



WHO CARES FOR SENIORS?

- According to Statistics Canada, about 2.1 million Canadians are caring for senior relatives either in their own homes or the senior's home.' As much as 90% of care provided for Canadian seniors in the community is provided informally. Frail, terminally ill seniors require one person's full time commitment to co-ordinate care and be present at night as well as regular home visits from the physician, the nurse, and other health care and social service providers.
- Within institutions, 30% of services are provided by informal networks.
- Two factors determine who is most likely to provide informal care - gender and age. Females are most likely to provide care. The estimates range from 60%-75% of eldercare in Canada being provided by women.' Caregivers are often the spouse, who may also have health problems, and daughters, particularly the eldest daughter. Most of the woman caregivers have other jobs and 25% were also looking after children under the age of 15." The age of primary caregivers tends to be between 52-84 years. A large proportion of the female caregivers are 60 and over. Married men represent the oldest group of caregivers." There are three typical patterns of care giving based on age: the youngest age categories are adult children providing assistance to a dependent parent; among spouse caregivers, women are younger than men; and women caregivers with children of their own are older than are men in the same situation.

Why *are* women the primary caregivers?

- responsibility for caring and concern for others is seen as central to women's identity
- the care giving role may be thrust upon women through the structures of society such as relationships between the generations, and between men and women
- the limited availability of public services
- the fact that men do not feel as responsible for assuming care giving activities within the family
- women's feeling that the responsibility of family care giving rests with them"
- women live longer and are in better health than men

Adult children as caregivers:

- Among adult children caregivers, approximately 70-80% of care is provided by daughters.
- As age and frailty increase, seniors are more likely to live close to adult children.
- Daughters are more likely than sons to provide "hands on" assistance and daily help with homemaking, personal care, home health care, transportation and psychological support.
- Sons are more likely to provide help with home repairs, handling finances, home maintenance and contacting organizations.



- Siblings who can work together in providing support to their aging parents may develop increased closeness through increased interaction that may lead to support and companionship into their old age.
- Care giving changes the parent/child relationship as the dependency roles change, and the adult daughter in particular may be forced to revisit old conflicts with parents with the parent who is now in need of care.
- Recent work in Saskatchewan indicates that approximately 20% of employees in that province spend time each week looking after children and older dependents.

Seniors **may** have more difficult access to informal care than younger patients for various reasons:

- Spouses may have health problems of their own
- Lower income due to retirement
- Children may have families of their own
- Family members may live far away
- Friends may be older and unable to provide support

However, family members provide much of the care for seniors at the end of life. Most of this care is provided by spouses (primarily wives) and daughters or daughters-in-law. This means that health care and social service providers must:

- be aware of the family caregiver's struggles in providing care for their family member at the end of life
- try to support these family caregiver in any way possible
- be aware that women are the main caregivers of seniors



BURDEN OF CARE

Caregiver burden is the emotional and physical demands and responsibilities of one's illness that are placed on family members, friends, or other individuals involved with the patient outside of the health-care system.

The concept of 'burdening' is one of the major components of the palliative care experience. Caregiver burden involves the impact that living with a senior has on the way of life and health of his/her significant others. This burden can have many significant consequences, such as caregivers ignoring initial symptoms of their own failing health and not seeking medical attention until after the senior's death.

- Already strained relationships within families may be tested further as an older parent approaches the end of life.
- Financial difficulties relating to medical costs, reduced income, disruption in employment and higher living expenses often present difficulties.
- Multiple care giving roles may negatively affect the caregiver's well being, and in fact, the needs of the caregiver may exceed those of the senior.

A wife who was caring for her husband in the last stage of Alzheimer disease stated: I had to occupy him. This was the worst part of it. I found that I had no life. I finally didn't think of anything else at all but Alzheimer's. Everybody was giving me papers to read, and I said, "I don't need this. I'm living it. He's not worried about anything. I do. I'm worried every hour. I'm the one who seems to be sick"

- More than half of caregiver exhaustion can be predicted by three factors: Lack of personal time, being employed in a job outside the home, and frequent behavior problems of the care recipient.
- Caregivers need better support than they are currently receiving. It is important to recognize that there may be a mismatch between professional caregivers' assessment of burden and that of the family caregiver.
- Caregivers often have a reluctance to use existing respite services.

The factors affecting caregiver burden are complex, involving developmental and cultural factors, in addition to the stressors of the illness itself as well as the caregiver's gender, coping style, social network and the caregiver's level of intimacy with the elder.



EMOTIONAL DISTRESS

Caregiver Burden

Caregiver burden is more likely to affect mental health than physical health or financial outcomes. A spouse caring for her husband who was receiving palliative care services stated:

“What was the worst part of the whole situation? It’s not that I was exhausted physically because you can be, obviously. Or not having a moment to myself, or not being able to just go for a walk for two hours without feeling guilty about it. The worse part was how emotionally drained I was.

Depression has been found to be higher among caregivers than in the general population, and more specifically, higher among women, who are a disproportionate percentage of the care giving population.

- Depression in well spouses during the final illness has been associated with the functional status of the terminally ill spouse, the patient’s depression, whether the well spouse quit work as a result of the partner’s terminal illness, and depressive symptoms during bereavement.

Untreated depression may lead to psychological difficulties within relationships with spouses and friends, enjoyment of leisure activities, general social adjustment, and overall contentment. These symptoms and resulting behaviors can affect the quality of life for both the caregiver and the care recipient, as well as the continuity and quality of care provided to the senior who is disabled.

- The needs for care of older frail seniors have been related to greater risk for depression in the caregiver indirectly through the hours of care provided and the caregiver feeling overloaded.
- Caregivers with a high level of mastery or emotional support are at lower risk of depression.
- Daughters are found to have more emotional strain than sons when caring for older frail parents. For daughters, the most important predictors of emotional strain were interference with work and quality of relationship with the parent. For sons, the most important predictors were behavioral problems of the parent and few informal helpers.
- In 1996, 29% of caregivers of persons with long-term health problems stated that care giving had altered their sleep patterns and 21% claimed their health had been affected.
- Elder abuse has become a problem. It can occur as passive neglect, active neglect, physical abuse, psychological abuse, material or financial misappropriation, violation



of rights, self-abuse, and self-neglect.

- Caregivers who may be at risk of abusing are those who already have other caregiver burdens such as an alcoholic spouse or delinquent child, those who live in overcrowded dwellings, face economic hardships, have a history of intergenerational conflict and/or are otherwise dysfunctional.

Work-home conflict:

- About half of caregivers reported that care giving had repercussions on their jobs (lateness, absenteeism)
- One recent study found that one third of employees who provided care to both children and elderly family members found it very difficult to balance paid work and home responsibilities. A daughter who was caring for her mother who was dying stated:

We also have (jobs), many of us are taking vacation days, we're taking stat holidays. I, myself, am choosing not to work in this period. We give pregnancy leave...we give paternal leave for the father to bond with his child, but when, at the other end of the spectrum, when people are dying, why don't we give caregiver relief?

Needing to alter work hours is associated with higher stress in caregivers. High work-life conflict is associated with:

- decreased wellness including greater perceived stress, depressed mood and burnout; and poorer physical health
- reduced job satisfaction and organizational commitment
- greater use of the Canadian medical system (i.e., increased number of physician visits, increased illness)
- increased absence from work

Canadian caregivers with a high work-family conflict were absent from work an average of 13.2 days compared with those who reported low level of conflict (5.9 days). What does this mean financially? A \$2.7 billion cost involving time off to deal with dependents and to deal with stress and illness caregivers encounter from their juggling act. A \$425 million cost to health care system of 86.9 million extra visits to physicians.



FINANCIAL BURDEN

The care provided by families is not free. The cash value of services provided by families far exceeds the combined cost of government and professional services to both seniors who live in the community and those who live in institutions.

- Caregivers also incur invisible' expenses, including home modifications, rented equipment, special foods, higher heating bills, and the "opportunity costs" of caregivers who forgo paid employment. This type of family support is estimated to be the equivalent of full-time work in about one-third of households providing elder care.
- Quality care in institutions can easily cost thousands of dollars per month.

Therefore, family caregivers experience a great deal of hardship in meeting the challenge of caring for older family members at the end of life. This hardship is generally in the form of physical exhaustion, emotional distress and financial difficulties. This means that health care and social service providers must:

- be aware of these stresses on the family caregiver
- offer support in any way possible from the resources that are available
- advocate for the development of new services and encourage their use.

THE CAREGIVING PROCESS

Differing disease patterns and levels of support are likely to have a major impact on the level of stress a caregiver experiences. The family's response to illness will in part be determined by whether the illness comes out of the blue with no warning, or whether they have time to adapt to changes. Families begin to develop their own timelines at the time of diagnosis. Discussions about the nature of the illness, its prognosis and prescriptions for management constitute a 'framing event' for families.