

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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