for the overall well-being of persons with Alzheimer's disease (AD).[13,14] PCC involves the establishment and maintenance of positive, supportive, social environments for persons with dementia (Table 2). In these contexts, personhood of individuals with dementia may be enhanced by strengthening the person's positive feelings, nurturing the person's abilities or skills and helping the healing of a psychic wound.[15]

Through the generation and/or sustenance of positive interactions, stability and secure relationships, the personhood of individuals with dementia is replenished continually. Specific psychotherapeutic techniques (Table 2) to facilitate these relationships include the following:

1) ***Validation*** – the acceptance of reality, and feelings of being alive, connected and real.
2) ***Holding*** – the provision of a safe psychological space where tension and vulnerability may be exposed. Holding may be both psychological and physical.
3) ***Facilitation*** – "enabling a person to do what otherwise he or she would not be able to do, by providing those parts of the action... that are missing."[5]

Table 1

Person-centred Dementia Care Defined

1. Care that is centred on:
   a. the whole person, not on the diseased brain;
   b. remaining abilities, emotions and cognitive abilities—not on losses;
   c. the person within the context of family, marriage, culture, ethnicity, gender.
2. Care that is centred within a wide society and its values.

Adapted from: Cheston R, Bender M. *Understanding Dementia: The Man with the Worried Eyes.* Jessica Kingsley Publishers Ltd., London 1999, p.12.

Table 2

Positive Interactions in Person-centred Dementia Care

Social interactions

Recognition:	individual known as a unique person by name; involves verbal communication and eye contact
Negotiation:	individual consulted about preferences, choices, needs
Collaboration:	caregiver aligns him/herself with care recipient to engage in a task
Play:	encouraging expressions of spontaneity and of self
Stimulation:	engaging in interactions using senses
Celebration:	celebrating anything the individual finds enjoyable
Relaxation:	providing close personal comfort (*e.g.*, holding hands)

Psychotherapeutic interactions

Validation:	acknowledging person's emotions and feelings and responding to them; empathy
Holding:	providing a space where the individual feels comfortable in self-revelation
Facilitation:	enabling person to use their remaining abilities; not emphasizing errors

People with dementia can take a leading role in:

Creation:	individual spontaneously offers something to the interaction; affirmation of this
Giving:	individual offers him/herself in a positive emotional or helpful way

Adapted from reference 15.

Signs of Personhood

PCC has been encouraged by first-hand accounts of the experience with dementia[16,17] and by a wealth of recent studies revealing qualities of personhood in individuals suffering from dementia.

The qualities of personhood include self-awareness,[18] subjectivity,[19,20] meaning-making,[21,22] meaningful talk,[23] sexuality,[24] expressive behavior,[25] autonomy,[26] social and cognitive abilities,[27] an intact sense of social and personal identity,[28] humor and individuality,[29] and agency and the capacity to value.[30] Although persons with dementia experience diminishing linguistic ability as the disease progresses, they often are able to compensate with extralinguistic communication (*e.g.*, gesture).[31] The individual with dementia is not simply a passive victim, but rather "seeks actively to make sense of and cope with what is happening."[12] Discussions on dementia care in bioethics literature also promote treatment and care based on personhood[28] and "ethics of the everyday,"[32] focused on an "embodied personhood expressed within a context, and through relationships."[33]

There also is evidence that individuals with dementia, who are given appropriate support, sometimes can experience "rementia"—learning and experiencing cognitive clarity despite degenerative neurologic impairment.[6,34] This work points to the significant potential of persons with dementia and the important roles they can play in their own care and in decisions affecting their lives, when provided with appropriate support and services.

Benefits of PCC

Several studies have revealed positive results from the implementation of PCC.

Quality of life. Burgener et al[35] found that a person-centred approach, including the maintenance of social activities, past pleasures and activities, was associated with positive quality-of-life outcomes in individuals with AD. They also found that the quality of the relationship between caregivers and individuals with dementia was associated with the care recipient's level of depression, psychological well-being, and productive behaviors.

Decreased agitation. Matthews et al[36] found that a client-oriented intervention for agitation and sleep patterns of persons with dementia, emphasizing freedom of client choice for activity scheduling (*e.g.*, meals, toileting, ward activities, bed times), resulted in decreased verbal agitation levels and staff feeling less rushed and more tolerant of residents' behaviors.

Improved sleep patterns. Richards et al[37] found that an intervention to individualize activities, with respect to each participant's past interests and current capabilities, led to improvements in nocturnal sleep and reduction in daytime napping.

Maintenance of self-esteem. Sabat et al[13] found that, when the positive attributes of dementia sufferers' selves are attended to by others in their social milieu, and when the opportunity for self-expression is provided, persons with dementia are better able to maintain self-esteem while minimizing anxiety, grief, anger, and the feeling of being a burden to others.

Specific strategies for the professional practice of PCC also have been discussed in the literature. These include:

- assessments which involve and recognize the choices of care recipients and family caregivers;[38,39]
- assessments which are non-judgmental and build trust and rapport;[38,39]
- the provision of alternate bathing methods, such as the towel bath;[40]
- activities which are appropriate with respect to the remaining cognitive abilities of the person with dementia;[26]
- culturally sensitive services;[41,42]
- continual assessment of the person with dementia and involvement of relatives in care planning;[25]
- recognizing vocalizations as attempts to communicate;[43] and
- the use of resident biographies and personal profiles.[44]

Central to these techniques is the development of positive relationships between all those involved in the caring process. In fact, high-quality care is dependent on understanding the care recipient's life and identity, and on the fostering of these relationships.

Barriers

Despite the positive findings with respect to implementation of PCC,

PCC is founded on the ethic that all human beings are of absolute value and worthy of respect, no matter their disability, and on a conviction that people with dementia can live fulfilling lives.[8]

several problems confront its promotion. First, there is little consensus on the definition of "person-centredness."[45,46] Schwartz et al[45] write, "... despite the ubiquitous promotion of these principles, practitioners of person-centred approaches are confronted with a paradox that hinders perception and understanding of its particular benefits, and obscures its focus; there is no broadly accepted definition of the person-centred approach itself."

PCC most often is described in abstract terms of quality, rather than in guidelines for how that quality may be achieved.[47] PCC is both a philosophical approach and a practical component of patient care, having formal and informal meanings and implications for practice—a dynamic concept which changes with a patient's physical condition and the environment of care.[48] Studies to date, however, have not explored the definition and implementation of PCC within a range of care programs and services, or how the philosophical approach is incorporated into practice. Furthermore, although PCC has been promoted for individuals at all stages of AD,[49] little research has been conducted to explore the meaning of PCC for individuals at different stages of dementing illness, or for individuals varying by gender, age or ethnicity. The absence of a clear definition of PCC places limitations on our understanding of its benefits for individuals with dementia, as well as for program administration, nursing staff, and caregiving families.

We have only a minimal understanding of the factors supporting or impeding the implementation and practice of PCC.[50] While PCC may focus on the needs of individuals, it still may be guided by the values of professionals, as opposed to the care recipient and the caregiving family.[32] Issues of institutional power, and of staff roles and responsibilities, may place professional staff in conflict with the very essence of "person-centredness."[51]

It becomes more difficult to implement PCC when the families of care recipients are not present at the time of admission to long-term care, or when care recipients have no family members to provide critical personal information.[52] There also is a scarcity of research on successful strategies for PCC.

It is impossible to further develop the practice of PCC without an understanding of the ways in which the philosophy of PCC has successfully been implemented by administration and nursing staff.

Next Steps

The future practice and development of PCC depends on several requirements. Care providers must be aware of the values forming their own definition of "personhood," how these values form the practice of caring, and the fact that definitions of PCC vary between administrative personnel, front-line nursing staff, family caregivers and individuals with dementia. Care providers also must carefully assess the factors which promote and impede PCC, and share their success stories with other care providers. Academic research also can support these goals—particularly qualitative research, which applies to the experiences of dementia and caring, and to the perspectives of all involved in the caring process.

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PERSPECTIVES

Personal Revelations, Experiences and Reflections of an AD Caregiver

Roberta Bedard is a caregiver for her husband who has Alzheimer's disease (AD). She has written many humorous and touching vignettes about her personal experiences in dealing with the development of the disease, and has graciously agreed to feature these vignettes as a series in this and upcoming issues of the *Canadian Alzheimer Disease Review*. Roberta's writings enable readers to share in her journey with AD caregiving, provide valuable insight on the human aspect of disease and stimulate contemplation on the deeper meanings of life and love. In this feature, Roberta discusses the ways in which she and her husband dealt with his diagnosis and came to terms with the impact it would have on their future.

CHAPTER 1

The Beginning

by Roberta Bedard

I cried. For three days. Straight. I cried when I woke up. I cried as I was driving to work. I cried as I sat in front of my computer. I cried when I tried to eat lunch. I cried on my husband's chest. I splashed tears into the pan as I cooked dinner. I cried when I was getting ready for bed. I weep now as I am writing.

Even though writing this article brings back the overwhelming emotions that assailed me when my husband and I began this journey into the black unknown that is Alzheimer's disease (AD), it must be done. And it is important for the reader to know that I am not a "Pollyanna." I am not one of those sunny people who seem to go through life facing devastating circumstances with unthinking optimism.

My husband and I view ourselves as survivors. The habits of a lifetime took over and we thought, "We will get through this." But how? This terrible disease would rob each of us of our best friend. Because, make no mistake, AD is a joint disease. Just as we have ownership of our condominium, so we have joint ownership of AD.

We decided to take advantage of the knowledge we already had. My husband, a retired social worker, had worked with AD patients in an auxiliary hospital setting. I had recently studied the sociology of aging, which included studying dementias from the sociological perspective. We then plunged into the depths of information provided by the Alzheimer Society of Canada. We read. We talked to each other and to anyone else we could find who could give us information.

We soon found that there is no shortage of available material about AD. And there is support for "caregivers" (my new label).

But as I learned more, my sense of panic grew. There were warnings about patient wandering, patients hiding things and about the constant anxiety and fear patients feel. And it seemed to me

that caregivers had to be one step removed from angels. We are to be understanding, to take abuse from our previously gentle loved ones, to live in chaotic households... to have no lives of our own.

I am not a saint! I have never considered myself a "caregiver." My approach to someone else's headache is to make sure they know where the aspirin are.

My beloved husband would become dependent on *me*? My heart ached for him. He would be in my hands, and those hands felt much too weak for the task.

Through all this initial turmoil, my husband was a bastion of strength. He kept reassuring me that I could cope. The knowledge he had gained while working with AD patients and their families in the auxiliary hospital setting comforted him—enough to be able to comfort me. We drew strength from each other, but in the beginning, I was the one making the heavy withdrawals.

As practical people, we knew the beginning period was the time to take action to protect us both from the future consequences of the disease. We drew up Enduring Powers of Attorney so that I would have the legal authority to conduct our financial affairs when my husband became incapable. I told his children and mine. We started organizing our household and making lists. We had taken to heart the "three months or ten years." If three months was all we might have, a lot had to be done.

And still, occasionally, I cried.

One day, in our local paper, there appeared a small article describing a medication that was newly available in Canada. Though not a cure, this medication could possibly slow down the progression of AD symptoms. Clutching my two-inch newsprint square of miracle, I talked to our doctor.

"It's not worth trying," he said. "It will only buy you six months. It doesn't work for everybody. It's expensive," he said.

Through the AD Society, we found a different doctor: one who had a different approach and who, at least, supported us in our desire to try.

And we learned again that part of our survivorship skills was stubbornness. Because we were among the lucky ones. The medication worked. It has already bought us an extra year. More than that, it has given us hope.

Matters were in good shape when I came across an article by Barry Reisberg on retrogenesis. As I read about the Retrogenesis Theory, my sense of competence grew. Vastly simplified, the theory is that stages of AD can be correlated to specific developmental stages in children. This correlation can help caregivers understand what can realistically be expected from our loved ones. For example, a patient at Stage 5 can be expected to function at the level of a five- to seven-year-old child.

My heart pounded as I read this information—for two reasons:

1) I, along with a great number of caregivers, have been a parent. I may have no experience with AD, but I do have experience with children;
2) what the article *didn't* say.

What the article didn't say is that five- to seven-year-olds are fun to be around. They are nice people. And I thought, "If I can get my mind past grieving for the 70-year-old husband I have lost, and find ways to enjoy the seven-year-old I may have in the future, maybe—just maybe—I can find joy."

I began to visualize going for walks, stopping to admire an anthill. I thought about bath time, with games and laughter. And I imagined myself laughing at the antics of Teletubbies—just as John Bayley did when he watched television with his wife, philosopher and novelist Iris Murdoch, after she developed AD.

Nowhere in the literature available to me was such a point of view expressed. As I talked to various professionals to see if my feelings made any sense, I found they agreed. Although *everyone* stated they had not thought about the disease that way. Therefore, I decided that something (a book or booklet) needed to be written.

Dr. Bernard Groulx, chief psychiatrist at Ste-Anne-de-Bellevue Hospital and an associate professor at McGill University in Montreal, Quebec, also thought I made sense. He graciously agreed to take time from his busy schedule to look over what I wrote, so that I would not inadvertently mislead anyone. So, while these writings are very personal, the facts about AD will be correct, and my interpretation of the research will be realistic (though colored by my feelings).

Please look for *Chapter 2: The Retrogenesis Theory* in the next issue of the *Canadian Alzheimer Disease Review*.

Alzheimer Society
CANADA

News from the Alzheimer Society of Canada

People in Early Stages Shaping the Future of their Care

This year, the Alzheimer Society of Canada (ASC) is celebrating its 25th anniversary. As we commemorate one quarter of a century of helping people affected by Alzheimer Disease (AD)—whether through support and education programs or by funding Canadian researchers—we recognize a significant change that has taken place recently in our history: a change that has greatly influenced how we provide programs and services for people with AD and their families.

In the past, people with AD were often too far along in the disease process to play a part in making decisions with respect to their futures. For most of our history, therefore, the Society has provided support programs and educational information for family members and caregivers of people with AD. And when feedback on new programs was needed, we consulted with family members and caregivers. But in the last few years, there has been a significant shift in how the Society serves "people affected by AD." Now, we also provide support programs and educational material for people with AD, because more and more they are being diagnosed in the early stages of the disease, and are able to participate in the management and care of their disease. Today, people with AD are increasingly playing a role in their own care and collaborating with the Society to provide input into the programs and educational materials that are created.

"The opportunity for early diagnosis of AD," said Stephen Rudin, executive director of the ASC, "is a significant advance in the history of the disease and one that the Alzheimer Society of Canada fully encourages people to seek. Early diagnosis empowers people with the disease and allows them to seek information and support from the Alzheimer Society, while also giving them more choice in the area of pharmacological treatments. The Alzheimer Society of Canada has benefited from having the insight of people living with the disease and we continue to partner with them to maintain and create new programs to serve them."

One such effort took place in the summer of 2001. The ASC coordinated focus groups, across Canada, of people in the early stages of AD or a related dementia. The objective was to gather information from these individuals to assist the ASC in producing materials designed specifically for them and others living with AD or a related dementia.

A list of questions was distributed to provincial and local Alzheimer Societies that offer support groups for people in the early stages of AD. Ten early-stage support groups participated in the survey, representing seven provinces. Fifty-four men and women took part, ranging in age from 52 years to 83 years.

A variety of questions were posed to the participants eliciting helpful, insightful and sometimes surprising responses. The questions were as follows:

- What information do you need at this time?
- What concerns do you have with respect to losing abilities/family/staying in your home/dying?
- What kind of things do you need help with?
- What would you say to another person with AD/dementia to help them?
- What is your life like having AD/dementia?
- What is important to you?
- What is your hope for the future?
- Any other comments?

Across the country, some common themes emerged. They were as follows:

- Better doctor education about AD
- Reducing stigma
- Support for people who live alone and/or services for remote communities

(All three themes are important to the ASC and reducing stigma was chosen as the theme for the 2003 Alzheimer Awareness Campaign.)

Perhaps of most interest to readers of the *Canadian Alzheimer Disease Review* were the responses concerning doctors of people with AD or dementia. Comments from the focus-group participants identified the need for family physicians (FPs) to communicate the diagnosis of AD in a sensitive and caring manner, and to listen to the person's questions and concerns. Below is a brief summary of some of the replies pertaining to FPs that were communicated during the focus groups:

- Some participants were very happy with the kind care they received from their doctors. Others felt their diagnosis was communicated too coldly, without any consideration for how devastating the news would be to them.
- Some participants were disappointed that their FPs didn't have more knowledge of the disease to offer to patients upon sharing a diagnosis. For example: "I would like information from my FP about the new medicines and maybe vitamins. I had to go to the pharmacist to find out what might help me. The doctor can't provide the answers. When I went back to him after he diagnosed me, I asked him why he didn't give me any information; he told me he didn't think about it."
- While people in the focus groups recognize how busy their FPs are, they regret that their FPs aren't more available to them.

As a result of the information learned through the focus groups, the ASC created a booklet and companion audiotape (a more effective medium of processing information for some people with AD) incorporating the insights and experiences gathered from the focus-group participants.

This resource, entitled *Shared Experiences: Suggestions for those with Alzheimer Disease*, was created to assist people living with AD. It provides detailed information on the following topics: dealing with emotions; telling people you have the disease; learning more about the disease itself; what you can do; exploring treatment options; and planning for the future. Practical tips and suggestions, offered by the focus-group participants, are included as a way of helping others who are living with AD or a related dementia.

As more people with AD, or a related dementia, are diagnosed earlier in the disease process, they will participate increasingly in their own care. Groups working with people with AD or a related dementia should recognize that it is important to listen to and partner with them. During the last few years, since the Society has taken this approach, we have appreciated how much people in the early stages can contribute to advancing our knowledge of dementia by helping us understand things from their perspectives. We are confident that we are better serving this group of people.

Shared Experiences, as well as other educational material produced by the ASC, is available by contacting your local Alzheimer Society or visiting *www.alzheimer.ca*.

The Alzheimer Society of Canada is a not-for-profit health organization dedicated to helping those affected by Alzheimer Disease. The Society provides support and educational programs for people with Alzheimer Disease and their caregivers. The Society also funds research into finding the causes and cure of the disease, and into improved methods of caregiving.

For more information on Alzheimer Disease and related dementias, Alzheimer Society programs and services, and how you can help, contact your local Alzheimer Society or visit the Society's website at www.alzheimer.ca or call 1-800-616-8816.