

What Coordinators of Palliative Care Volunteers in New Brunswick, Canada Have to Say About their Programs, Themselves, and their Program Management Practices

Stephen Claxton-Oldfield, Mount Allison University, Sackville, New Brunswick, Canada
Jane Claxton-Oldfield, Sackville, New Brunswick, Canada

The Canadian Hospice Palliative Care Association (CHPCA, 2002) defines hospice palliative care as care that "aims to relieve suffering and improve the quality of living and dying" (p. 17). The philosophy of hospice palliative care (referred to as "palliative care" in the remainder of this article) emphasizes care that not only addresses the physical needs of dying persons, such as pain control and symptom management, but also the emotional, social, spiritual, cultural, and practical needs of patients and families who are living with a life-threatening illness. In addition to the help and support provided, for example, by doctors, nurses, social workers, spiritual advisors, complementary therapists, family members, home support workers, neighbours, and friends, trained volunteers are an indispensable part of Canadian palliative care.

Across Canada, there are approximately 650 palliative care programs, with many of these offering training programs for volunteers (CHPCA, 2004). The work these volunteers do is very important and can make a real difference in the lives of the patients and families they support. The volunteer role may include accompanying patients to hospital or doctor appointments, reading to the patient, listening to life stories, helping the patient with letter writing, providing respite breaks to family members, and so on (Black & Kovacs, 1999; Brazil & Thomas, 1995; Downe-Wamboldt & Ellerton, 1986), although often it is not "doing" but "being" (i.e., being a quiet presence or simply holding the patient's hand) that is most important.

Volunteers play a vital role in supporting patients and families and are often in a better

position to spend more time with families and their dying loved ones than most of the other members of the palliative care team (e.g., doctors, nurses) (Briggs, 1987). The volunteers, in turn, are supported in their work by the coordinator of volunteers (sometimes called the volunteer manager or director of volunteers). Although there have been studies conducted to identify the role of palliative care volunteers (e.g., Brazil & Thomas, 1995; Downe-Wamboldt & Ellerton, 1986), there is a lack of research to understand the work done by the coordinators of palliative care volunteers.

Typically, the coordinator of volunteers is responsible for, among other things, recruiting and training volunteers, assigning volunteers to patients, and providing ongoing support and training opportunities. Other responsibilities include receiving palliative care referrals, overseeing the running of the palliative care office, community relations (e.g., speaking engagements), and meeting with board members (Rothstein & Rothstein, 1997). As Doyle (2002) states, the work of the coordinator "calls for managerial, organizational, and leadership skills and an informed and profound understanding of hospice and palliative care, how it is provided and who its patients and providers are" (p. 7). The coordinator also provides a link between the volunteers and the other members of the palliative care team "and must assume responsibility for keeping information flowing" (Lafer, 1991, p. 165).

Given the aging of Canada's population, and the increasing number of Canadians facing a life-threatening illness, the demand for effective palliative care services is going to

Stephen Claxton-Oldfield, PhD, is Assistant Professor of Psychology at Mount Allison University, Sackville, New Brunswick, Canada. He is also a member of the Tantramar Hospice Palliative Care Organization, Sackville, New Brunswick, Canada.

Jane Claxton-Oldfield is a member of the Tantramar Hospice Palliative Care Organization, Sackville, New Brunswick, Canada.

grow. According to the CHPCA (2004), more than 220,000 Canadians die each year, with an estimated 160,000 of these needing palliative care services. According to a 2001 report prepared by Hospice Saint John and the New Brunswick Hospice Palliative Care Association (NBHPCA), over 6,000 people in New Brunswick die annually and over 4,000 of these deaths are the result of a life-threatening illness.

At the present time, very little is known about the palliative care programs in New Brunswick that offer volunteer support. The purpose of this research was to produce a general picture of the palliative care volunteer programs in New Brunswick and to understand who the coordinators of these programs are and what they do in their work. This was done by visiting and conducting one-on-one interviews with the coordinators of these programs in order to obtain information about (1) their programs; (2) themselves; and (3) their program management practices.

METHOD

The Context

In 2002, a list of palliative care volunteer programs in New Brunswick was compiled by (1) contacting hospitals in New Brunswick's seven health regions; (2) searching the CHPCA's directory of hospice palliative care services in New Brunswick; (3) placing a news item in the NBHPCA's Fall 2002 newsletter, inviting coordinators of volunteers who had not been contacted regarding the study to get in touch with the first author; and 4) word of mouth. A total of 14 palliative care volunteer programs were identified. Thirteen of the 14 coordinators of volunteers (92.9%) were visited and interviewed about their programs, themselves, and their management practices; one coordinator was not available for interview.

Procedure

All 13 coordinators of volunteers (referred to as "coordinators" in the remainder of this paper) were interviewed in person; all interviews were tape recorded and the interview responses were transcribed verbatim. The interviewer, a former coordinator of palliative

care volunteers, traveled to the participants' offices to conduct the interviews. The main topics covered during the face-to-face interview included (1) a description of the palliative care volunteer program (e.g., how long the program has been running, how it is funded, number of clients/families helped per year, number of volunteers); (2) the coordinators themselves (e.g., educational background, their role as coordinator, what is the most/least rewarding part of their work); and (3) their management practices (e.g., recruitment, screening, training).

Participants

The 13 coordinators were all females, with a mean age of 47.5 years ($SD = 12.3$). The youngest coordinator was 27 years old; the oldest was 76 years old. Nine of the 13 coordinators (69.2%) had a university degree and four did not. The mean length of service as coordinator was 5.8 years ($SD = 5.2$), with a range of 1 to 15 years. Eight of the 13 coordinators (61.5%) were responsible for all of the volunteer programs in the hospital, while five (38.5%) were responsible for the palliative care volunteers only.

Nine of the 13 palliative care volunteer programs (69.2%) are funded by the hospitals in which they are based and are part of the hospital's general volunteer programming. Of these programs, eight of the coordinators are general coordinators of volunteers and oversee all of the voluntary services in the hospital. Six of these nine coordinators work full-time; two work part-time, and one is unpaid. For most of the full-time general coordinators, it was difficult for them to say how many of their paid hours were spent specifically coordinating palliative care volunteers (e.g., "the palliative care program is only one small component of my job"). Of the four non hospital-funded palliative care volunteer programs, one coordinator works full-time, two work part-time, and one is paid for four hours per week. Hourly rates of pay for the coordinator's position ranged from CAD\$12-\$30 per hour. In addition to their paid hours, nine of the 13 coordinators indicated that they also put in volunteer hours in palliative care (between 1 and 20 hours per week).

RESULTS AND DISCUSSION

Palliative Care Volunteer Programs in New Brunswick

Based on the responses of the coordinators, the oldest palliative care volunteer programs in the province of New Brunswick are Hospice Saint John, which has been running "since 1984," and Hospice of Charlotte in St. Stephen (which started in "1984 or 1985"). The newest palliative care volunteer program is located at the Miramichi Regional Hospital (which had been running for about a year at the time of the interview). Some of the coordinators were not certain when their palliative care volunteer programs started running.

The coordinators of the hospital-funded programs are not under pressure to raise funds in order for their programs to continue. Three of the four non hospital-funded programs (23.1%) have their offices based at their local hospital, but are run independently and are responsible for raising funds themselves from the community and through charitable donations. The other non hospital-funded program operates out of a crisis centre. When asked if there was money in the budget for themselves and their volunteers to attend conferences and workshops, 12 of the 13 coordinators (92.3%) said "yes," although most qualified their answer by adding, for example, "it's a very limited budget."

Not all of the coordinators could answer the question concerning the number of patients/families helped per year. For those who could, estimates ranged from between 10 and 200 patients/families per year. The mean number of active palliative care volunteers in the 13 programs was 21.1 (SD = 16.5), with a range from 6 to 70.

Eleven of the 13 coordinators (84.6%) indicated that, when a patient has died, their program offers some kind of bereavement support service to family members either directly or through another program—bereavement support is emotional support to help the bereaved. This can be offered in different ways, for example, a volunteer offering an empathic ear, sending a letter of condolence, sending a letter or card on significant dates, making follow-up phone calls to the family to find out how they are doing, attend-

ing memorial services, or making a referral to a social worker or psychologist. Four programs offer support through group work, with a further three coordinators stating that plans for a bereavement support group were "in the pipeline"; two coordinators said that their program did not offer bereavement support.

Coordinators were asked if their program was able to meet the needs of clients from other cultures and backgrounds (New Brunswick has English, French and Native Canadian cultures.) Specific concerns raised by some of the coordinators included the lack of French-speaking volunteers (about one-third of the people who live in New Brunswick are French speaking) and native volunteers. Six of the 13 coordinators (46.2%) said "yes," their program does meet the needs of clients from other cultures and backgrounds (e.g., "we do have several bilingual volunteers," "we have people to talk about the Micmac culture, etc."), while some stated that they "don't really live in a culturally diverse community."

In summary, the majority of the palliative care volunteer programs in New Brunswick are hospital-based and hospital-funded. In all but one of the hospital-funded programs, the volunteers are managed by a general volunteer coordinator who oversees all of the voluntary services in the hospital. As mentioned in the NBHPCA newsletter (2003), "New Brunswick is underdeveloped in the area of community hospice palliative care programs, with only four community hospice programs working with the medical/clinical team to relieve suffering and improve the quality of living and dying" (p. 3). Almost half (49.6%) of New Brunswickers live in rural areas (Statistics Canada, 2005) where access to palliative care services is more limited.

The Coordinators of Volunteers

There were a number of common responses when the coordinators were asked to describe their role. These included recruiting, screening, interviewing, educating and supporting volunteers, attending rounds and meetings, "providing a link between the volunteers and the nurses, doctors, etc.," and

“making contact with the families and assessing the needs in order to make a good match between client and volunteer.”

When asked what was responsible for bringing them into this work, five of the 13 coordinators (34.5%) mentioned personal experience with someone who was dying. Three of the coordinators (23.1%) had previously been volunteers themselves. A couple of the coordinators admitted that they “kind of fell into it” and another said she had heard that palliative care “wasn’t just a job, it was a way of life.”

In response to the question about what they find to be the most challenging aspect of their work, seven of the 13 coordinators (53.8%) mentioned dealing with volunteers (e.g., “trying to make everybody fit somewhere and feel comfortable”). Other challenges mentioned by coordinators included the following: funding, especially when money is not available for volunteer expenses; recruitment; getting others (e.g., “the nursing staff”) to recognize the services as valuable; getting feedback from the volunteers; the “red tape and bureaucracy in the health care system”; families in denial; leaving work behind at the end of the day; the lack of palliative care knowledge among general doctors and nurses; and staying “patient-focused.”

When asked what the most rewarding part of their work was, four of the 13 coordinators (30.8%) mentioned “working with the patients and families” and “client contact,” four (30.8%) mentioned seeing personal growth for the volunteers, and three (23.1%) mentioned the expressions of gratitude and thanks they receive from the families. The least rewarding part of their work, mentioned by four of the 13 coordinators (30.8%) was administrative tasks/constraints. A couple of coordinators talked about problems with volunteers (e.g., “volunteers not showing up”).

Eight of the 13 coordinators (61.5%) indicated that they were included in family meetings, team meetings, and/or hospital rounds when a client was being discussed; five (38.5%) said they were not included.

Program Management Practices

The most common method of recruiting volunteers, mentioned by 9 of the 13 coordi-

nators (69.2%), was word of mouth. Other methods included the following: notices in church bulletins; ads in local newspapers; and flyers, pamphlets, and posters.

All of the coordinators indicated that new volunteers were interviewed and screened prior to or after training, or both. Eight of the 13 coordinators were asked specifically about police checks. Five of these eight coordinators (62.5%) said that police checks were not done; two coordinators said “yes,” and one coordinator was “not sure.” Eleven of the 13 coordinators (84.6%) said they checked the references of potential volunteers; two (15.4%) said they did not.

In response to the question, “What makes a good volunteer?,” eight of the 13 coordinators (61.5%) said “good listening skills.” Other characteristics mentioned by at least two of the coordinators included compassion; the ability to be quiet, calm and present in the moment; the ability to maintain confidentiality; respectfulness; good communication skills, the ability to be nonjudgemental; a sense of humour, and life experience.

Ten of the 13 coordinators were asked specifically about whether their volunteers did any “hands-on” patient care (e.g., lifting, bathing, feeding). Five of the ten coordinators (50%) acknowledged that their volunteers are involved to some degree in physical care (e.g., “They’re given a nursing skills module and they can do back massages, foot massages”); the other five coordinators (50%) answered “no” to this question (e.g., “No, except for feeding. But they will not lift or turn or give a bath.”)

When asked how they kept volunteers on board, six of the 13 coordinators (46.2%) mentioned offering parties/social get-togethers; five (38.5%) mentioned hosting recognition events (e.g., “pins for hours”); four (30.8%) cited providing ongoing training, workshops, and support; three (23.1%) mentioned being accessible to the volunteers, and three (23.1%) mentioned taking an interest in the volunteer’s life. Coordinators also mentioned holding regular volunteer meetings, including volunteers in decision making, good matching, and providing ongoing support to the volunteers.

The number of hours of training that volunteers received varied from 6 to 30 hours (not all coordinators could say exactly how many hours of training their volunteers receive.) One program, for example, gives a general orientation to the hospital along with videos and readings for "home study." In this program, shadowing another volunteer for at least a couple of days is also considered part of the training. Three other coordinators also mentioned using a buddy system (e.g., "we buddy them with two or three palliative care volunteers on their shift so that they can see hands-on what the palliative care volunteers do, how they interact with the family.") Two other coordinators also mentioned the use of videos as part of the training program, and one program relies exclusively on videos for their training. Most of the programs have a structured approach to training. In 11 of the 13 programs (84.6%), the coordinator, with or without outside "resource people," facilitates the volunteer training. For one program, the training is given by "people from outside" and in another, the receptionist hands out the training videos to volunteers, who take them home to watch. Topics covered in training, mentioned by at least two thirds of the coordinators, included the following: grief and bereavement; communication; spirituality; signs/stages of death and dying; definition of palliative care; and the palliative care team/roles.

All 13 coordinators indicated that volunteers receive ongoing training and education (e.g., "we do have a few in-services every year when I can get some guest speakers.") In seven of the 13 programs (53.8%), the volunteers serve only in the hospital. In the other six programs (46.2%), volunteers can visit patients in the hospital, "in their homes, ... at a nursing home, or the special care home."

Of the nine coordinators who were specifically asked whether their volunteers visit everyone in the unit or if they have one particular patient that they visit, five coordinators (55.6%) said they matched volunteers with patients (e.g., "we match a volunteer with that client, usually based on religion and interest.") The other four coordinators (44.4%) said that their volunteers work shifts and visit all patients who happen to be on the unit.

Ten of the 13 coordinators (76.9%) indicated that they did evaluate their volunteers' performance; four coordinators give an evaluation form to their volunteers (for self-evaluation) yearly, two coordinators mentioned doing initial evaluations, and five coordinators indicated that there is no formal evaluation (e.g., "it's not formal, but you just kind of keep an eye on how they're doing.") As one coordinator put it, "My greatest evaluation is a letter that says thank you from the families of the patients that we've served. Those are the most important evaluations that we get."

Only four of the 13 programs (30.8%) included the visiting volunteer in team meetings when a client was being discussed; in nine of the programs (69.2%), the volunteer's input was not sought. In the opinion of 9 of the 13 coordinators (69.2%), the volunteer should be included (e.g., "they are part of the team ... they are there 24 hours ... sometimes they know things we don't"); the other four coordinators (30.8%) thought that volunteers should not be part of team meetings, (e.g., "because ... it would cause problems with confidentiality.")

CONCLUSIONS

Volunteers are absolutely essential members of the palliative care team, as are the coordinators. At present in New Brunswick, however, a number of inconsistencies appear to exist with respect to the selection, training, and evaluation of volunteers by coordinators. In order to ensure consistency and high quality service, the findings of this study suggest the need for the development of provincial (or national) standards for coordinators to select, train, and evaluate palliative care volunteers. Based on the findings of the current study, the following recommendations are offered.

1. An application form should be completed by any person interested in becoming a palliative care volunteer. The form should request, at a minimum, information about skills, motivation, and what they would like to do to help (e.g., direct patient care volunteer, administrative volunteer).
2. Police checks should be conducted by the coordinator.

3. References should be checked by the coordinator.
4. An informal interview should be conducted by the coordinator before the person is accepted into the program (to screen for appropriateness).
5. A confidentiality agreement should be signed.
6. The training of volunteers throughout the province (country) should be standardized to ensure a common minimal knowledge base, e.g., 24 hours of training with a core curriculum that introduces the volunteer to the following topics: philosophy of palliative care, communication, spirituality, the palliative care team/roles, signs/stages of death and dying, grief and bereavement.
7. Guidelines should be developed regarding what volunteers are allowed to do with respect to hands-on or physical care of patients (e.g., lifting, bathing, feeding).
8. Coordinators and volunteers should be provided with ongoing opportunities for training (e.g., workshops, conferences).
9. Volunteers should be formally evaluated by coordinators on a regular (e.g., yearly) basis. Lafer and Craig (1993), for example, have produced a scale of 27 descriptors of appropriate volunteer behaviour (e.g., "demonstrates the ability to be a good listener").
10. Coordinators should make sure volunteers are made to feel part of the palliative care team by educating other team members (e.g., doctors, nurses) so they have a greater awareness of, and appreciation for, the important role that volunteers play in the lives of the patients and families they support.
11. Coordinators' and volunteers' input should be sought at meetings when a patient they support is being discussed.

Hopefully, the findings of this study will be helpful to others, in similar communities, who are currently involved in or attempting to start palliative care volunteer programs.

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REFERENCES

- Black, B., & Kovacs, P. (1999). Age-related variation in the roles performed by hospice volunteers. *Journal of Applied Gerontology, 18*(4), 479-497.
- Brazil, K., & Thomas, D. (1995). The role of volunteers in a hospital-based palliative care service. *Journal of Palliative Care, 11*(3), 40-42.
- Briggs, J. (1987). Volunteer qualities: A survey of hospice volunteers. *Oncology Nursing Forum 14*(1), 27-31.
- Canadian Hospice Palliative Care Association (2002). *A model to guide hospice palliative care: Based on national principles and norms of practice*. Ottawa, ON, Canada: Author. Available from Canadian Hospice Palliative Care Association. Web site: www.chpca.net.
- Downe-Wamboldt, B., & Ellerton, M. (1986). A study of the role of hospice volunteers. *The Hospice Journal, 1*(4), 17-31.
- Doyle, D. (2002). *Volunteers in hospice and palliative care: A handbook for volunteer service managers*. Oxford University Press.
- Hospice Saint John and the New Brunswick Palliative Care Association (August, 2001). *Hospice Palliative Care in New Brunswick: The Facts, the Figures*. Presentation to the Honourable Dennis Furlong, MD, Minister of Health and Wellness, New Brunswick.
- Lafer, B. (1991). The attrition of hospice volunteers. *Omega, 23*(3), 161-168.
- Lafer, B., & Craig, S. (1993). The evaluation of hospice home care volunteers. *The Hospice Journal, 9*(1), 13-20.
- New Brunswick Hospice Palliative Care Association (2003, Spring). *A Report from the New Brunswick Hospice Palliative Care Association*.
- Rothstein, J., & Rothstein, M. (1997). *The caring community: A fieldbook for hospice palliative care volunteer services*. British Columbia Hospice Palliative Care Association.
- Statistics Canada (2005). 2001 Census of Canada. Available at <http://www12.statcan.ca/english/census01>