

Discourse

Looming Dementia Care Crisis: Canada Needs an Integrated Model of Continuing Care Now!

Dorothy A. Forbes and Anne Neufeld

According to the 2006 census, Canadians aged 55 to 64 are the country's fastest-growing population group (expected to reach 30% by 2017), followed by those over 80 (Statistics Canada, 2007). The 9.9 million baby boomers (those born between 1947 and 1966) are beginning to turn 60 (Foot & Stoffman, 2004). They are entering the age of greatest risk for dementia. Eight percent of Canadians 65 years of age and older and 35% of those over the age of 85 have or will have dementia (Canadian Study of Health and Aging [CSHA], 1994a). Thus, we have a narrow window of time to prevent dementia from causing a health and economic crisis of unprecedented proportions (Alzheimer Society of Ontario & Knowledge Exchange [ASO & KE], 2007).

Over the past two decades the proportion of older adults receiving care in institutions has been declining. In 2001 less than 10% of senior women and 5% of senior men resided in health-care institutions (Cranswick & Thomas, 2005). Thus, greater numbers of persons with dementia are living in their communities, with most of their care being provided by family and friends. Currently, family caregivers provide up to 90% of the in-home care for persons with dementia (Keating, Fast, Frederick, Cranswick, & Perrier, 1999). There is strong evidence that supportive services are an essential and cost-effective component of home and community-based care for persons with dementia and their family caregivers. Within the current health-care system, however, many challenges impede the delivery of high-quality care in a cost-effective manner. These challenges to in-home care call for an integrated model of continuing care that includes the dimension of continuity of relationship between care recipients and care providers (Gantert, McWilliam, Ward-Griffin, & Allen, submitted, under review; McWilliam et al., 1997).

The need for such a model, one that recognizes the contribution of home care in the context of a national framework and addresses the necessity of qualified health-care providers who are able to develop trusting partnerships (Forbes, Markle-Reid, et al., in press; McWilliam et al., 1996; McWilliam et al., 1999), cannot be overstated. Advanced dementia results in extreme functional disability, behavioural disturbances, and dependence on informal caregivers (Forbes, Markle-Reid, et al., in press). Persons with dementia eventually become dependent on others for every aspect of their care (ASO & KE, 2007). Compared to caregivers of the cognitively intact elderly, caregivers of a family member with dementia are more likely to experience chronic health problems, depression, and social isolation (CSHA, 1994b). Although the costs for home care clients are 40% to 70% less than those for patients/residents in facilities (Hollander, 2001), health-care costs will rise substantially if family caregivers are not adequately supported when caring for persons with dementia (Hux et al., 1998; Ostbye & Crosse, 1994).

The components of such a model are readily apparent. The largest community-based health service is home care, defined as “a range of health and support services received at home with costs being entirely or partially covered by a national/provincial/territorial health plan” (Canadian Institute for Health Information [CIHI], 2004, p. 2). Core program services include maintenance, rehabilitation, long-term supportive care, acute-care substitution, and end-of-life care (CIHI, 2004). Home care programs have undergone enormous growth over the last 30 years, for several reasons: the downsizing of Canada’s inpatient hospital sector and the shifting of care to the home and community, medical and technological advances, and a growing elderly population. Most Canadians prefer to recover from an illness or surgery at home (Canadian Home Care Association [CHCA], 2004), and the frail elderly wish to remain in their own homes as long as possible (Forbes, 1996; Health Council of Canada, 2006). There is strong evidence for the cost-effectiveness of home care and the importance of home support services as a substitute for the more expensive services provided in long-term-care facilities (Béland, 2007; Greenwood, 2006; Hébert et al., 2007; Hollander, 2001; Hollander, Chappell, Havens, McWilliams, & Miller, 2002; Landi et al., 1999; Landi et al., 2001; Pedlar, 2006; Rigg, 2006; Scuvee-Moreau, Kurz, Dresse, & National Dementia Economic Study Group, 2002; Stuart & Weinrich, 2001; Weissert, Lesnick, Musliner, & Foley, 1997). For example, when 1,121 home care clients who received additional supportive services to remain at home were compared with similar long-term-care residents, a saving of \$30 million per year was revealed (Greenwood, 2006).

However, although home care programs continue to expand, the growth has not kept pace with the demand (Forbes et al., 2003). In 2002 one in every three family caregivers identified the need for additional home care services (Decima Research Inc., 2002). An analysis of data from the 2003 Canadian Community Health Survey that examined a subset of persons with dementia found that only one third (31%) of Canadians diagnosed with dementia received publicly funded home care; a slightly higher proportion received home care not covered by government (35%) (Forbes et al., 2008). This finding is of great concern given that all were diagnosed with dementia, 42% were over the age of 80, the majority reported needing help with activities of daily living, and nearly half had difficulty dealing with an unknown person and with initiating and sustaining conversation.

Despite the clear need for home care services, Canada's spending on home care is among the lowest of all member countries of the Organisation for Economic Co-operation and Development, with only 3.5% of public health expenditures directed towards home care (Health Council of Canada, 2006). Although Canadian home care programs strive to offer broad health and social services (Shapiro, 2003), limited resources and a directive from the 2003 First Ministers' Accord on Health Care Renewal (that ignored the needs of persons with chronic conditions and their caregivers) have forced these programs to target post-acute care as a priority (CHCA, 2003; Forbes et al., 2003). As persons with dementia primarily need support services related to their cognitive impairment, not "medical" services related to physical impairment, this mismatch between needs and rationed services may be why so few survey respondents received publicly funded home care (Coe & Neufeld, 1999; Forbes et al., 2008).

Family caregivers of persons with dementia also face challenges in securing satisfactory assistance from the resources that are available. Ethnographic studies that included in-depth interviews and focus groups with female family caregivers report such difficulties as insensitive interactions, ineffective or inappropriate resources, and insufficient support (Neufeld & Harrison, 2003; Neufeld, Harrison, Hughes, & Stewart, 2007). Male caregivers were found to experience similar non-supportive interactions. Although the men valued interactions with individuals who guided them through the maze of caregiving decisions to be made, such experiences were inconsistent and sporadic. What the men wanted was a personal "coach" to assist them in negotiating all the decisions that are necessary when one is caring for a relative with dementia. They sought a person who would be consistently available to them over time, relate with sensitivity to their changing situation, facilitate the whole caregiving

experience in relation to multiple sources of support, and be their advocate (Neufeld, Kushner, & Rempel, 2007). In a mixed-methods study (Forbes et al., 2008, in press) examining the role of home care services in dementia care, family caregivers reported most frequently that home care services were not accepted and were discontinued because of inconsistency of care providers (Forbes et al., in press). Other issues identified by family caregivers included insufficient information on the disease process and lack of guidance on how to handle difficult behaviours. Additional concerns identified were inappropriate treatments and provision of care; lack of respectful, gender-sensitive, and culturally sensitive care; inflexible programs, especially for employed caregivers; and the high cost of supportive services (Forbes et al, in press). All of these challenges accentuate the need for a continuity of relationship model that ensures consistency of care providers who are willing and qualified to develop trusting partnerships with persons who have dementia and their family caregivers in the home setting.

Another challenge facing provider agencies is ensuring that health-care providers are basing their practice on the best available evidence. On Canadian nurse registration examinations, the low grades for questions related to the care of persons over 80 reveal that nursing graduates are not well prepared to care for this population (Canadian Nurses Association, 2006). Undergraduate nursing programs need to place greater emphasis on the care of seniors and to integrate education programs such as P.I.E.C.E.S.TM (Hamilton, Harris, & Le Clair, 2006) throughout the curricula. Continuing education programs for home care providers (such as P.I.E.C.E.S.TM and U-First; Hamilton et al., 2006) that address ways of managing the difficult symptoms of dementia and non-supportive aspects of service provision may be costly in the short term but could offer a cost-effective way of promoting home care best practices in the long term.

A shift is needed in Canadian health-care policy, from a focus on individual sectors to a broader, integrated model of continuing care. Hollander (2003a) argues that administrative and fiscal control over a large, integrated system of care would facilitate the cost-effective substitution of home care for acute care and long-term residential care (Hollander, 2003a, 2003b, 2006). However, Chappell (2000) cautions that the provinces would have to ensure that the home care funds received from the federal government are indeed used for home care and not for the funding of other sectors.

The essence of the continuing care model is the integration of medical, health, supportive, community, and institutional care into one system. Such a model would ensure that care continues over time and across types of service (e.g., hospital to home care; Hollander, 2006). This

is possible if there is a shift in values, from the current focus on acute care to an inclusive vision of home and community-based care that puts more emphasis on chronic care management (Shamian, Shainblum, & Stevens, 2006) and includes not only medical care but also social care, health promotion, and disease/disability prevention (Chappell, 2000).

A national home care framework of this nature, along with national standards to support its implementation, would ensure that all Canadians have access to appropriate, high-quality, timely services and a consistent relationship with a care provider regardless of where they live or the environment in which the care is provided. The necessary services would be available with a seamless transition between levels and settings of care for persons with dementia and their family caregivers. The national standards would address the inconsistencies across provinces and regions that now exist in program goals and in care providers, eligibility criteria, costs, and types of service. The national framework would have features such as single point of entry, comprehensive assessment of persons with dementia and their family caregivers, and care management (rather than case management) that includes the broad determinants of health. A national framework could also address the need for more professional care providers and the low wages, lack of fringe benefits, and lack of career trajectories that define the non-regulated and professional home care workforce. Ultimately, a national framework would direct more funding to home care.

As baby boomers enter the age of greatest risk, and as the demographics of family caregivers change due to fewer children, Alzheimer disease and related dementias threaten to become the health crisis of the 21st century (ASO & KE, 2007; Keefe, Légaré, & Carrière, 2007). Until governments recognize home care as a major component of the health-care system, and until they embrace an integrated continuing care model that incorporates a continuing-relationship approach, the needs of persons with dementia and their family caregivers will remain unmet. As a result, costs to the health-care system will increase, especially if family members are unable to continue in their caregiving role. There is a narrow window of time in which to address these issues. We must act now.

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Dorothy A. Forbes, RN, PhD, is Associate Professor, School of Nursing, University of Western Ontario, London, Canada. Anne Neufeld, RN, PhD, is Professor, Faculty of Nursing, University of Alberta, Edmonton, Canada.