



In Canada, older adults are the most likely of all age groups to experience chronic health conditions. Most Canadians living with disabilities or chronic conditions and most older adults are supported by family members or close friends. Caregivers frequently describe the emotional, physical, and financial burdens associated with the caregiver role. Accessible support programs can improve health outcomes for family/friend caregivers of older adults with chronic conditions. Practitioners can use the strategies presented to help caregivers access timely and accessible support resources.

Key words: family caregivers, caregiver support, older adults, home care, chronic conditions

Support for Caregivers of Older Adults with Chronic Conditions: A Canadian Perspective

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Introduction

Disability rates increase with aging. According to Statistics Canada's 2001 Participation and Activity Limitation Survey, 40.5% of older adults had disabilities, 31% were between ages 65 and 74, and 53% were over the age of 75.¹ The prevalence of older adults reporting at least one chronic disease increased from 87% in 2001 to 91% in 2005.² Common chronic diseases include diabetes, heart disease, hypertension, arthritis, and chronic pain.² Vulnerable older adults who are frail require assistance to remain in their homes. Frailty is associated with risk of dependency for basic activities of daily living,³ decreased physiologic reserve and resistance to stressors, and vulnerability to adverse outcomes such as disability, morbidity, falls, hospitalization, institutionalization, and death. One of the most challenging conditions is Alzheimer's disease and other related dementias. It is estimated that one in 13 Canadians over age 65 has Alzheimer's disease or a related dementia; the figure rises to one in three adults over the age of 85 years.^{4,5}

Most older adults with disabilities and chronic conditions live in the community. In 2001, less than 10% of older women and about 5% of older men lived in health care institutions.⁶ Close to half

(45%) of community-residing older adults received help only from family and friends, also referred to as unpaid care providers⁶ or informal caregivers.⁷ Of those older adults receiving formal or paid assistance (55%), half were also receiving assistance from family and friends.⁶ Further, there are estimates that suggest 80–90% of Canadian older adults' care needs are met by family and friends.⁸ Care in the home can be acute, chronic, preventative, or palliative.⁹

In the report of the Commission on Future of Health Care in Canada, Commissioner Roy Romanow⁸ argued for home care to be included in the Canada Health Act as an essential service accessible to Canadians. A national platform to fund home care would include support for informal caregivers in the form of tax breaks, job protection, caregiver leave, and respite care.⁸ Currently, formal home care is funded primarily through the provincial government and private sector and minimally by the federal government.⁸ Nationally, there is wide variability in the determination of who receives home care services and what types of services are provided. Home care is understaffed and the turnover rate of care workers is high. Until a national home care program is established, how do primary care providers address caregivers' support needs?

In this paper, a profile of home caregivers and care recipients is presented with a focus on older adults who have chronic or progressive conditions, such as dementia. The experiences of family and friends who provide care to older adults and the types of support they require as care providers are described. We also examine existing support services and models of health care that support caregivers. Practitioners can help caregivers identify support resources by considering the issues and strategies presented here.

Types of Family/Friend Caregivers

Family/friend caregivers fall into two main cohorts: 1) adult children or relatives under 65 years, and 2) other older adults such as spouses, siblings, or friends aged 65 years or older. Informal caregivers represent over two million Canadians 45 years and older; 85% are 45 to 64 years and 15% are 65 years or older.¹⁰ More than 1 in 12 Canadians age 65 years or older are caring for at least one other older individual who has a chronic condition.¹¹ They provide care to spouses (25%), close friends (33%), or neighbours (19%).¹¹

Adult children caring for their own children as well as for their older parents have been described as the "sandwiched generation." In 2002, 27% of the 2.6 million Canadians between 45 and 64 had children under 25 residing with them, and 27% of this group also participated in care for parents, parents-in-law, friends, neighbours, or co-workers.¹² Indeed, 26% of the sandwiched generation is caring for two or more older adults.¹² Most of these caregivers (80%) are also working. As the Canadian population ages, there is indication that people providing serial caregiving will become more common than people in the sandwiched generation.¹³ In other words, an adult child may be in retirement before providing care for an older parent.

Gender, relationships, and proximity have been examined as characteristics of care networks. In a study of the care networks of 1,104 frail older adults,

researchers reported that networks ranged from 1 to 8 people. However, when caregivers providing only emotional support and regular check-ups were excluded from the network, the average network size declined to 1.5 members.¹⁴ Close to 67% of these frail older adults relied on one family/friend caregiver and slightly over 23% relied on two caregivers to assist them with care tasks that included meal preparation, transportation, and household maintenance. Although female-only networks comprised over 50% of cases, male-only networks represented 28% and mixed male and female networks made up 22% of cases.¹⁴ Therefore, in this sample, 50% of frail older adults had male family/friend caregivers involved in their care. Nevertheless, middle-age women and older women dedicate more time than their male counterparts to caregiving tasks.¹¹ Women tend to perform personal care and household tasks, while men help with household maintenance or transportation.¹¹ Finally, it is noteworthy that the majority of frail older adults (78%) relied on a kin-only network, and close to 95% of older adults had entire networks that lived within a half-day's travel by car.¹⁴

Experiences and Support Needs of Family Caregivers

The burden of caregiving is financially, emotionally, and physically significant.¹⁵ Family caregivers report extra expenses, lost income, reduced hours of work, changed work schedules, quitting work, or declining jobs.^{7,9} Family caregivers are vulnerable to negative mental and physical health outcomes¹⁶ and increased health care utilization.²⁵ Compared to noncaregivers, family caregivers exhibit significantly higher levels of loneliness¹⁷ and greater social isolation, leading to lower levels of psychological well-being.¹⁶ Chronic conditions create adverse effects on the emotional health, social activities, leisure time, and family relationships of caregivers.²⁵

The ongoing need for support in chronic illness situations can burden family caregivers and drain the social network resources that contribute to support for the ill person.¹⁵ In a prospective study

conducted in Montreal, spouses, adult children, and other relatives were monitored after their older relatives ($n=159$) made initial visits to an emergency department.¹⁸ Spouses were most at risk for a decline in general health, mental health, and physical functioning, measured on SF-36 (a short-form health survey with 36 questions yielding an 8-scale profile of functional health and well-being scores) one month later. Adult children were at risk for decline in physical health one month following the event.¹⁸

Primary care physicians should be aware of potential caregiver distress when an older adult under their care visits the emergency department. Indeed, family caregivers have been referred to as "forgotten patients."¹⁸ As caregiver burden is a significant predictor of use of health care services by older adults with chronic conditions and by caregivers themselves, health professionals should conduct an initial screen for depression or depressive affect, life satisfaction, perceived physical health, general distress, and subjective burden.¹⁹ Family caregivers who often accompany their senior relatives to health appointments should also be made partners in the care through decision-making and planning.²⁰

Family caregivers of older adults with chronic conditions need support and guidance as they experience the stressful demands of caregiving.²¹ Caregivers of people with dementia or frailty report more health problems than caregivers of healthy older adults.²² Interventions that slow the progression of dementia will not necessarily reduce caregiver burden.²² In one study of older caregivers caring for other older adults, only 18% said that someone else could take over their responsibilities should they need respite.¹¹ Further, little is understood about help-seeking behaviour among the many ethnic groups in Canada. Language barriers can prevent an older spouse caregiver from accessing support services. Depending on cultural expectations and family dynamics, large kin networks do not imply a large pool of support.

Table 1: Examples of Support Services for Family Caregivers in Canada

Resource	Comments
Canadian Red Cross www.redcross.ca/article.asp?id=012952&tid=001	In Ontario and the Atlantic provinces, the Red Cross offers home care programs that include assistance with personal care, home management, respite and companion care, as well as an equipment loan program.
Alberta Caregiver College® www.capitalhealth.ca.acc	A virtual college that provides courses to caregivers of individuals with a variety of conditions. For example, a course for caregivers of individuals who sustained brain injury or stroke is delivered twice a year. Caregivers can access the courses via videoconferencing and learn about topics as introduction to caregiving, understanding brain injury, physical rehabilitation, mental and emotional rehabilitation, caregiver stress and community resources. These courses are free of charge and available to remote sites with trained facilitators. ³¹ This service provides mainly informational support. The videoconferencing allows two-way communication and can be used to facilitate affirmational support if participants are willing to participate in peer-to-peer interactions.
The Good Samaritan Society TeleCare® www.gss.org	Available in Alberta and British Columbia. This Emergency Response Equipment Loan and Monitoring service can be accessed by older adults by pressing a button they wear on their wrist. This is a 24-hour monitoring/response service. The telephone service can be customized to call older adults with reminders about medications, appointments, or meal schedules. Staff may engage in social conversations, which can help relieve burden for absent or long-distance family members. As this strategy is directed at the care-recipient, thereby helping to reduce caregiver burden, it is an example of instrumental support.
Comprehensive Home Option for Integrated Care of the Elderly (CHOICE®) Offered through three organizations: Capital Health/Capital Care The Good Samaritan Society See: www.capitalhealth.ca/ProgramsAndServices , www.capitalcare.net/Programs/choice.htm ; www.gss.org/choice.html	The program targets frail community-residing older adults who have complex medical needs. The older adult's primary care physician, pharmacist and other members of a multidisciplinary team provide integrated care. Transportation is provided to allow older adults to attend day programs, and telecare is used to provide 24-hour monitoring. Clients have immediate access to care beds for treatment and respite. An evaluation conducted in 1998 indicated that the CHOICE program reduced pharmaceutical claims by 86%, in-patient acute care length of stay by 55%, in-patient acute care admissions by 30% and cost by 55%. ³² This strategy is another example of instrumental support for caregivers. As care for vulnerable older adults is integrated, caregivers need only approach the CHOICE program to address all issues related to their caregiver role. They can access respite care through day programs and overnight care for their loved ones.*
Alzheimer Society of Canada see www.alzheimer.ca for provincial and local chapter offices.	The chapter offices offer support groups for caregivers as well as early stage support groups for people who have been recently diagnosed with Alzheimer's disease (examples of emotional and affirmational social support). The Alzheimer Society of Canada is well known for the informational support it provides through a wide variety of materials in print and video format as well as online resources that benefit caregivers.
Heart and Stroke Foundation of Canada http://www2.heartandstroke.ca and www.strokerecovery.org	Caregivers of persons who have had a stroke can access information from the Heart and Stroke Foundation as well as from various stroke recovery association chapters across Canada, which also offer support groups and informative websites.

* Another model of community care for frail older adults, *Système de services intégrés pour personnes âgées en perte d'autonomie*, or SIPA, has been delivered as a demonstration project in Montreal, Quebec.³³

Key Points

Although the proportion of Canadian older adults with chronic conditions is increasing, the proportion of older adults living in institutional care is declining; at present, most frail and vulnerable older adults live in their homes in the community.

The vast majority of older adults (80–90%) have care needs met by family/friend caregivers.

Older adults' caregivers age 45 to 64 tend to be actively employed in the work force and may look after more than one older adult in addition to their own children.

Caregivers age 65 or older make up a smaller proportion of the caregivers, but this may be an underestimate as spouses may not consider certain tasks, such as cooking and housekeeping, to be related to caregiving.

Older adults' caregivers are at risk for financial, social, physical, and psychological burden.

Health professionals should be aware of caregivers as "hidden patients" and aid them in accessing emotional, instrumental, informational and affirmational social support.

What support strategies do caregivers desire? In a Canadian study, caregivers of older adults with dementia reported higher levels of perceived burden than the comparison group of caregivers.²³ Only 10% of the caregivers expressed interest in support or self-help groups, and identified transportation, time constraints, and lack of respite as barriers to attending such groups. In contrast, almost half reported they would be interested in receiving phone support by a professional or fellow caregiver, and through a newsletter.²³ Although a few (14.5%) were interested in receiving emotional support, more caregivers expressed interest in receiving volunteer help with caring (24%) and household tasks (23%). Finally, while 43% of caregivers had access to a computer, only 15% wanted to receive information by computer, and only 12% wanted to use the computer to communicate with other caregivers.²³ The data in this study were originally collected in 1996 as part of the Canadian Study of Health and Aging (SCHA-2). Given that internet access and technologies for delivering online course content have progressed significantly, it is possible that caregivers' opinions about using the computer to meet their support needs have changed over the past decade.

Social Support

Emotional (e.g., support groups, lending

an ear), instrumental/practical (e.g., transportation, financial), informational (e.g., resources, brochures), and affirmational (e.g., feedback, advice, positive appraisal) supports are provided by spouses, family, friends, peers, and professionals.^{24,25} Social support can be a key protective factor in resilience,²⁵ and a resource for coping²⁷ with both indirect and direct influence on health status, health behaviour, and health services used.²⁸ Support can moderate the effects of stressors on health and functioning.²⁶ The most influential theoretical perspective proposes that support reduces the effects of stressful life event on health (i.e., acts as a stress buffer) through either the supportive actions of others (e.g., advice, reassurance) or the belief that support is available.²⁹ Based on previous studies of social support for family caregivers of people with chronic health conditions such as Alzheimer's disease and stroke, support interventions have the potential to: a) improve coping skills; b) increase competency and confidence; c) decrease overall support needs; d) increase support satisfaction; e) decrease loneliness and isolation; and f) enhance quality of life.³⁰

Health professionals should become adept at prescreening caregivers and identifying support resources targeted to their needs. Interventions designed to enhance the well-being of caregivers should mini-

mize the impact of social isolation and provide social support in a variety of forms (e.g., information, affirmation, and emotional and instrumental support).¹⁶ Support services for caregivers need to be accessible and, through the use of technologies, reduce caregiver burden.

Sample of Existing Support Services for Family Caregivers

Services that support caregivers and their care recipients vary across Canada. Strategies or programs targeted at helping caregivers look after vulnerable older adults (mainly in the city of Edmonton, Alberta) are illustrated in Table 1 and categorized by types of social support. Practitioners should consult with provincial or local organizations to identify comparable resources.

Conclusion

Clearly, family members and other informal support networks form the backbone of older adult care in the community. Until a coordinated system of home care is incorporated into Canada's health care system, support for caregivers will continue to be fragmented. Successful caregiver support strategies would offer instrumental support that provides respite time to allow caregivers to access other forms of social support. Family caregivers who accompany their older relatives to health care appointments should be made partners in decision-making and planning. Support for family caregivers requires the combined efforts of primary care physicians, home care professionals, and informal networks.



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