between July 1, 2008 and June 30, 2009, more than 240,000 people died in Canada. By 2020, with the aging of Canada’s baby boomers, it is estimated that that figure will rise by over 35% to 330,000, creating a potential crisis in the health care system and in our ability to care for our elders. Furthermore, despite the fact that most Canadians indicate that they would prefer to die at home, fully 75% of all deaths occur in hospital or in long-term care facilities. Whether we will be able to meet these challenges and, in the process, be able to die under the conditions we want will, to a great extent, depend on whether we are willing to come to terms with death.

This willingness is a reflection, in part, of our collective understanding of how the varied roles and spheres of formal and informal caregiving intersect at this critical juncture of life and death. End-of-life care is a place where values, feelings, legalities and medical processes collide, where public and private responsibilities and obligations can blur, and where fear, uncertainty, and silence can undermine the best of intentions.

To illuminate this increasingly important area of caregiving research and practice, this article will examine the direct experiences of hospice volunteers - a group of people who have chosen to face death head on through their work with dying people and their families. Drawing on testimony from in-depth interviews conducted with 15 hospice volunteers (12 women and 3 men), ranging in age from 42 to 80, I hope to show how this type of end-of-life care serves both the volunteers and the dying people, and how it supports and enhances existing family care networks, often providing critical support when families are unable or unwilling to do so.

Death and dying are essential aspects of living. Volunteers, as the “heart and soul of hospice care,” provide support for people as they approach the end of their lives and for their families and friends, as they prepare to bid farewell to the person they love.

What is a hospice?
The term “hospice” dates back to the Crusades, when monasteries provided refuge not only for the sick and dying, but for weary travellers, women in labour, the poor, orphans, and lepers. Modern hospices trace their origins to Dame Cicely Saunders, pioneering physician and founder of St. Christopher’s House in London, England in 1967. The first hospice programs in Canada opened in 1975 at St. Boniface Hospital in Winnipeg and at Montreal’s Royal Victoria Hospital under Dr. Balfour Mount, who coined the term...
When a hospice volunteer tells someone about their work, the response is virtually always the same: “You must be a saint!”

“palliative care” as an alternative to the word “hospice” which, in Quebec, still carried the stigma as a place of last resort for the poor and derelict.

Today the terms hospice and palliative care are used more or less interchangeably to denote “multi-disciplinary care [focussing on comfort, pain and symptom relief] for people living with terminal illnesses and for their families and caregivers.” (www.virtualhospice.ca/en) Hospice care can be provided within a specialized palliative care unit in a hospital, in a patient’s home through visits by community nurses, palliative care physicians, and hospice volunteers, and in free-standing residential care facilities, such as the Hospice at May Court in Ottawa. Although relatively few in number, free-standing hospices have become an important model for the delivery of services, providing an alternative to home, when medical needs or personal circumstances may make a home death unrealistic, or when a hospital death - the most costly – is undesirable.

The Hospice at May Court
The Hospice at May Court, a free-standing hospice in Ottawa, Canada, was established in 1987 with a small home visiting program operated from an office in a downtown church. Now located in a beautiful, home-like facility provided by the May Court Club, the hospice has over 300 volunteers, serving as drivers, fundraisers, public speakers, receptionists, and gardeners in addition to direct client care. The hospice runs four programs: family support, day hospice, home support, and the residence, all of which serve people with a life-threatening illness and their families. Three days a week, Day Hospice provides up to fifteen “guests” with a morning snack, happy hour with wine or juice, and a gourmet lunch, as well as activities such as painting, massage, and guided relaxation. In Home Support, patients receive a weekly visit from a volunteer, who might cook a meal, play cards, or sit quietly while the patient sleeps, providing much needed respite for family caregivers. Family support provides counselling services and grief and bereavement support for family members.

In the nine-bed residence, approximately 50 volunteers, each working a four hour shift, provide psycho-social support for terminally ill patients and their families. Volunteers assist staff in bathing, repositioning, and changing patients, cook meals, feed patients, and engage in conversation. When a person is actively dying, a volunteer will sit with them until family arrives (or, in the absence of family, until death) to ensure that no one dies alone.

Drawing upon the lively, open, and moving conversations I had with volunteers through my research, and upon nearly a decade’s experience as a volunteer myself, I have begun to answer some compelling questions about what brings people to hospice work, and the impact that hospice care has on volunteers, patients, and their family networks.

What motivates people to volunteer in hospice care?
When a hospice volunteer tells someone about their work, the response is virtually always the same: “You must be a saint!” This is followed quickly by the assertion that “I could never do what you do.” Given this widespread attitude, the question of what motivates someone to become a hospice volunteer looms large.

Eleven of the 15 volunteers involved in my research had experienced the death of someone close to them prior to coming to the hospice. For some, this was life-altering. “Lots of experience with death and dying at a young age,” including the death of a classmate when he was 9 and his sister when he was a teenager, led to Ron’s life-long commitment to hospice/palliative care. Rosy, at 42 the youngest person I interviewed, experienced many deaths in her family, including her father at 49, her mother at 59, and her favourite aunt. The interview demonstrated her deep awareness of death and her enormous commitment to helping people facing illness and the end of life. Mary attributed her involvement to her father, a doctor who took charge of his own dying process. “He helped us see that death wasn’t frightening.”

In my own case, caring for my sister when she was dying of cancer at 51 helped me to overcome a paralyzing fear of death. “You’re going to be an expert at this by the time you’re done with me,” she told me, shortly before her death. Little did I imagine that four years later I would find myself volunteering at May Court, a place where I immediately felt that I belonged.

Not everyone identified an experience of death as the reason for their initial involvement. Some, like Brenda, had more philosophical reasons. “I didn’t think that as a society we did a very good job with supporting people in the dying...We do a great job of
welcoming people into the world but not at the end.”

Volunteers who had worked in health care brought not only a familiarity with illness, but a determination to provide an alternative to hospital death. Polly, a retired RN, noted: “I’ve been in hospitals a long time. I know what it’s like to die there. It’s really not nice. I always felt that people had the right to die well.”

What keeps people committed to hospice volunteering?
I wanted to find out what keeps volunteers coming back week after week and whether their reasons differed from their original motivation.

Mary, a 5-year veteran of day hospice, said: “It feels like an extremely privileged place for me to do volunteer work. I’m using the skills I have, expanding my own understanding of myself and the world, and I’m being part of a community.” When I asked her if her reasons had changed, she responded: “I think the fact that it’s even more satisfying than I could ever have imagined.”

Wes, a retired Anglican priest, said: “I think the reasons didn’t change. I think they’ve grown deeper in the understanding of what it means to be in a community where people are at the end of their life. I think it’s a privilege that you can share that part of a person’s life.”

Several volunteers described the hospice as a privileged place to be. Brenda considers it “a privilege to be able to … be with somebody at the end of their life,” the most vulnerable and intimate time of their life. Sylvia, a long-serving home support volunteer, echoed these words: “I really feel that it’s a privilege that people have accepted you. They haven’t necessarily wanted to but they have. So I’m really privileged that they’ll let me come in and share that much.”

All of the volunteers commented on how meaningful the work is for them. Rosy explained: “If I were to die tonight, I would know I have helped somebody who didn’t have that help … It really does give me a sense of peace.”

Brenda, who came to hospice largely for philosophical reasons said: “The commitment to the concept is still very strong. But the reason that I stay is because I have made a difference in someone’s life.”

Volunteers in the residence talked about how grateful patients and family members are for the help they provide. Family members have often been providing care almost single-handedly in the home before their loved one is admitted to the residence. Now they are able to simply be family members, as staff and volunteers assume the physical burden of care. “You guys are all so amazing,” family members often comment. When a volunteer leaves at the end of their shift, they know that it mattered that they showed up that day.

Being present with a person as they approach death is considered an honour. Janice and Alex, hospice shift buddies in the early days of the residence, each described a moment that had an almost sacred quality. Alex: “We had a woman who was dying of ovarian cancer. I walked in and Janice was in her room rubbering her extended belly. And I was so moved by that. This woman was a Bible person, and after a couple of weeks, I was allowed to read. On the Monday before she died … she called both of us into her room and she said, ‘Janice, you can massage my feet, and Alex, you can read what I tell you. And both of you are to not say a word.’”

What challenges have volunteers faced?
What supports them in their work?
“Don’t you find it depressing?” people often ask, when they hear that someone volunteers in a hospice. That phrase echoed in many of the interviews I conducted. There can be no doubt that working in hospice care can be emotionally challenging. In the residence, for example, as many as five of the nine patients may die in a single week, leaving a volunteer with little time to come to terms with their passing before getting on with the tasks at hand.

Being with a person facing illness and death can be at once intimate and poignancy. People often open up to a volunteer in ways they might not with family members. Most hospice patients are acutely aware that they have no time to waste. Patients who may be reluctant to talk to a family member about their fears may seek a confidante in a volunteer. A husband dying of prostate cancer told one volunteer about his wife of 65 years who had never written a cheque in her life. “How will she manage? I worry so much about her.”

Interviewees concurred that being with younger people, particularly a parent of young children, is the hardest part of the job. One recalled watching a 45 year old man arrive at hospice, walking slowly with a cane. “He didn’t want to come in a wheelchair;” his wife explained. Their 9-year old son pulled his father’s suitcase down the long hallway to his room. Nothing can really keep volunteers from feeling the poignancy of these moments.

In light of the attention given to “compassion fatigue” and burn-out among health care workers, I asked volunteers what helped them to deal with these emotional challenges. Responses ranged from changing their schedule to find time for reflection after a shift to going for a massage or to a yoga class, or writing in a journal. Others make a point of taking time to acknowledge a person’s passing before starting their next shift.

To prevent volunteers from becoming too emotionally involved
with patients, hospice policies around boundaries are strictly enforced. Volunteers work only four hours per week and cannot drop in on patients or give out their home phone number, a request that is made more often than one might imagine. In home support, volunteers work a maximum of six months with a patient before being transferred to another case. While some respondents told me they found this policy “cruel,” most felt it was essential for maintaining their emotional well-being.

One thing rang out loud and clear in the interviews. If volunteers knew that their work had made a difference in someone’s life, they were able to deal with sadness and loss. But if they felt there was little for them to do, or that they were spending all their time doing “busy work,” and very little time at the bedside, then they began to question the value of their service. As the demand for volunteers increases in the years to come, hospice administrators and staff will need to ensure that volunteers feel they are truly part of the inter-disciplinary team.

**How does hospice work change volunteers and, in turn, influence the people in their lives?**

“I don’t mind dying,” Woody Allen once quipped. “I just don’t want to be there when it happens.” This remark reflects the attitudes of our death-de-nying culture. Hospice volunteers, in contrast, choose to face illness and death on a weekly basis. The people I interviewed credited their hospice work for making them more open, centred, and appreciative of each day. I wondered whether this had in turn affected the people in their lives.

While friends and family might not be ready to sign up for hospice duty themselves, being close to someone who works in hospice care inevitably brings the subject of death to the fore, even if the specifics of the work are never broached. Evelyn, a 12-year day hospice veteran, explained: “Over the years, I’ve seen a huge difference in my husband who hated hospitals and was scared of anything medical. And he was just very, very good with his Mum in her last time on earth, and with his Aunt.”

As Mary explained: “We’re changed. People see us differently. They approach us when they are facing death, or the death of someone they love. People know that they can talk to us about death. They know that … we’re by and large not afraid.”

**In the End**

Much like family caregivers who commit daily to providing care and support to ailing, frail or dying members of a kin-based network, hospice volunteers are an indispensable component of the palliative care team, providing, in the words of one researcher, “a unique contribution to individuals approaching the end of their lives… The presence of volunteers restores the human relationship to palliative care, and this is essential to patients’ comfort, peace, and reconciliation with this difficult stage in life.” (Guirguis-Younger and Grafanaki, 2008).

These volunteers provide an equally critical buttress to the more informal systems of care that typify family caregiving. Moreover, in the process of end-of-life caring, volunteers themselves are transformed. More open, less judgemental, they have learned the importance of living in the present moment, by sitting at the bedside of people who are dying. As one volunteer explained, “We have been given a gift. We are allowed to be with someone in that intimate time and space.” In turn, volunteers share this gift with the people in their lives. Through their calm acceptance of death and their willingness to accompany people who are dying, hospice volunteers open up a space for discussions about death and dying, and about how we want to face the end of our own lives.

**Katherine Arnup** is a professor of Canadian Studies at Carleton University and a hospice volunteer with nearly a decade of service. She served as a family care-giver for her sister and her parents when they were dying. The author of Education for Motherhood: Advice for Mothers in Twentieth-Century Canada and of more than two dozen articles on the changing Canadian family, she is currently writing a book about death and dying.