

VOICE in Health Policy

The Role of Informal Caregivers in Hospice Palliative and End-of-Life Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges

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Preface

The Canadian Hospice Palliative Care Association (CHPCA) provides leadership in hospice palliative care in Canada. Its goal is the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened.

The organizations that are members of the CHPCA believe that:

**Every Canadian has the right to die with dignity, free of pain,
surrounded by their loved ones, in a setting of their choice.**

The CHPCA recognizes that informal caregivers play a key role in hospice palliative and end-of-life care, and their role continues to evolve and change. The tasks that informal caregivers are asked to do are shaped and influenced by a number of factors, including larger social, demographic and economic trends, the unique experience associated with caring for someone who is dying, and changes in health policy and services.

There is growing evidence that informal caregivers, as a result of both the growing preference of many Canadians to die at home and changes in health services, are taking on a wider range of tasks and responsibilities. Given these changes, what are the legal, moral and ethical issues that informal caregivers face in providing palliative care? Do current health policies empower and support informal caregivers, or is there a need for new policies to reflect informal caregivers' changing role?

The purpose of this paper is to:

- *spark discussion of the legal, moral and ethical issues that arise for informal caregivers providing hospice palliative care, and for the professionals who work with them*
- *begin to identify health policies that will empower and support informal caregivers, and address the legal, moral and ethical issues they face.*

This discussion paper is based on information gathered through a review of the literature, anecdotal reports, and key informant interviews with informal caregivers, health care professionals (e.g., nurses, physicians, social workers) who work with informal caregivers, and experts in law and ethics. It also includes feedback from a policy forum hosted by the CHPCA. It is not an exhaustive study, but an attempt to identify issues and questions that should be explored when developing policy recommendations.

Background

This paper and the policy forum are part of a collaborative project between the CHPCA and Health Canada, funded by the Voice in Health Policy, Voluntary Sector Initiative (VSI). The goal of the VSI is to strengthen the capacity of the voluntary sector to contribute to health policy.

The CHPCA gratefully acknowledges the guidance of the advisory committee for the project:

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Informal Caregivers in End-of-Life Care: Who Are They?

Compassion, demographics and diminishing resources will dictate that each one of us has been or will be an informal caregiver at some time in our lives.

*Ann Soden
Chair, National ElderLaw Section
Canadian Bar Association
April 2004*

In hospice palliative and end-of-life care, informal caregivers are the family members (i.e., spouses, partners, parents, children, siblings, extended family), friends and neighbours of people who are dying. Traditionally, the majority of informal caregivers have been family members but, as a result of demographic trends, that is changing. In a highly mobile society, families no longer live as close to one another as they did in the past. There are also a growing number of single women in Canada, and people living alone. According to the 2002 General Social Survey, about 35% of women and 16% of men over age 65 live alone (Statistics Canada, 2002). These trends likely mean there are fewer family members to share end-of-life care, and may explain the growing number of friends and neighbours now providing hospice palliative care.

According to both informal caregivers and professionals interviewed, informal caregivers continue to be primarily women – usually the partners, mothers, daughters, sisters, daughters-in-law and friends of the dying person. These anecdotal reports are supported by research that indicates that between two-thirds and three-quarters of informal caregivers are women (Guberman, 1999).

While women continue to be the primary informal caregivers (Guberman, 1999), there are indications that men are becoming more involved. About 42% of men in Canada report that they are willing to provide care for family members (Ipsos-Reid poll, 2004), and about the same proportion of men as women over age 45 report providing some care for one or more seniors (Statistics Canada, 2002).

In terms of informal care, men tend to focus on practical tasks around the house, on outside work and on financial matters, while women provide most of the hands-on, personal care (Statistics Canada, 2003; Guberman, 1999). When men are placed in a primary caregiving role, they appear to be effective at organizing help. In one study, almost all the men had a nurse in the family who helped with caregiving or had organized a group of caregiving women to help them (Stajduhar, 2004).

In hospice palliative care, the age of the informal caregiver can have implications. The average lifespan for most Canadians is now over 80 years for women and 75 for men, as opposed to 71 and 62 in 1951 (Statistics Canada, 1995). This means that more informal caregiving is falling on older, frailer spouses, partners, and siblings, and on older children, who may themselves have age-related health problems. When it is a child who is dying, the parents may be quite young, less established in their careers, and face the added responsibility of caring for other children.

The Unique Nature of Palliative/End-of-Life Care

The CHPCA recognizes that the challenges of informal caregiving extend far beyond end-of-life care. Many families are providing ongoing informal care for children with congenital problems or developmental disabilities, and for family members who have long-term chronic conditions or who are recovering from illness or surgery.

However, hospice palliative care comes with its own unique stresses and needs. Informal caregivers are asked to provide care at a time when they are also dealing with their own sense of impending loss and grief, and when their main focus is on being with the dying person and providing emotional support through the process of dying. In the context of hospice palliative care, the “adaptational tasks of the caregiver parallel those of the patient ... the caregiver must integrate and acquire medical information while simultaneously mobilizing coping strategies.” (Glajchen, 1997)

Goals of Hospice Palliative Care

- Pain and symptom control
- Support for the “last things”
- Concern for family and loved ones
- Importance of “presence” and non-abandonment

The closer people are to the end of life, the more important the informal caregiver or intimate other’s role is. In the goals of palliative care – farewells, reconciliation, support – informal caregivers are essential, and professionals play a much less dominant role. In this situation, the informal caregiver can face “an enormous challenge in trying to meet the patient’s needs for emotional and practical support, while dealing with his or her own impending loss and separation.” (Glajchen, 1997)

The Changing Demands on Informal Caregivers in End-of-Life Care

People at the end of life have complex care need, which are different from the needs of those who are not facing impending death. Their needs include:

- medical care (e.g., disease management, pain and symptom management, side effects of medication)
- personal or practical care (e.g., feeding, bathing, household activities)
- psychological, social and spiritual care (e.g., relationships with family, fears, values, meaning)
- loss, grief and bereavement care (e.g., planning for death and bereavement, mourning)

According to the professionals interviewed, informal caregivers used to focus primarily on last two needs: psychological, social and spiritual care, and on loss, grief and bereavement. Their main role was to “be” with the person and provide emotional support through the process of dying.

The roles of informal caregivers in hospice palliative care are:

- assisting the dying person in understanding palliative care
- helping the person access palliative care
- advocating for optimal palliative care
- supporting the decisions of a competent person
- making decisions for a person who can no longer make decisions for him/herself
- assisting with communication at all levels
- bereavement.

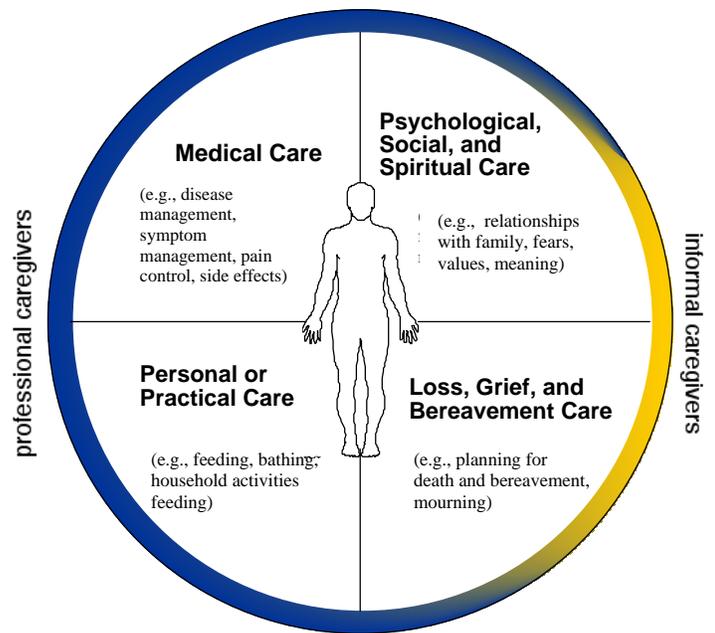
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May 2004*

Because of changes in the health care system, informal caregivers are now providing a significant amount of personal care and, in some settings, medical care. It appears that informal caregivers are being asked to take on a larger burden of care.

The following text and diagrams attempt to show how the role of informal caregivers has changed in each of the settings where people die: residential hospices, long term care facilities, hospitals and at home. (In the diagrams, the light part of the circle indicates the role of the informal caregiver, while the dark part indicates the role of the professional caregiver.)

In residential hospices. In residential hospices, the role of informal caregivers continues to focus on “being with” the person who is dying, and providing emotional support. Residential hospice programs are staffed and organized in such a way that professionals and/or trained volunteers provide any medical care and most personal care. Informal caregivers can choose to be involved in the dying person’s personal care. Those who do report they receive a lot of support from staff. Informal caregivers in a hospice setting are involved in decisions about the dying person’s care.

**Roles in End of Life Care
in a Hospice Setting**

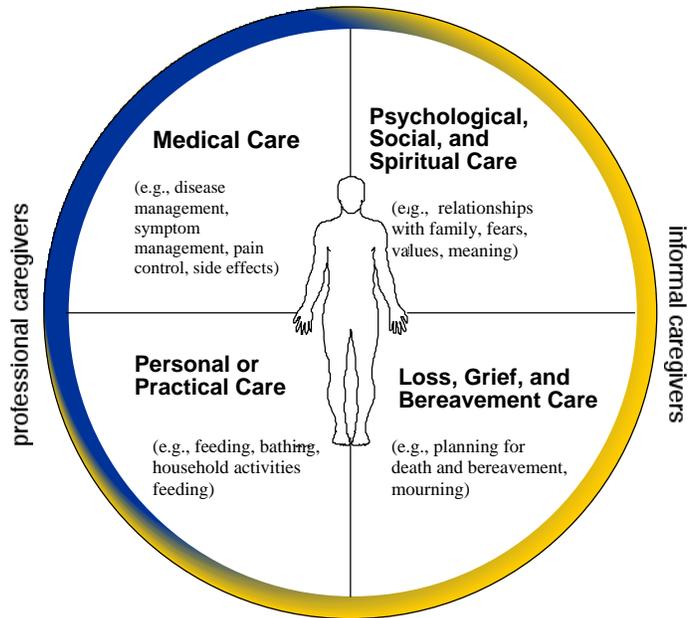


In long-term care facilities and hospitals.

In both long-term care facilities and hospitals, the role of informal caregivers has expanded to include more personal care, such as help with bathing, feeding, shaving, and exercise. Although professional staff in these settings are expected to provide personal care and do provide most of the bladder and bowel care, they are often caring for many residents or patients with very complex health care needs. According to key informants, these settings are not adequately staffed to provide timely personal care. Informal caregivers often take on these tasks so the dying person does not have to wait, and the system has gradually become dependent on them to provide this assistance.

Informal caregivers report that they feel responsible for advocating for the dying persons in these settings in order to ensure they receive the care and attention they need when they need it. Although informal caregivers are able to get more rest when the dying person is in a long-term care facility or hospital than when they are caring for the person at home, they often experience significant stress because they worry the person may not receive timely care in their absence. It is also becoming increasingly common for informal caregivers to hire private nurses to provide extra care in these settings when they are not able to do so.

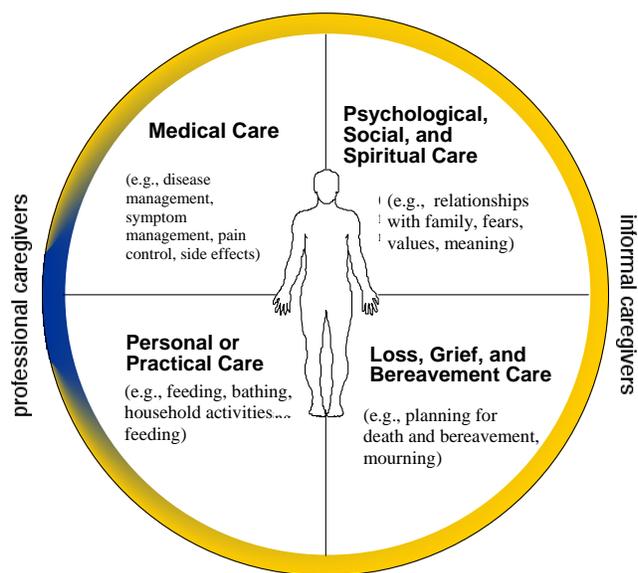
Roles in End of Life Care in a Hospital or Long-Term Care Facility



At home. While the demands on informal caregivers have increased in all settings, the change has been most extreme for those caring for people at home. According to key informants, informal caregivers providing hospice palliative care at home undertake a wider range of tasks in an environment where they typically have less support from professionals. Their tasks may include:

- psychological, social and spiritual care
- personal care, including bathing, toileting, bowel care, bladder care, massage
- medical care, including administering medications, giving injections, cleaning and changing catheters, changing dressings, keeping records, turning patients
- homemaking services, including cooking and cleaning
- advocacy and care co-ordination, including dealing with the different care providers who come to the home, and organizing the equipment and services the dying person may need
- financial support – families often have to purchase medications, supplies and equipment that would be provided free if the person were dying in a hospital
- other responsibilities, such as caring for children or another older person in the home.

Roles in End of Life Care at Home



The most significant difference for informal caregivers at home (besides the 24 hour a day role in care) is the responsibility for medical care. In all other settings, there is a clear line between what formal caregivers and informal caregivers can do: trained professionals are responsible for all medical care. In the home, this is typically not the case. More and more medical care, including administering medications for pain and symptom management, is being delegated to informal caregivers, who are being asked to take on what a nurse – and sometimes a physician -- would do in an institution.

The Current Policy Environment

Are current health or other social and economic policies and trends helping or hindering informal caregivers providing end-of-life care? What are the implications of existing trends in health policy? Are policies introduced for non-health reasons having unintended consequences for informal caregivers?

According to caregivers and professionals, there have been a number of recent policy trends or developments that will have positive implications for informal caregivers, including:

- the new federal Compassionate Leave benefit, which will allow informal caregivers to use the employment insurance system to compensate for some loss of earnings if they take a leave from work when a family member is dying. The policy also encourages employers to protect the positions of people who take compassionate leave. The program has not been in place long enough to determine its effectiveness. (Note: the benefit is available for six weeks, which may not meet the needs of all dying people and their caregivers. It is also limited to partners, parents and children. Current eligibility criteria do not reflect the wide range of people involved in informal care.)
- changes to some provincial labour legislation that allow people to use the Compassionate Leave benefit
- changes to the Quebec labour code that allow for paid family days
- new policies introduced by various provinces, including:
 - the development of hospice palliative care programs/teams and home hospice programs in Manitoba and British Columbia
 - B.C.'s Palliative Benefits Program, which provides funding for drugs and equipment required for people dying at home (Note: the program is only available to assist people in the last six months of their lives, which is difficult to predict. It often takes people longer than 6 months to die.)
 - Manitoba's palliative drug plan
- increases in the federal and some provincial tax credits for costs associated with informal caregiving (Note: tax credit programs provide some relief, but they can only be accessed after the fact. They do not help families who do not have the resources to pay for medication, supplies or equipment when they are required.)
- greater awareness on the part of professionals about the importance of hospice palliative care – and the more specialized training available
- the trend to more hospice palliative care at home for people who want to die at home and informal caregivers who choose to provide the support
- greater public recognition of the role of informal caregivers, and the need to support them
- the recommendations of the Romanow and Kirby reports, which support informal caregivers and end-of-life care.

Key informants also identified some policy trends or developments that may have negative implications for informal caregivers:

- the shift from institutional care to community care without the resources required to support effective community care
- the trend to “privatize” health care and shift more responsibilities and costs from the system to individuals
- the trend to shorter hospital stays (Note: professionals report that this policy can mean that people are discharged home to die with significant care needs)
- the pressure on families and informal caregivers to care for dying persons at home, which is based on the implicit assumption that the family will be there to provide assistance
- cutbacks and restructuring in home care services, which have reduced the amount of home care available, including nursing care and practical care in the home, and increased the burden on informal caregivers (Note: nurses still visit but may not have time to provide psychosocial support; hours for support services, such as shopping, cooking, and house cleaning have been reduced)
- lack of development of the psychosocial area in hospice palliative care. Hospice palliative care programs are supposed to have spiritual programs in place but many do not. According to professionals interviewed, hospice palliative care programs faced with budget pressures typically cut social workers.
- restrictive criteria for some programs, such as services available only to people dying of cancer, or workplace policies that allow employees time off to care for a child but not a parent
- the lack of policies that focus specifically on the needs of informal caregivers
- provincial disparities which raise the issue of equity.

Legal, Ethical and Moral Issues

As informal caregivers take on a larger role and more responsibility in end-of-life care, they and the professionals who work with them are facing a number of complex ethical issues and possibly some legal issues. Most of these reflect the dilemma of trying to find an appropriate balance between social and family responsibility in end-of-life care. We generally expect individuals and families to take responsibility for themselves but, when the burden becomes too great, our systems step in to help and society shares the responsibility. The willingness of the system to help depends on how much it values the care of the dying – particularly compared to how much it values other more active types of care. With the changes that have occurred in the health care system, there is some question whether we are asking too much of individuals in providing hospice palliative care, and whether our systems are there to provide support when needed.

As a first step in the process of looking at the role informal caregivers and the possible policy implications, the CHPCA has identified the following ethical and legal issues:

- the “idealization” of dying at home and the growing pressure on informal caregivers to provide care at home, regardless of their ability/capacity to do so
- the expanded role of informal caregivers
- pain and symptom management
- the lack of support for informal caregivers providing hospice palliative care
- substitute decision making and confidentiality
- the added complexity created by culture, disability and marginalization
- the transition from active to palliative care.

1. The “Idealization” of Dying at Home and Pressure on Informal Caregivers to Provide Hospice Palliative Care at Home

The desire of people to die at home combined with the shift from institutional to community-based care is giving professionals, patients and informal caregivers the strong message that “home is best”. For people who want to die at home and the informal caregivers who choose to provide hospice palliative care at home, this is a positive trend; however, according to professionals who work with informal caregivers, some informal caregivers are feeling increasingly pressured to provide care at home. Faced with the desire of a dying person to die at home and the message from the health care system that “home is best”, some informal caregivers report that they do not feel free to say “no”. To refuse would make them feel like less than a good and loving family.

Even informal caregivers who choose to care for someone at home report that, when they made the decision, they “didn’t realize what they were getting into”. In many cases, they take on the role without a clear understanding of the responsibilities involved. The implications of an uninformed choice can be significant: caregiving can have a negative impact on informal caregivers’ health and well-being, particularly if they are ill-prepared or feel overwhelmed.

- While it is probably not possible for individuals to truly understand or appreciate what is involved in providing hospice palliative care at home, there are steps that could be taken to reduce the pressure and ensure that families are aware that they have choices, such as: having

open discussions between health care workers and informal caregivers/the dying person about the options (i.e., home is not necessarily best for everyone)

- communicating clearly that situations can change and, when they do, the system will be there to assist (i.e., it is possible to try providing care at home and to make a change if it becomes too stressful)
- ensuring there is a basket of consistent services available to help/support informal caregivers in all settings (i.e., home, hospital, long-term care facility).

The shift from institutional to community-based care and the pressure to provide more hospice palliative care at home can also create ethical issues for professionals, who struggle to balance their responsibility to the patient/informal caregivers and their responsibility for use of health care resources. Some report feeling intense pressure from their institutions to discharge people to home or the community as soon as possible, regardless of the situation. Some suggest that there should be an objective way to assess whether informal caregivers will be able to manage the care required.

In an attempt to ensure informal caregivers are willing and able to provide palliative care at home (as opposed to in another setting) and to support more informed decision making, the Victorian Order of Nurses is now using a caregiver assessment tool in five sites, and the Department of Pain Medicine and Palliative Care at the Beth Israel Medical Centre is developing a similar tool. Most participants in the forum discussion support a more consistent approach to helping people make the transition from active to palliative care, including choosing the best setting. But they caution that any assessment of either the dying person's or the informal caregiver's ability to make an informed choice must be culturally sensitive and avoid making assumptions that some people, because of a disability (e.g., hearing impairment) may not be able to make an appropriate choice.

Participants also cautioned that the shift of hospice palliative and end-of-life care to the home may have the long-term impact of reducing the health care system's obligation to provide care: an increase in care at home can result in a decrease in beds available for inpatient hospice palliative care, and fewer choices for individual or families.

2. The Expanded Role of Informal Caregivers

The growing trend to move people out of institutions is being supported by advances in medical treatment and symptom management. With these advances, more care – and much more complex care – can now be delivered at home. In many cases, this involves high tech equipment, complex drug regimens and record keeping, and intrusive procedures, such as giving injections. This can be a particular issue for families in rural areas, where they are farther way from support if there is a problem.

While a high level of involvement in providing care gives some informal caregivers a greater sense of control over the situation and the feeling they are “doing something”, it causes other informal caregivers great stress. Some, particularly older caregivers, may not feel confident about their ability to provide complex care. Even those who accept or welcome this expanded role acknowledge the heavy responsibility and question their competence. Some of their stress and anxiety could be reduced by providing appropriate training; however, it may not be practical or

moral to expect someone providing end-of-life care to participate in training at this highly emotional time in their lives.

Some worry that they might be legally liable if something goes wrong or if they make a mistake. Although informal caregivers do not have to adhere to the same standard of care as a professional, they are expected to provide the same level of care that a reasonable person with normal abilities would provide, and they could be held criminally liable if they intentionally cause harm or damage someone physically, mentally or morally (Soden, 2004). According to a lawyer interviewed for the project, the trust placed on informal caregivers carries some important legal and many more ethical responsibilities. These are not intended to frighten or deter people from providing care, but they should be understood so informal caregivers can fulfill their role.

For many informal caregivers, the increasing care demands in all care settings can blur the boundaries between their role as a family member or friend and their role as a caregiver, and affect their relationship with the dying person. For example, a son can find it extremely difficult to bathe or provide bowel or bladder care for his mother.

There is also the risk that the Compassionate Leave benefit will create the perception that informal caregivers are being “paid” to provide care – which could lead to even greater expectations and demands. Participants in the policy forum were concerned that more responsibility and burden was being transferred to informal caregivers without providing adequate emotional and financial support.

The burden of care can be particularly heavy for families caring for children who dying. In many cases, children take longer to die and will often go through periods of remission. Because there are few pediatric hospices in Canada, the knowledge and expertise in pediatric hospice palliative care remains in the tertiary care centres and may not be easily accessible to all families. If informal caregivers are going to be asked to take on a greater burden of care, then there is a need for adequate and appropriate supports, including:

- a structured assessment of the caregiver, and home situation
- access to information, training and capacity building
- access to adequate respite services available in both urban and rural areas
- access to 24-hr on-line and telephone support for caregivers
- more education of formal caregivers about the supports required in pediatric hospice palliative care
- a clearer delineation of social responsibility and family responsibility in end-of-life care.

Delegating increasingly complex care to informal caregivers may also raise legal and ethical issues for the professionals who work with them. Could professionals be held legally liable for delegating responsibilities to someone who is not capable? Should professionals be responsible for providing appropriate training and ongoing monitoring to ensure that informal caregivers are able to fulfill an ever increasing role in providing medical care?

Delegating complex care also raises the larger question of “what is hospice palliative care” and the “medicalization” of hospice palliative care? Does it/should it involve active care and

interventions, or should it be refocused on pain and symptom management, and support for the “last things”?

3. Pain and symptom management

According to researchers in the Department of Pain Medicine and Palliative Care at the Beth Israel Medical Centre in the United States, informal caregivers are playing a greater role in pain and symptom management.

“Caregivers of chronic pain patients assess and report pain, together with, or independent of, the patient. It often falls to the caregiver to administer pain medication, obtain, fill and refill prescriptions, and make decisions about dosages. Caregivers can encourage patients to report new symptoms and side effects, and remind them to take their medications as prescribed. With the advent of high-tech home care and pain management, family caregivers are also expected to help manage patient controlled analgesia pumps, epidural catheters and home infusions.

“A 1998 study of caregivers ... illustrated the impact of caregiving for chronic pain patients on caregivers’ quality of life. Caregivers reported high levels of psychological burden in having to make decisions for the patient, and in being expected to provide encouragement and companionship. Caregivers expressed a sense of physical burden, in having to help with activities of daily living and assume additional roles for the patient with pain. In addition, caregivers reported high levels of medical burden, as described by assisting with medication administration, attending medical appointments, helping with exercise and massaging painful areas for the pain patient. In a focus group, caregiving was described as an all-consuming responsibility that affected mood, work, relationships and enjoyment of life. Caregivers described feelings of exclusion, invisibility and isolation in their interactions with the health care system.”
(Glajchen & Fraidin, 2000)

According to the key informant interviews conducted for this project, all informal caregivers experience anxiety when asked to administer medications for pain and symptom management. Many struggle with a sense of guilt that something they do for the person may hasten his or her death. These ethical, legal and moral issues are compounded by informal caregivers’ lack of knowledge about the amount of medication required to relieve symptoms and the amount required to kill, which is often based on the dying’s person changing condition (Soden, 2004).

Being responsible for administering medication can also put the informal caregiver in the position of having to deal with the dying person’s request for assisted suicide, or of coming face to face with their own desire that the person’s pain “be over”. It is extremely difficult for informal caregivers – and for professionals – when a dying person is begging to be relieved of pain only one hour into a four-hour medication schedule.

In the view of forum participants, many of the ethical issues that may arise around pain and symptom management can be reduced through a combination of communication and policy. For example:

- Informal caregivers are more likely to be comfortable in this role when they understand the place of pain and symptom management in the goals of palliative care, and when formal

caregivers communicate with them about the use of drugs, such as morphine, that have been stigmatized.

- There is an obligation on the part of formal caregivers to ensure informal caregivers receive adequate sensitive training in the use and administration of drugs for pain and symptom management (although there remains the issue of whether it is moral to be providing training during a time of great emotional stress).
- In terms of determining the appropriate timing and dosage for pain and symptom medication, it is important to have a plan and goals of care that are reviewed and revised as necessary throughout the course of providing palliative care. The palliative care community should develop a common tool to establish, revise and communicate goals of care, and promote national standards for end-of-life care.
- When informal caregivers do not agree on the goals of care, formal caregivers must be available to provide counseling for the caregiving unit.
- Efforts to communicate about pain and symptom management must take into account cultural differences on the use of pain and symptom medication as well as any cultural views/use of complementary therapies.
- It is also extremely important for informal caregivers to understand the limits of what palliative care can do. As one forum participant stated, “It is not possible to get rid of symptoms 100% of the time, so expectations should be realistic.”

4. Support Available for Informal Caregivers

Informal caregivers often provide care at great personal cost to themselves. In the course of caring for a dying person, their health may suffer. According to research done in the United States, informal caregivers who provide care 36 or more hours a week are more likely than non-caregivers to experience depression or anxiety: for partners, the rate is six times higher; for those caring for a parent, the rate is twice as high (Cannuscio et al, 2002). Caregivers use prescription drugs for depression, anxiety and insomnia two to three times as often as the rest of the population.

Informal caregivers may also pay a price in terms of their social lives, incomes¹ and out-of-pocket costs. According to Statistics Canada, a significant proportion of informal caregivers providing personal care for someone over age 65 report a loss in social activities, a drop in income, and an increase in costs. The cost of equipment and medications required to provide hospice palliative care at home, and the cost of extra help, such as private nurses, to assist with hospice palliative care at home, in a long-term care facility or in hospital can create a severe financial burden for informal caregivers, particularly if the dying person does not have private insurance. When the informal caregivers’ budget begins to affect quality of care, the cost of care can become an ethical issue.

For example, if a medication a dying person needs at home is not covered by the provincial drug plan, the person may have to settle for a less effective, more affordable alternative. If that person were being cared for in a hospice, hospital or long-term care facility, the informal caregivers would have 24 hour access to health professionals, and the cost of the medication is usually

¹ The Compassionate Leave benefit should reduce the loss of income.

covered by the institution.² If the person were dying in certain provinces, where informal caregivers have more consistent access to hospice palliative care teams or where the government has introduced policies to cover the cost of medications or equipment required for hospice palliative care at home, the situation for informal caregivers is much better.

Both informal caregivers and professionals report that the lack of consistent support from the health care system can increase the pressure on informal caregivers, lead to exhaustion and burn-out, and have long-term negative consequences for the informal caregivers' health. Conversely, in jurisdictions where informal caregivers have more support, it is much easier for them to provide care and they experience fewer negative consequences.

According to forum participants, effective care planning would provide a roadmap for informal caregivers that would: set out goals of care, track changes in the patient's needs and caregivers' capacity, encourage communication, and identify the resources required. The question still remains whether the system is willing or able to provide those resources.

5. *Substitute Decision Making and Confidentiality*

As part of their role, informal caregivers may take on responsibility for substitute decision-making for the dying person.

“The first principle behind all substitute decision-making, regardless of jurisdiction or statutory provisions, is that the dying person’s wishes are to guide all decision-making, whether those wishes are expressed in writing or verbally, or are simply known by virtue of the values, lifestyle and standards the person maintained throughout his or her life. The second principle is that the dying person should be assisted and empowered, regardless of his or her competence, to participate in decision-making and determining his or her life. Both professional and informal caregivers should foster the dying person’s autonomy and independence. Even if the person is passing in and out of lucidity, he or she should remain actively engaged in making his/her decision right up to the end. Informal caregivers often erroneously believe that when they are designated a substitute decision maker, they have replaced the person. Even trained health professionals often ignore the dying person and turn to the substitute decision maker to discuss care.

“The principles of acting in the “best interests” of someone does not mean imposing one’s own values and wishes. It means knowing what the dying person would want and following those wishes” (Soden, 2004)

As part of their education, most professionals receive training to help them understand and deal with the conflict they may encounter when a patient's decisions and values do not reflect their own. Even though they have had this training in ethics, many professionals struggle to allow dying people to make their own choices.

The Role of the Substitute Decision Maker

To help the dying person make care decisions by:

- facilitating dialogue
- providing information
- ensuring maximum control and dignity at every level of residual capacity
- not damaging relationships / maintaining personal integrity.

² An exception to this is when families decides to hire a private nurse to augment the services available in the institution.

When people are cared for at home, the situation becomes more complex. Informal caregivers may not understand their legal obligation to respect the wishes of the dying person. They may have their own histories and agendas. They may knowingly or unknowingly try to influence the dying person's decisions. They may take over the decision-making and make decisions based on their own values, rather than the values or wishes of the dying person. There may be conflicts between informal caregivers. For example, one informal caregiver may be trying to follow the wishes of the dying person and the advice of the professionals while others argue for a different course of action. This type of conflict can affect the informal caregivers, their relationship with the dying person, and their relationships with one another long after the person has died. It can also lead to verbal, emotional and physical abuse of informal caregivers.

Certain steps can be taken help avoid some of the legal and ethical issues that can arise around substitute decision-making, such as:

- encouraging people to talk about their wishes with family members and formal caregivers. According to an Ipsos-Reid poll (2004), most Canadians – 83% -- feel it is very important to discuss their wishes with a family member, but fewer than 44% have done so, and fewer than 9% have discussed their wishes with their doctor.
- encouraging people to prepare advance directives, living wills and powers of attorney, so their wishes will be clear. According to the same Ipsos-Reid poll (2004), 70% of Canadians do not have a living will.
- reassuring people that they can change their minds: what they value when they prepare an advance directive (e.g., do not resuscitate) may change, and it can always be reviewed and altered
- involving the dying person in decision-making as much and as long as possible (i.e., during times when the person is lucid)
- educating substitute decision makers about their responsibility to fulfill the dying person's wishes
- providing support for informal caregivers who are making decisions in the absence of a living will or the person's stated wishes
- providing counseling and education when the substitute decision maker appears to not be acting in the best interests of the dying person.

While advance directives and living wills can make it easier for informal caregivers to make decisions for the dying person, the law has not expressed itself in all jurisdictions across Canada about the place of these documents (Soden 2004). Not all provinces have advanced directives available, and advance directives are not followed or enforced in the same way in all provinces (Soden, 2004). This is an issue that should be addressed.

To support informal caregivers in their role as substitute decision makers, more research is required on:

- educating informal caregivers, health care providers, and substitute decision makers on the legal and ethical considerations of decision making
- the role of trans-disciplinary support teams in shared decision making

- policies that provide checks and balances
- how to define competency/capacity
- providing maximum control for the dying person
- provincial/territorial disparities.

In the course of providing palliative care, informal caregivers may also face issues of confidentiality. In the process of dying or as a result of medication, the dying person may communicate private thoughts and memories, and informal caregivers may be privy to these revelations. In their caring role, the informal caregivers are in a privileged position of trust. They have a responsibility to keep the dying person's communications confidential, and not allow their own self-interest or over-protectiveness to abuse that trust. Information communicated by the dying person should only be disclosed with the person's consent or to the extent required to fulfill the dying person's wishes and care.

Protecting the dying person's confidentiality may raise difficult ethical and legal issues for the informal caregiver, particularly if the communication revealed something that could affect family relationships.

6. The Added Complexity Created by Culture, Disability and Marginalization

The issues faced by informal caregivers providing end of life care are difficult and complex. They become even more complicated in situations where there are cultural differences, communication problems, disabilities and marginalization. For example, when professionals and informal caregivers do not have a common language or when the person dying or the informal caregivers are hearing impaired, it can be difficult to communicate. In many cases, the health care system has both a legal and ethical obligation to provide culturally sensitive service. For example, the hearing impaired have the right to access free interpreting services in hospitals and other medical facilities but, according to forum participants, many professionals do not comply with this law.

Disability can have a profound effect on the support available for informal caregivers and on the experience of dying. For example, if the dying person is physically or intellectually disabled, there is a greater risk that he/she will not be appropriately consulted or involved in making care decisions, or that his/her wishes will not be respected. If the informal caregiver is disabled, there is a risk that formal caregivers will make inaccurate assumptions about his/her ability to provide care.

Caregiving can also be more difficult and stressful when the dying person or informal caregivers face discrimination because of their sexual orientation, religion beliefs, race or socio-economic status. The issue for the formal health care system is how best to support informal caregivers in these situations, and ensure they have the same access to support and services.

7. The Transition from Active to Palliative Care

In the view of forum participants, many of the ethical issues that arise in end-of-life care relate to the fact that we are a "death defying" society. The focus of the health care system is to prolong life. Most people avoid talking about or planning for death, which often affects the quality of the care when they do become palliative. It is a paradox: people don't want to be labeled palliative

but, if no planning is done, the supports they need – including support for informal caregivers -- may not be in place when they are dying. It may also mean that they are denied the spiritual benefits of palliative care, and the opportunity to talk about values, forgiveness and reconciliation.

It is important to clarify that end-of-life care is a crucial goal of medicine and is central to health care (Kenney, 2004). A core part of Canadian entitlement to excellent health care must be the right to expert, compassionate, interdisciplinary care at the end of life. (Kenney 2004).

According to forum participants, the key to greater valuing of hospice palliative care and a more effective transition from active to end-of-life care, is openness and education – of health professionals, patients and informal caregivers. When people are more knowledgeable and see the place of planning for death in the midst of living, they can make more effective decisions, the journey can be more positive, there is less stress, and the legal and ethical issues that do arise can be managed.

Conclusion

Every Canadian has the right to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice.

Informal caregivers play a vital role in providing hospice palliative care. Their willingness to provide care makes it possible for many Canadians to die in the setting of their choice, and relieves some of the pressure and workload on health professionals. When informal caregivers provide care at home, they also help free up beds in hospitals and long-term care facilities that can be used for people with more acute health care needs.

Informal caregivers are a valuable resource. Given our demographics, the aging of the population and the pressure to manage health care costs, the system will become increasingly dependent on informal caregivers. To safeguard this resource, the system must look at effective ways to support and empower informal caregivers. Every effort must be made to identify and address the legal and ethical issues informal caregivers face, develop policies and programs that support them, and minimize the personal, social and health costs associated with providing end of life care.

In this initial effort to explore the legal, ethical and moral issues facing informal caregivers providing end-of-life care, it is clear that minimal research has been done in this field. More research and discussion is required to identify the types of legal and ethical issues that can be dealt with effectively through policy, legislation and/or education.

In the process of addressing these issues, it will be critical to involve the public in determining the types of services that we value as a society, and identifying the supports that should be available from the health care system during end-of-life care.

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