

GUEST EDITORIAL

The practice and ethics of dementia care

The focus in dementia research on discovery of *cause* and *cure* often leaves the *care* part of the triad hidden from the spotlight. While clinicians, caregivers, and policy makers eagerly await these scientific developments, daily they face challenges in striving best for quality of life for people with dementia and their family caregivers. This issue of the Journal addresses six topics: three relate to service delivery – at assessment, in the community and at end of life; and one each focus on ethics, driving and suicidality.

Diagnosis is the cornerstone of management but the gap from first symptoms of dementia to diagnosis is estimated to be 2–3 years and about half of the patients with dementia seeing their GP receive a diagnosis (Alzheimer's Disease International, 2011). In his narrative review of the evidence for the provision of memory services, Banerjee (2015) cites anecdotal reports highlighting deficiencies in the current system and advocates for the provision of memory *services* as exemplified by the Croydon model (Banerjee *et al.*, 2007). He emphasizes the difference from memory *clinics*, in that services provide treatment and care beyond diagnosis.

Ambitiously, based on a catchment area of 50,000 older persons, Banerjee aims to assess and provide services to 1,000–1,500 new patients per year or 20–30 new assessments per week. The considerable organization and resources for such a service are countered by evidence of cost-effectiveness based on certain assumptions using UK figures, principally that savings will result from a delay in nursing home admission despite costs of community care rising (Banerjee *et al.*, 2009). Wisely, he cautions readers about the lack of evidence of the positive and negative impacts of receiving a diagnosis and the timing of diagnosis, earlier or later, and the empirical uncertainty of how best to provide memory services.

As dementia progresses, home care services can help maintain people living in the community where, in developed countries, about two in three persons with dementia live. Home care encompasses a broad range of services from personal care to rehabilitation in the home. Low and Fletcher (2015) review four overlapping models of home care: case management, integrated

care, consumer directed care, and restorative care. The evidence for each model is limited, studies often small and often based on older populations generally rather than those with dementia specifically. The details of service delivery are critical such as its intensity and whether the service is reactive or proactive. Outcomes include enhanced consumer satisfaction and increased community care but benefits in clinical outcomes or delay to admission to a care home have not been demonstrated. Economic analyses are mostly lacking. A notable exception is one study that reported 28.8% more people in the restorative care group no longer needed usual community services compared to a control group, but this study *excluded* people with dementia (Lewin and Vendermeulen, 2010). Low and Fletcher conclude that it is timely for trials of restorative care in people with dementia.

One of the most difficult decisions facing clinicians helping people with dementia especially at the time of diagnosis are the possibility of patients becoming suicidal. Draper (2015) summarizes the evidence for suicidal ideation, deliberate self-harm and attempted suicide, and suicide. Risk factors common to all of these are presence of psychiatric comorbidity especially depression and alcohol, pre-dementia psychiatric illness, early dementia often within three months of diagnosis (presumably while insight is still preserved), and younger age. Draper also considers self-injury and indirect self-destructive behavior in residential care which can include food or medication refusal, eating foreign objects, and self-cutting. Finally, Draper considers the moral and ethical debates that continue about assisted suicide, euthanasia, rational suicide, and advance directives. While management recommendations of suicidal behavior are a topic for further review, this paper outlines the importance of clinicians being aware of these issues, of more subtle presentations of suicidal equivalent behaviors and which persons with dementia are at greater risk of suicidality.

Driving is a second contentious area, one that commonly leads to patient angst and antagonism to and even personal threats of law suits against the clinician. Doctors in particular are caught between Scylla and Charybdis: if they do not report patients who may be a risk to themselves or others on the

road they may be liable if accidents occur; and if they do report to authorities, the doctors will be at risk of alienating patients and families or incurring their wrath and, in some jurisdictions, of breaching confidentiality. Cognitive tests are poor at predicting driving ability or future accidents, on-road driving assessments are of variable quality and specialist on-road assessors with trained occupational therapists or driving rehabilitation specialists are expensive and not readily available. Carr and O'Neill's (2015) very practical review examines the utility of cognitive tests, process of referral and importance of counseling about transition to non-driving and the physician's legal and ethical obligations. They highlight how patients' medications and comorbidities such as macular degeneration, cardiovascular disease, sleep apnea, hypoglycemia, and musculoskeletal conditions can also influence driving ability.

Dementia is under-recognized as a palliative care condition by geriatric, psychogeriatric, and even by palliative care specialists. Volicer and Simard (2015) advocate that a palliative care approach should start early in the disease specifically with patients letting others know what their priorities and wishes are and providing advance care directives. Clinicians caring for people with late stage dementia would be better able to decide on thorny issues such as care of cardiopulmonary resuscitation, transfer of patients to acute care, artificial nutrition, and use of antibiotics if they and patients' families were aware of the patients' prior wishes and of the data about utility or more often futility of many of these measures.

The final paper in this sextet brings into sharper focus new ethical issues, especially those emanating from advances in Alzheimer's biomarkers. Johnson and Karlawish (2015) carefully and comprehensively consider current controversies. Should asymptomatic people at risk have testing for Alzheimer's pathology when there is not disease modifying treatment available? Should they be enrolled in drug trials when there is probability but neither certainty that they will develop clinical dementia nor confidence as to when this would occur? Once tested for Alzheimer's biomarkers what effects will these results have on their standing in community, their life, their health and long-term care insurance, and their personal relations? Will they suffer stigma and discrimination? The proliferation of direct-to-consumer genetic testing adds further complications. Ethicists and clinicians struggle with these issues, researchers are inventing new methodologies to circumvent these hazards and the law lags far behind in providing guidance.

Enrolling people with dementia in research requires informed consent which is usually provided

by a proxy once the person can no longer give this. Advance directives for research participation would be a logical solution except that people change their views with time and are able to weight up new knowledge that would have accrued since the directive was signed. Other topics examined by Johnson and Karlawish include end of life care, workforce issues in providing care and rights to drive and to vote.

Readers reflecting on these six papers should be mindful of the cultural and economic differences across the world. For example, capacity to drive is an issue which varies in importance internationally depending on how much motorized vehicles are used. Advanced care directives may be a fantasy where there is no care available. In some respects diagnosis and medical management of Alzheimer's and other dementias is straight forward compared to the conundrums that clinicians face in the continuing care of their patients. For many of these questions, data are lacking, investigation is logistically difficult and research funding hard to obtain particularly when competing with hard-edged biological scientific studies for limited funds. It is important to quarantine research spending to ensure psychosocial, service delivery, and ethics receive their fair slices of the research pie. For many of us working in these convoluted labyrinths, the intellectual, and moral complexity is stimulating and resolution of issues in conjunction with patients and their families rewarding.

Conflict of interest

None relevant to this guest editorial. In the last three years, I have been a consultant for Eli Lilly, Nutricia, and Merck and my department has received payment to conduct drug trials from Sanofi, Servier, and Tau Therapeutics.

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