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# Burdens of Family Caregiving at the End of Life

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### Abstract

A patient's ability to be cared for and to die at home is heavily dependent upon the efforts of family caregivers. Considerable stresses are associated with such caregiving, including physical, psychosocial and financial burdens. Research has shown that unmet needs and dissatisfaction with care can lead to negative outcomes for caregivers. While many family caregivers also report caregiving as life-enriching, some report that they would prefer alternatives to care at home, primarily because of these associated burdens. Little is known about which interventions are most effective to support family caregivers ministering palliative care at home. Well-designed studies to test promising interventions are needed, followed by studies of the best ways to implement the most effective interventions. Clinically effective practice support tools in palliative home care are warranted to identify family caregiver needs and to ensure that patients and their family caregivers have a choice about where care is provided.

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The aging population, the growing number of Canadians diagnosed with chronic life-limiting illness, and the fact that a large majority of Canadians report that they prefer to spend their final days at home [1,2,3] are converging to prompt government policy to press for more and better care of dying people in the community [4]. Patients' ability to be cared for and to die at home, however, is heavily dependent upon the efforts of family caregivers [5]. Even where patients receive home care services, the likelihood of dying at home is dramatically reduced if family caregivers are unable to provide care [6].

About 80% of all care at home is provided by family caregivers [7]. Recent estimates suggest that Canada's 1.5 to 2 million family caregivers provide \$25 to \$26 billion worth of care annually and incur \$80 million in out-of-pocket expenses annually [8]. Not only are family caregivers the 'invisible' providers within our health care system in Canada, but they have emerged as the principle source of support for patients who are dying at home. Though normally willingly undertaken [9], caregiving at the end of life entails considerable cost for family caregivers and the wider family, incurring emotional, social, physical and financial costs [10,11]. The toll of care extends even into bereavement; people who are at least somewhat distressed by caregiving are 63% more likely to die in the four years following the patient's death than those who were not distressed or than the bereaved who did not give care [12]. Indeed, the Public Health Agency of Canada identifies the issue of 'seniors caring for seniors' as a public health concern in need of attention.

### Canada's Family Caregivers: Who Are They?

The vast majority of family caregivers in Canada are female (77%); about 70% are 45 years of age or older and about 25% are at least 65 years of age. Thus, women aged 45 and older comprise 51% of Canada's family caregiver population [13]. Consistent with these characteristics, Canada's family caregivers are most likely to be retired or homemakers, particularly if the caregivers are older women [13]. When a child is dying, the parents may be quite young, less established in their careers, and face the added responsibility of caring for other children [14]. A growing segment of family caregivers in Canada consist of family members, friends, and neighbours who simultaneously provide unpaid care to older adults and their own children while also participating in the paid labour market [15]. Often referred to as the 'sandwich generation,' these (mostly) daughters, daughters-in-law and female spouses provide almost 30 hours per month of caregiving tasks in addition to being employed [16]. The time commitment and intensity of caregiving grows in the context of end of life care where dis-

trressing symptoms arise, where the patient becomes more functionally- and sometimes cognitively-impaired, and when death is imminent [17]. In these cases, family caregivers often temporarily stop working or reduce their paid work to provide care [17,18].

Family caregivers have many functions including, but not limited to, domestic chores and household tasks, providing personal care and assisting the dying person with activities of daily living, managing symptoms such as pain and constipation, providing emotional and social support to the dying person, being a spokesperson, advocate and proxy decision maker and coordinating all aspects of the dying person's care [18]. While family caregiving has considerable rewards, including allowing caregivers to facilitate closure after death and helping them find meaning in their experiences [19], it is physically exhausting, difficult to recover from, and fraught with emotional and financial burdens [20]. Therefore, it is not surprising that the health and well-being of family caregivers often suffer when they provide end of life care at home [18,21].

### The Burdens of Family Caregiving at the End of life

Recognition of family caregivers' contributions and the importance of assessing family caregiver's needs in practice have been acknowledged [22]. Within the palliative care literature, the experience of caregiving has been described as fundamentally uncertain, in part because of the unpredictability of the trajectory [23,24]. There is a sense of a disruption in 'normal life' [9, 25], and experiences of helplessness and vulnerability are commonly noted [26,27]. Care demands can be particularly onerous towards the end of life, and emotional stresses can be particularly high as family members grieve successive losses, have vivid awareness of impending death and face an uncertain future. Social isolation is common [28,29] and obtaining support is hampered by the fact that many family members do not identify themselves as legitimate recipients of help, focusing instead on the dying person [9,30]. High levels of psychological distress are common; for example, 41-62% of family caregivers providing palliative care in Quebec experienced a high level of psychological distress compared with 19% of the general population [31]. This percentage increased as the patient's health declined and as patients became less able to care for themselves [31].

Many family caregivers have anxiety levels in the clinical range; higher than that of the dying patient's [32,33]. Studies show that family caregivers experience levels of depression similar to patients and greater than the general population [32]. Psychosocial and mental health challenges are accompanied by physical burdens. Long hours of care provision

are often associated with significant fatigue and sleep deprivation [34,35]. The physical demands are often a result of the excessive 'work' involved in the caregiving process and the 24 hour responsibility that many family caregivers have. Evidence suggests that some family caregivers do not look after themselves particularly well; they do not eat properly, often cease activities outside of the home and postpone their own medical appointments [36]. Adding to this, many family members feel ill-prepared for caregiving roles [9] and uncertain about their abilities [37]; many feel pressured to provide such care [19] yet feel ambivalent about providing it [30]. This is more challenging when the patient being cared for and the family caregiver have pre-existing tension in their relationship [38].

Providing care at the end of life can also result in occupational and financial consequences [32,39]. Canadian-based research led by Dumont has found that the welfare state, the family and not-for-profit organizations sustained 71.3%, 26.6% and 1.6%, respectively, of all costs associated with end of life care [40]. A recent examination of Canada's Compassionate Care Benefit [41] also suggests that even where benefits are available, family members can experience challenges in negotiating the system; this study found that family members were concerned about limitations of the benefit, such as strict eligibility criteria and the relative short duration of assistance. In terms of workplace policy, many Canadian family caregivers have no paid leave or job security if they take time off work. A recent report from the Economist Intelligence Unit ranking the quality of end of life care around the world highlights that Canada suffers in the overall ranking because the cost of community-based care results in significant financial burdens to families [42].

### Dispelling Assumptions

Despite feeling overburdened, many family caregivers report that caregiving is a life-enriching experience [19]. Family caregivers can derive significant benefits from caregiving, reporting a sense of accomplishment in fulfilling the final wishes of the patient and a belief that they are able to give something back to the person for whom they are caring. Caregiving also allows family members to spend intimate times together and share final moments that are meaningful. These positive aspects of the experience have contributed to dying at home being viewed as the gold standard when defining a 'good death' [43]. Indeed, there are many instances in which dying at home is likely the best option for patients and their family caregivers; however, in Canada, there is an assumption by health care providers and government that dying at home is preferable to patients and their family caregivers [19]. Although there is a prevailing as-

sumption that patients, if given a choice, would prefer to die at home, one Canadian investigation revealed that patients and family members only agreed half of the time about the preferred location of death [44]; more patients wanted to die at home and more family members preferred an institutional setting such as a palliative care unit.

Research has shown that family caregivers believe they have few choices when it comes to providing care at home [19]. Instead, many family caregivers make promises to care at home out of a sense of duty, love and obligation, while feeling ambivalent about it [9,45]. Aside from the desire to be in a more familiar environment [19], a primary motivator for care at home seems to be related to poor experiences with acute care, usually around the time of diagnosis or in the treatment period following acute care [9]. Recent analyses of bereaved family caregivers' satisfaction with end-of-life care in acute care medical units suggest there is much room for improvement in these settings. In a cross-sectional survey of bereaved family members, several startling findings emerged: 69% of family caregivers said they were less than satisfied that they knew the doctor in charge of their family member's care; 69% said they were less than satisfied that the emotional problems of the dying person, such as depression, were relieved; 50% were less than satisfied that someone was available to help the dying person with personal care; 46% were less than satisfied that they had had opportunity to have discussions about options for end of life care; 43% were less than satisfied that their family member received good care when they were not there; and 43% were less than satisfied that they understood what to expect at the end stage [46]. Findings such as these underscore the need for improving end of life care in acute care settings.

### Future Directions to Support Family Caregivers

Research has shown that unmet family caregiver needs and dissatisfaction with the quality of care can lead to negative outcomes, such as prolonged and pathological grief, increased use of health services, caregiver burden and decreased quality of life [47-49]. A sizable body of evidence exists that describes the family caregiver's experience and needs [10,11,50,51]; however, very little is known about which interventions are most effective for supporting family caregivers as they provide palliative care. Three recent studies suggest some promising interventions such as: (a) a pilot-study of a night respite service aimed at reducing family caregiver fatigue and sleep promotion [52]; (b) a three-session group psycho-educational program that increases perceived family caregiver competence and preparedness to care [53]; and, (c) a program designed to increase a family caregivers' sense of hope [54]. All of these interventions re-

port improvement in at least one outcome over time, but none of these interventions had a comparison group. Results from intervention studies with comparison groups are mixed. In one study, an intervention designed to assist family caregivers in problem-solving improved their quality of life and decreased the patient's symptom burden [55]. Conversely, a six-session group psycho-educational intervention had no effect of family caregivers' emotional well-being [56]. In general, the evidence around interventions for family caregivers is relatively weak [11]. Well-designed studies are sorely needed in this area to test promising interventions, followed by studies to evaluate the most effective ways of implementing the most effective interventions. Clinically-effective practice support tools are also required to assess family caregivers in palliative home care as a way to make their needs visible [57]. Such assessment could help identify and ameliorate some of the burdens that caregivers are likely to face in the course of providing care to dying patients at home.

While government costs constraints and aging demographics will continue to fuel the trend for more people be cared for and to die at home, the reality in Canada is that the large majority of people die in inpatient settings [58]. The poor quality of care received by Canadians dying in acute care settings has been documented [59,60]. Poor quality hospital care, however, should not be the reason why patients and family members want to stay at home at the end of life. Improved care of dying patients in the acute care setting is required, and, where possible, alternate venues such as hospices require further development to ensure patients and their family caregivers have a choice in where care at the end of life is provided.

Finally, consideration of funding models to better support the work of family caregivers is required. Hospice palliative care programs in Canada, many of which support care of the dying at home, rely disproportionately on charitable giving and may not have funds to support family care work. Publicly funded home care services provide nursing care and coverage of equipment and drug supplies in most Canadian provinces, but it is still the case that family caregivers bear a large part of the cost of supporting individuals at home. In Canada, home care costs in the last six months of life are almost double that required for all other home care clients [61]. While it is likely that promotion of home care programs for the dying will continue, it must come with a commitment to expand resources to better support family caregivers so that we are not adding to what can be an already burdensome experience for them.

## Conclusion

Fulfilment of the wish of many patients to remain at home towards the end of life is heavily dependent on the caregiving efforts of family members. Palliative caregiving entails considerable health risks for the family caregiver. Provision of appropriate support for family caregivers can ameliorate these risks and enhance family members' quality of life. As the population ages and people are living longer with increasingly complex morbidities, family caregivers will be increasingly called upon to provide care at the end of life. Finding the best ways to support family caregivers should be a healthcare priority.

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