

In this issue we present the first of a new type of leading article, the 'Personal View,' which will appear from time to time in the journal in place of the Editorial. Written by specially invited distinguished researchers, academics, and physicians, it will express viewpoints that do not necessarily represent those of the journal or the International Psychogeriatric Association, its officers, directors, or employees. The 'Personal View' column is intended to stimulate lively debate among our readership on a broad range of important topics.

Personal View

Harbinger of Hope or Commodity Fetishism: "Re-cognizing" Dementia in an Age of Therapeutic Agents

Choices abound while we await that pharmacogenetic fix that will save each one of us from all that is our individual and collective fate, contingent of course upon panopticon surveillance of our genetic susceptibilities and environmental triggers. The past decade has offered hope to those families facing the impenetrable shroud characterizing cognitive decline and dementia. Sufferers and their physicians have a growing compendium of pharmaceutical therapeutic interventions to attempt to stave off the usual, if not necessarily mindful, course of illness progression. In January 2001, the acetylcholinesterase inhibitors donepezil, rivastigmine, and galantamine were made available in the National Health Service in the United Kingdom, and some are on the formulary of five provinces in Canada. Those provincial pharmacare programs still refusing to provide these therapies

free to the elderly cite lack of evidence of efficacy, following Cochrane guidelines based upon systematic review of the best evidence available using randomized controlled trials. Advocates for public funding of the pharmaceutical agents, on the other hand, cite a narratively rich, heartfelt host of behavioral and affective symptoms stabilized or boosted by these drugs. And so, the two solitudes are drawn between science and humanity, between the cold guardians of the public purse and the caring humanitarians.

But wait, as always, cultural dualisms give way to hybrid pluralisms of beliefs and practices. The scientists and clinicians themselves are questioning their instruments. Perhaps not coincidentally, a major research and clinical effort is under way to ascertain subtle cognitive impairments earlier, to differentiate the subtypes of dementia, and to identify individual

responder subtypes to available agents in a given population (e.g., Graham et al., 1997; Hageman & Arrindell, 1999; Mitnitski et al., 1997; Ritchie, 1997; Ritchie et al., 2000). And, rather than relying on those standardized, objective psychometric measures of efficacy required since 1990 by the United States Food and Drug Administration (Leber, 1990), which was concerned that pharmaceutical companies might not be rigorous in their testing procedures, there is now a call for sensitivity to more clinically meaningful outcomes (Joffres et al., 2000; Kielhofner & Barrett, 1998; Mallinson et al., 1996). This necessarily requires a different approach to measuring outcomes. Although clinical meaningfulness—in the form of the Clinician Interview-Based Assessment of Change (CIBIC)—of standardized testing has been mandated as part of the regulatory approval process (Leber, 1997), and behavioral ratings and functional activities of daily living have been added to the cognitive assessment, physicians and regulatory agencies are now asking what the data actually mean. At the same time, the reliability and validity of these objective measures are being called into question (Demers et al., 2000).

How do we make sense of this strange turn of events: where the clinicians are questioning scientific standards and asking for narrative meaning? While the brain may hold the key to the plaques and the tangles, and to the Lewy bodies and white-matter changes, the scientists are trying to get to the heart of the matter through the stories of the sufferers. The pieces of the puzzle represent a constellation of signs, symptoms, and social and technical relations. Just as we are reconfiguring the subtypes of the various dementia disorders in light of the differential diagnostics, we must also attempt to disentangle

the noise from these heterogeneous sociotechnical relations, to pay attention to the patterns in the narratives that do not in themselves make sense (Law, 1997). These include Alzheimer's, frontotemporal, vascular, and/or Lewy body narratives and their evolving diagnostic criteria, the assessment tools currently used and being developed to determine change (decline or improvement), and regulatory constraints that provide routes for the therapeutic agents to travel to the sufferer under the guise of diagnostic recognition. In so doing, we will be "recognizing" dementia.

Throughout the 1980s, Folstein and colleagues' (1975) Mini-Mental State Examination and the Alzheimer's Disease Assessment Scale—Cognitive (ADAS-Cog; Rosen et al., 1984) were used to measure progressive worsening of memory and other cognitive functions. With the advent of therapeutic agents, it was assumed that they could also measure cognitive improvement when the elderly sufferers participated in clinical trials by the pharmaceutical industry. But we were left to wonder whether improvement in copying pentagons or spelling "world" backwards would translate into a meaningful treatment effect. Despite several industry-sponsored studies showing a small but statistically significant effect of anti-dementia therapy using the ADAS-Cog (e.g., Burns et al., 1999), an improvement in global functioning (Greenberg et al., 2000) or quality of life (Birks et al., 2001) has not been adequately demonstrated to convince all regulatory approval bodies that government funding is appropriate, though some allow that a small symptomatic delay is worthwhile. Perhaps *Prescrire International* says it most poignantly: "These drugs are incapable of halting the cognitive deterioration; at best,

they simply delay the deterioration by a few months in some of the least severely affected patients . . . Donepezil (and rivastigmine) can be prescribed to satisfy the family's demand for drug therapy of this debilitating disease . . . the effects are only moderate and of doubtful clinical relevance" (Anonymous, 1999).

So we are prescribing and funding drugs, despite the lack of strong, publicly sponsored best evidence of efficacy, to satisfy family (and one presumes clinician and industry) demands. Now, trickling into the package of tools to ascertain efficacy are qualitative techniques to qualify change, which started with the CIBIC (Knopman et al., 1994). Everyday life activities and social relationships are being invoked to describe (and measure) the individual. The personal is indeed social. Although Ray Tallis (1996) stated that "the gap between neural activity and subjective experience is unbridgeable" (p. 80), we are seeing a concerted effort to describe and measure these experiences in order to find associations with pathology.

Here is a critical caution to consider the social relations that go into the making of the agent. As a commodity, a therapeutic treatment has an exchange value: To satisfy families, the pharmaceutical agent generates profits above and beyond its actual effectiveness (use value). Efforts to establish, reify, and place value on the personal demand new qualitative measures emphasizing meaningfulness. Mediated by the market, the commodity, not the person, dominates the social relations (including those between clinicians and patients). In commodity fetishism, the use value (satisfying natural needs) comes at the cost of the exchange value (accumulating profits) (Taussig, 1980, after Marx). The pill and profits come at the cost of social relations and of the person

just as they fashion a new socially interactive, if still memory-lost, person in the process.

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