

Caring for elderly people at home: the consequences to caregivers

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Abstract

THE EMPHASIS ON HOME-BASED CARE is one important aspect of health services restructuring initiatives in Canada. Fundamental to the preference for home-based care over institutional care is the expectation that family caregivers will be available in the home to support patients who would otherwise be in an institution. The authors explore the potential impact of this devolution of services from institutions to the home in 2 vulnerable patient populations — elderly patients with dementia and elderly patients with terminal illnesses. Community-based surveillance strategies are needed to determine the true health, quality-of-life and economic outcomes of these restructuring initiatives.

Résumé

L'ACCENT MIS SUR LES SOINS À DOMICILE est un aspect important des initiatives de restructuration des services de santé au Canada. On s'attend à ce que les soignants des familles soient disponibles à la maison pour appuyer les patients qui seraient autrement institutionnalisés, ce qui est essentiel à la préférence accordée aux soins à domicile plutôt qu'aux soins en établissement. Les auteurs explorent l'impact qu'un transfert de services des établissements à la maison pourrait avoir sur 2 populations de patients vulnérables — les patients âgés atteints de démence et ceux qui sont atteints d'une maladie en phase terminale. Il faut des stratégies de surveillance communautaire afin de déterminer l'état de santé réel des intéressés, leur qualité de vie et les résultats économiques de ces mesures de restructuration.

Care provided in the home, or on an outpatient basis, is preferable to institutional care.¹

The conclusion above, drawn in 1991 by the British Columbia Royal Commission on Health Care, typifies the conventional wisdom about one aspect of restructuring health services in Canada. On the surface, it seems correct. On closer reflection, however, it is troublesome. Fundamental to this preference for home-based care is the expectation that caregivers are available to support patients in the home. Caregivers fall into 2 broad categories: caregivers working for pay who are part of the formal health care sector (e.g., homecare workers) and unpaid "informal" caregivers (usually family members)²⁻⁴ who are motivated by a deeper commitment to the patient. This tradition of family caregiving is fundamental to our society.⁵ (In this paper we will use the term "family caregiver," although it is recognized that sometimes the informal caregiver may not be related to the patient.)

As Canada's elderly population grows, an increasing number of elderly people will have health problems that prevent them from caring for themselves. The ideal picture is one of families caring for seniors or seniors caring for other seniors. However, this same picture may place elderly people in double jeopardy: demographic trends suggest that family members may not be available to provide care when needed and that seniors may be suffering from a chronic illness when they are needed as a family caregiver.⁶

In this paper we will explore how the devolution of services from institutions to



Society

Société

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homes may place seniors in double jeopardy. We will begin with a brief review of the literature on the caregivers of 2 vulnerable elderly populations: those with dementia and those with terminal illnesses. We will then examine the larger social context in which health services restructuring is taking place, in terms of the changing demographics of the Canadian family and the impact restructuring will have on family caregiving. These changing demographics underscore the importance of the formal health care sector, specifically, provincially funded homecare programs, in supporting family caregivers. The need to initiate surveillance strategies to monitor the outcome of our increasing reliance on home-based health care becomes more urgent as services devolve from institutions to the home.

Elderly people with dementia

Caring for a patient with dementia is one of the most difficult challenges facing caregivers. The cognitive deterioration of Alzheimer's disease, for example, is steadily progressive, with no possibility of remission. These cognitive problems impair the social skills of the patient and may lead to disruptive behaviour or changes in personality; patients generally suffer significant physical disability as well. Ultimately, people with advanced dementia require 24-hour surveillance.

Several studies have shown that the stress felt by the caregiver increases with the patient's deterioration and that the stress of caring for a patient with dementia is typically worse than, for example, the stress of caring for a patient with cancer.⁷ Although there is hope that new therapies will alleviate cognitive problems, the first generation of treatments appear to delay rather than prevent the onset of symptoms.⁸ This may exacerbate the caregiving problem, because both the patient and caregiver will be older when symptoms develop.

Dementia afflicts about 8% of Canadians over the age of 65, half of whom live in the community.⁹ Roughly 94% of those in the community are cared for by family or friends: 36% by their spouse, 28% by a daughter and 9% by a son.¹⁰ A family member remains actively involved in the care of about 78% of patients with dementia in institutions.¹⁰ Because spouses are most often the informal caregivers, the rapid increase in the prevalence of dementia with age often means that an informal caregiver is not available for a patient with late-onset dementia.

Caring for an elderly family member with dementia at home may create a situation of chronic stress, which may adversely affect the caregiver's emotional and physical health.¹¹⁻¹³ Although there are rewarding aspects of caregiving, virtually all studies report increased symptoms of depression among caregivers; several report high rates of clinical depression and anxiety.^{10,12,14-18} More detailed analy-

ses suggest that spouses providing care may be more affected than adult children, and that woman and men caregivers may be affected differently.^{11,15} Family caregivers report less depression when the person with dementia is in an institution than when he or she is being cared for at home, even when the dementia in the institutionalized patient is more severe.¹⁰ Evidence that caregiving causes physical illness is more equivocal; that it has a modest effect on chronic sickness is suggested, but evidence that there is an impact on the rate of acute, infectious disease, perhaps through immune function, is clearer.¹⁹

Studies of the way caregivers cope have given rise to 2 competing hypotheses: a "wear-and-tear" model, which holds that the caregiver's health will decline as the patient's dementia progresses; and an adaptation hypothesis, which posits that caregivers eventually adapt to the demands of caregiving.^{19,20} Adapting includes looking for a way out of the situation when the caregiver can no longer cope. Thus, for example, the person with dementia may be placed in an institution when the caregiver finds the burden too much.²¹⁻²³

Because informal caregivers play such an important role, programs have been established to assist them. Commenting on the Canadian situation, Chappell²⁴ noted, "If formal support is not provided, there is a danger that informal caregivers will burn out. Then, not only will the elderly person require more formal care (in many instances institutional care), but the caregiver as well could become a recipient of care within the system. That is, there is both a humane and an economic incentive for assisting caregivers in the care of their seniors." Although there are some support services for caregivers of patients with dementia,^{10,25} more support for family caregivers is needed.^{10,24,25} The Canadian Study of Health and Aging, for example, suggested that when patients were matched for level of disability, those with dementia received *fewer* community support services than those without.¹⁰ There are many reasons for this: support may be too expensive, the caregiver may deny needing support, the caregiver may have personal conflicts over temporarily abandoning the caregiver role, the caregiver may be embarrassed about needing assistance, there may be a perceived stigma about the disease, or the caregiver may worry that changing caregivers will be disruptive to the patient. Because people caring for patients with dementia frequently delay seeking support services, interventions have been designed to encourage the use of support and to provide techniques to manage stress. Evaluations are mixed: some suggest satisfaction but no symptomatic benefit,²⁶ some report a reduction in the symptoms of strain,²⁷ and some report no significant improvement over a wait-list control group.²⁸

Elderly people with terminal illnesses

Most patients with a terminal illness prefer to die at



home.^{2,29} Unless 24-hour homecare is available, the involvement of a family caregiver is essential to keep patients who are in need of palliative care at home.^{2,29-34} However, many patients do not even have the option of dying at home because they do not have a family caregiver^{29,30,35} or because a family caregiver is no longer able to cope with the burden of care.^{30,35,36}

Family caregivers of terminally ill patients experience significant psychosocial,^{13,37,38} physical and economic burdens, which negatively affect their quality of life.³⁹ Unlike caregivers of patients with dementia, those of terminally ill people face a task that is, by its very nature, limited. Nevertheless, because the acuteness and intensity of the situation produces a great deal of stress, the emotional needs of family caregivers often exceed those of the patients.⁴⁰ The proportion of caregivers experiencing anxiety (14%) and depression (17%) is often greater than the proportion of terminally ill patients experiencing anxiety and depression.^{37,40} The degree to which the patient relies on the caregiver is independent of the effect caregiving has on the physical well-being of the caregiver.³⁹

The economic burden of caregiving is significant. Family caregivers report substantial financial losses associated with the role. These include direct out-of-pocket expenses and lost wages because of time taken off work.^{4,41,42} The widely held view that home-based care is more cost-effective than institutional care does not take into account the indirect costs (opportunity costs, lost wages and family labour costs) borne by patients and their families.⁴²⁻⁴⁵ In fact, when family labour costs are included in the analysis, caring for a patient with a terminal illness at home is no less expensive than caring for the same patient in a nursing home.⁴²

Caregiving: the impact of current demographic trends

The capacity of families to meet the expectations required by health services restructuring — as illustrated by the needs of elderly patients with dementia or terminal illnesses — is affected by the changing structure of families, which today are smaller, move more often, have less free time and break up more often.⁴⁶ Families are also more diverse in terms of structure (e.g., 2-parent, single-parent, step-parent), patterns of functioning (single and dual wage-earning) and heritage. Canadian families today are racially, culturally and linguistically diverse as a consequence of recent trends in immigration, which, in and of itself, will have no significant effect on the overall process of societal aging.⁴⁷ Nevertheless, preferred patterns of caregiving may differ among ethnic or linguistic groups, which means the support provided or required by these groups to do so may differ as well.

In 1994 life expectancy at birth was estimated to be

75.1 years for men and 81.2 years for women, up from 70.5 and 77.8 respectively in 1976.⁴⁸ This difference in life expectancy between men and women explains why societal aging has a female face. In 1990, 31% of the entire population 65 years and older lived alone: 42% of women but only 16% of men over 65 lived alone; 64% of men and 37% of women over 65 lived with a spouse. However, 67% of women over 80 lived alone, whereas 68% of men over 80 lived with their spouse.⁴⁹ These statistics make the point that women are more likely to face an illness without a spouse to provide care.

The aging of our society is primarily a consequence of low Canadian birth rates. This trend is expected to continue; 1 study found that only 9% of Canadians intend to have 4 or more children; close to 50% intend to have 2, and 9% intend to have only 1 child.⁴⁹ Because the average family size has been decreasing since the baby-boom years, elderly people will have fewer children on whom they can depend for care.

The fact that more women have joined the labour force compounds the problem of decreasing family size, since for the most part family caregivers have been — and continue to be — women.^{28,50,51} Between 1976 and 1994 the rate of women participating in the labour force rose from 42% to 52%, and women now make up 45% of all paid workers. It is now women between the ages of 25 and 54 who have the highest rates of paid employment; 70% of women between 25 and 44 and 66% of women between 45 and 54 hold paying jobs.⁵² Of women in the labour force, 74% are employed full-time.⁵²

Women are in the labour force to stay. This trend toward the dual wage-earning family will not be reversed. Men no longer earn a wage sufficient to support the number of financial dependants their fathers and grandfathers did. Seven out of 10 couples raising children now rely upon 2 wages to make ends meet.⁵³ Accordingly, most women have joined the labour force because their families need the money. In addition, to support the greater costs associated with the health, social and income security of a proportionally larger population of retired senior citizens, all people of working age will feel increasing pressure to participate actively in the paid labour market.

These statistics raise concerns about the availability of family caregivers, both now and in the future. It is encouraging to note that currently 50% of Canadians who do not live with their parents still live within 50 km of them, and most of those live within 10 km.⁴⁹ It has been estimated that between 85% and 90% of the care now provided to elderly patients is done informally in the home by relatives.⁵⁴ According to Martin-Matthews, "For every one person living in an institution, we know that there are two people with the same level of disability who are living in the community."⁵¹



The role of homecare

Homecare services are essential to support people who are caring for elderly patients in advanced stages of disease,^{25,31,55} and they may be the critical factor in making dying at home, for those who wish to, possible.^{30,31,56} The responsibilities of family caregivers today, however, often extend well beyond basic personal care and can involve quite sophisticated forms of treatment.

The extent of homecare services available in Canada varies with the service descriptions and eligibility criteria established provincially. Programs vary and service plans take into account the informal support system available to the patient and the patient's financial ability to supplement publicly funded care. Although caregiver support is not a *prerequisite* for care in provincial homecare programs (Lesley Larsen, Canadian Homecare Association, Toronto: personal communication, 1997), funding limitations do not typically allow 24-hour care. Therefore, safe and appropriate homecare often requires the involvement of a family caregiver. This, in practical terms, means that a family caregiver must be in the home for a patient with dementia or a terminal illness to remain at home. As noted earlier, the absence of a willing and able caregiver has been identified as a major obstacle to providing palliative care services in the home.^{35,57,58}

One of the principal recommendations made by the Canadian Forum on Health was to increase resources to homecare services.⁵⁹ It remains uncertain whether the federal government plans to uphold this recommendation.⁶⁰ However, provincial discretion to determine both the funding parameters and policy framework of homecare programs across Canada has led to pronounced regional variations in services offered. It is important that physicians be aware of the scope and limitations of the homecare program in their region before assuming that necessary services will be available to patients and their families.

Conclusion

Most health services restructuring initiatives in Canada currently focus on the downsizing of institutional care and the devolution of many services to the home.^{50,61} As exemplified, informal caregivers are vital if elderly patients with dementia or terminal illnesses are to remain at home. Informal caregivers are most often family members, most often spouses and most often women. A review of the literature on caregiving and the changing demographics of Canadian families, however, raises concerns that an increased reliance on home-based care places seniors in double jeopardy: as patients they are in jeopardy of being without the necessary caregiver support when they need it; as caregivers they are faced with the health and economic consequences of caregiving.

Although the notion is compelling that being cared for in the home is preferable to being cared for in an institution, there is little evidence supporting the benefits or the cost-effectiveness of either.^{61,62} This accentuates the need to evaluate the quality-of-life, health and economic outcomes to patients and their families of the shift away from institutional care.⁶¹ There must be a means of monitoring the impact of health services restructuring on society as a whole, and on health services in particular.^{50,61} There must be mechanisms to monitor the quality of homecare, whether it is provided by a professional or a family caregiver. Vulnerable elderly people who remain in the community (either as patients or as caregivers) are often invisible to traditional surveillance strategies that tend to be institution-based. However, there are currently no strategies to monitor outcomes of community-based care. Because of the lack of surveillance strategies we have no way of determining the impact that health care restructuring will have across health care sectors, either within or among jurisdictions.^{62,63} Implementing community-based surveillance strategies — such as the Canadian Institute for Health Information minimum data-set for community care⁶³ — is essential to ensure that we are fully aware of the true outcome of the population-based health services research experiment on which we are embarking.

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A Canadian face on aging

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