

Brief on Family Caregivers of People at the End of Life

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in Palliative and End-of-life Care New Emerging Team

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Introduction

This brief is based on the work and knowledge of the New Emerging Team on Family Caregiving in Palliative and End-of-Life Care previously funded by the Canadian Institutes for Health Research (CIHR 2004-2009), as well as my experience with palliative care researchers across the country as the former leader of both the Canadian Cancer Society Sociobehavioural Cancer Research Network Palliative Care Team and the CIHR Strategic Training Program in Palliative Care. I am also the Research Director for Palliative Care at McGill.

Like most roles in today's society, the family caregiver defies neat categorization. As family structures have evolved, so has the face of the caregiver. She is the working woman struggling to manage a career and young children while caring for a husband succumbing to cancer. He is the senior citizen with major illnesses of his own trying to keep his wife with Alzheimer's home as long as possible. She has three children at home and lives thousands of kilometers away from her only sibling who is dying of heart failure, with several hospitalizations over the past few months. Family caregivers can be found within all cultural groups, economic classes and all demographics, although they are predominantly women.

As a result, family caregivers have varied needs and challenges that are directly related to access to services, time constraints, financial capacity, and their own and the patient's health. Most face significant physical and emotional challenges and struggle to meet their own, the patient's, and society's expectations of providing end-of-life care while taking on and often learning many of the patient's former household tasks. Many struggle with increased expenses at a time when their income is reduced and/or the patient's employment income is gone.

Despite these difficulties, most want to help their loved ones at the end of life and endeavor to keep them at home as long as possible. They are willing to make sacrifices to provide care, but they do not anticipate the poor health consequences or loss of financial security that often accompanies the role of the caregiver.

It is clear that family caregivers of people at the end of life need:

- Governments who support systems approaches to and health care professionals who are concerned about caregiver health and wellbeing along with the health and wellbeing of their patients.
- Access to resources for support, advice and education about caregiving to enable them to provide competent care
- Practical support for household tasks and financial planning
- Improved access to hospice/palliative care resources that provide choices at the end of life for caregivers so that they do not need to compromise their own health while caring for others
- An improved and more accessible Compassionate Care Benefit that covers a range of

financial and employment situations, so that they are not faced with choosing between financial distress and not providing care.

Governments and health care professionals need to be concerned about family caregivers' health and wellbeing

Bedside care of hospitalized patients at the end of life is done by 2-3 shifts of nurses daily. The individuals who provide these services are protected by unions to ensure that their working conditions do not endanger their health - and if they are sick, they get time off.

Primary family caregivers enjoy no such support. They provide care 24/7 for weeks, months, or, with some diseases, even years. Up often at night to provide care and sleeping lightly with an ear out for the patient's call, they are sleep-deprived. Their tasks are many and varied, and often performed with inappropriate or negligible training or education.

Caregivers who are caring for someone in a hospital or long-term care institution have to keep the household going, perhaps care for others (children, parents, pets, etc), may be employed, and may need to travel back and forth significant distances to be with the patient. Concerned that their family member may be too weak or confused to call for help alone in the institution, or worried that they may die alone, the caregiver often spends much of those last weeks or days sleeping in a chair in a hospital room.

Many caregivers are elderly and/or have significant health problems of their own, and they are expected to fulfill their role, many times at the peril of their own health. Add to this the stress and sadness of watching a family member die and it's not surprising that these caregivers experience significant depression, anxiety and exhaustion.

Our current health system is not organized to care for family caregivers along with patients. Instead, they are treated as health care workers without the education or support given to the professionals who work alongside them. And because there is currently no way for the home care service, hospital, long term care institution, nurses or doctors to bill for the care they provide to family caregivers or to have a schedule flexible enough to incorporate this care, they are often left to perform their role without any resources to manage their own emotional and physical needs.

Caregiving finishes the day the patient dies; in most cases that is the day the health care system loses interest in the caregivers. Their bereavement needs during that first crucial year are not assessed and/or addressed, despite the fact that caregivers have a 63% higher mortality during bereavement than others who are bereaved.

By ignoring the needs of caregivers, we create unnecessary suffering that often results in them becoming patients themselves. A proactive family caregiver program can break the cycle, supporting caregivers as they provide care and helping them to maintain their own health during care and bereavement. This approach may potentially be cost-neutral, in addition to being more caring and fair to this large segment of our society to which most of us will one day belong.

Family caregivers need access to resources for support, advice and education about caregiving to enable them to provide competent care

Your family member is dying and you are the only person to care for them. How do you:

- manage a patient who is confused and wants to go to the bathroom alone although they are too weak?
- efficiently change bedding, clothing and diapers for someone who is incontinent?
- manage the patient's anger about dying when the anger is directed at you?
- speak to a loved one about their impending death?
- change the bedsheets while the patient is still in the bed, without hurting the patient or your back?
- manage complex pain?

These questions are but a small sample of caregiver responsibilities – responsibilities that must be performed while also facing the emotional impact of a loved one's dying. Palliative care professionals receive training for this, yet family caregivers are given little or none. They perceive this situation as stressful, are fearful of doing the wrong thing, and feel guilty if despite their best efforts the patient is not comfortable. Family caregivers who feel less prepared to provide care cope less well during care and have more difficulty dealing with the death.

Family caregivers need practical support for household tasks

In addition to their usual household tasks, family caregivers usually have to take over those that the patient used to do - such as preparing a meal or taking care of household finances. For some, this will be the first time they have ever handled these responsibilities. Caring for the patient usually increases household tasks as well, from more laundry, to special meal preparation, to organizing legal and banking issues in preparation for death. The sheer number of these extra tasks, along with increasing amounts of patient care, can be overwhelming.

Practical support is needed to:

- teach family caregivers what they don't know about household tasks and financial responsibilities
- provide respite breaks for rest and renewal
- allow caregivers to take a break from their new role – to spend time being the patient's spouse, daughter, etc (rather than a caregiver), with the opportunity and time to talk and simply be with the patient during their last weeks and days.

Family caregivers need improved access to hospice/palliative care resources that provide choices that take their own health into account

Patients and caregivers should be able to choose the setting of care that is most appropriate for their situation. Patients often want to spend their last weeks at home and families want to support that wish – but support for patients and caregivers to make this feasible is not universally available or even possible in some situations. For caregivers, this disconnect can incur a significant emotional burden. Research also suggests that only half of patient/caregiver dyads studied actually agreed on the preferred location of death. Usually, a family caregiver's promise to the patient to care for them at home is made without really knowing what that promise entails: how difficult - if not impossible - it may be to keep the patient comfortable at home, what the caregiver role involves, and how exhausted and overwhelmed most family caregivers become.

Unfortunately, access to care that can optimize the quality of life at the end of life for patients and family caregivers is spotty at best:

- Sufficient support for the patient and caregiver who wishes to provide care at home from an interdisciplinary team knowledgeable and skilled in palliative care is not available in many areas in Canada.
- In most areas, there is a lack of hospice or palliative care unit beds that could enable care to take place where it is most appropriate for the patient or caregiver.
- Often, staff in other care settings (such as long term care institutions and acute care hospital units) lack the training and time to provide the care required by people at the end of life and their family caregivers. Family caregivers of people who die on acute care medical units or extended care units are less satisfied with care than those who die on intensive care units or palliative care units.

An improved and more accessible Compassionate Care Benefit is required so that family caregivers are not faced with a choice between financial distress and not providing care.

Financial burdens for caregivers range from the loss of employment income of the caregiver and that of previously employed patients whose health forces them to retire to costs associated with patient care. These costs can include costly medications, ramps or other house renovations, the purchase and installation of safety equipment, bedside commodes and other accommodations, transportation to medical appointments, household support and out of pocket expenses for the caregiver or her family when spending time with a hospitalized patient. These burdens are significant - a 2007 survey of health care in Canada (Health Care in Canada Survey 2007) suggests that 41% of Canadians use personal savings to support themselves when caring for loved ones at the end of life, and 22% miss one or more months of work. These financial burdens are not also borne by the individuals but society as a whole in terms of decreased productivity due to absenteeism.

Along with diminished financial support, caregivers are challenged by a lack of legislation regarding job security in caregiving situations. Canadian family caregivers have traditionally

been dependent on the good will of their employers even if they wish to take unpaid leave, forcing many to continue working at a time when they need to be at the bedside of their loved one. The burden of having to remain in the workforce while providing care is significant, and it typically negatively affects the physical, emotional, and mental health of family caregivers.

Government programs and services such as the Compassionate Care Benefit (CCB) are intended to support caregivers during this time, however they are limited both in terms of access and length of coverage, particularly for caregivers who are caring for an individual with an uncertain trajectory of death or for caregivers who are not employed outside the home.

Successful CCB applicants can receive up to 55% of their average insured earnings, to a maximum of \$413/week, over a 6-week period to care for a family member at risk of death within 6 months. Successful applicants are required to undergo a 2-week unpaid waiting period before receiving payments and to determine when payments will start (within 28 days of making the claim). In order to qualify, applicants must have worked a minimum of 600 EI-insurable hours over the preceding 52 weeks.

They must also meet the designation of “family member” and provide a medical certificate from the doctor of the gravely ill family member indicating that death is imminent (i.e., within 6 months). Eligible family members are (in relation to the care recipient): child; child of spouse or common-law partner; wife/husband/common-law partner; father/mother; or father’s wife/mother’s husband or common-law partner.

The Compassionate Care Benefit, while useful for some caregivers, presents significant barriers to successful caregiving:

- the two-week waiting period is not feasible for many low-income Canadians
- access to the benefit is tied to regular employment
- applying for the benefit is a complex process
- the definition of a family member is limiting– today’s extended families and the high prevalence of separated families (both legally and geographically) can mean that the caregiver may not fit within the eligibility requirements or may in fact not even be a ‘family’ member
- an uncertain trajectory towards death or an extended period of caregiving can make the timing for applying for the benefit a difficult task.

Recommendations

Short-term

1. Review the Compassionate Care Benefit and how it is accessed, funded and administered to improve its benefits to caregivers, particularly in cases with an uncertain trajectory towards death
2. Compile existing information for family caregivers in various user-friendly and accessible formats (e.g. The Canadian Cancer Society's 2010 booklet "Living with Advanced Cancer").
3. Fund the development and pilot testing of new services and models of care to support family caregiver wellbeing
4. Fund surveys and critical reviews of existing volunteer services (in Canada and internationally) to help family caregivers during the care period and bereavement, including a review of barriers- such as changing demographics of volunteers and recruitment challenges. This should be followed by pilot testing evidence-based models in different types of communities (e.g. remote; rural; large city; different cultures)

Medium to long-term

Federal, Provincial, and Territorial governments need to change the health care system to ensure the wellbeing of those who choose to be family caregivers, as they represent the majority of Canadians and form an integral part of the health care system. This requires:

1. Funding for and administrative changes to allow health care providers to provide emotional and educational support for caregivers as part of patient care
2. Advanced resources for caregivers and patients who choose a home-based end-of-life care setting. Resources specifically directed to the wellbeing of family caregivers should be based on the results of the pilot projects described as short-term goals
3. Ensuring that high quality end-of-life care is available throughout Canada, in all settings of care and through the duration of the end-of-life period. Where appropriate, it should be seamlessly integrated with care aimed at cure or life prolongation so that patients and family caregivers do not need to first acknowledge that the patient is dying to receive the care needed
4. Assessment of wellbeing and provision of services as needed during bereavement
5. The development and administration of volunteer services both during care and bereavement, based on the results of what is learned through achievement of the short-term goals

Conclusion

Most Canadians will be required to become a family caregiver for a loved one at least once in their life. Most choose to provide care willingly, but should not have to do so while jeopardizing their own wellbeing and financial security.

We must support the vital role of the caregiver. This may mean giving them a break from the caregiving role so that they simply be with a loved at the end. It may mean regular assessments to ensure that the caregiver is capable of providing care – some are not able to do so. It means recognizing that quality end-of-life care must be available in the care setting of choice, which often changes rapidly, as it is closely tied to both the patient's and the caregiver's state of health.

Societal trends make it more likely that people will find it difficult to be family caregivers. Families are more widely dispersed; smaller families mean there are less adult children to care for the dying parent; the population is aging; there is more chronic illness, therefore the duration of caregiving increasing; there are more women, who traditionally and to this day provide the majority of care, in the workforce. If we do not support them, rather than lose their job or health, many will choose not to be caregivers: imagine the financial cost to governments, and human cost to them and the patients.

As societal trends and demographics evolve, so do the health needs of Canadians. Caregivers currently play a key role in our health system –a role that will continue to grow as our population ages and resources become strained. A proactive approach that formally recognizes and supports this critical component of our health system is vital to the viability of a strong, balanced health system that truly supports all Canadians.

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