Community-Based Participatory Research

to Support Hospice Volunteers and Caregivers

Ann MacLeod
Nursing

Mark Skinner
Geography

Eleanor Low
Hospice Peterborough

Across Canada, as more and more responsibility for health care shifts into the community, individual patients and their caregivers are increasingly reliant on community-based organizations and volunteers for support. Key studies argue that volunteer and informal support networks are the most important “first line” of resources for people in need of home and community care. Relatively little attention, however, has been directed to understanding the needs of individuals who provide care on a volunteer and informal basis. Nowhere is the need to understand the challenges facing volunteers and caregivers more acute than in the palliative hospice sector. Indeed, the critical role of hospice volunteer and caregivers is captured best in the words of the Hospice Peterborough Client Services Coordinator:

Recently, two Hospice volunteers were assigned to visit with a young woman who I will call Barb. Barb and John live in the country east of Peterborough and have three children 12 years and under. Unfortunately, Barb has an inoperable cancer which has metastasized to her brain. She has lost her ability to care for the kids, clean, cook, initiate any activity or remember anything longer than a few minutes. She does not eat or drink unless she is shown how. Despite all this, she is able to chat and visit with the volunteer. She knows that she is going to die and wonders how John, her husband will be able to handle the kids. “How will they remember me?” she asks the volunteers.

The Access Centre Case Manager, her nurses and personal support workers as well as two Hospice volunteers are scheduled to cover as much of the week as possible in order to let John work. The volunteers spend two afternoons a week with Barb and they now have a wonderful rapport with her. The visiting nurse has recently asked the volunteers if they could work with Barb to leave a legacy of letters or journal entries for her kids. This project is well underway now and in years to come these letters, dictated to a volunteer, will be treasured by the children. A Hospice volunteer, visiting with no other agenda other than to be present, is the one person who can create the safe space in which difficult ideas are raised, discussed, put to rest or written about. It’s the volunteer who makes eye contact, sits still, holds hands, hugs, reads or dries the tears. It’s the volunteer who never judges or attempts to try to find a quick fix.

This vignette was the preface to the development of a community-based research project aimed at identifying the challenges, capacities, community resources and potential coping strategies of volunteers and informal caregivers associated with Hospice Peterborough, a nonprofit organization that provides end-of-life support to individuals and their caregivers. Guided by community-based participatory research (CBPR) principles, a team made up of the Hospice Peterborough Client Services Coordinator, Central East Local Health Integration Network (LHIN)
Caregiver Project Coordinator, Trent University faculty from Nursing and Geography, and an undergraduate research assistant completed a multi-phase mixed-methods pilot study in 2008-2009. The overall goal of the participatory project was to involve individual volunteers and caregivers as well as home and community care stakeholders in the identification of needs and development of positive support strategies that could be implemented by Hospice Peterborough and used to inform Central East LHIN policies and programs. Using a social determinants of health framework, the specific objectives were to (i) prioritize the needs of volunteers and informal caregivers of families experiencing life threatening illnesses; (ii) identify the capacities and resources available in the community to meet the needs of hospice volunteers and caregivers; and (iii) develop strategies tailored to meet their needs in their context that are sustainable. The team applied CBPR principles because hospice volunteers and caregiver clients were acknowledged to be a distinct and vulnerable community of study that could build upon their strengths and resources to collaboratively foster capacity building at Hospice Peterborough and in the Peterborough community at large.

Starting in spring 2008, three methods of data collection with hospice volunteers and caregivers were undertaken: a telephone survey, focus groups and narrative diaries. Hospice Peterborough staff were interested in a telephone survey because they felt caregivers were already strained and that the survey would garnish a larger return rate. Hospice staff also realized that support group meetings offer a depth to understanding participants’ experiences and were often transformative with end-of-life caregiving. Separate focus groups for caregivers and volunteers were facilitated due to their differing needs. Narrative diaries, collected following the focus groups, allowed research participants to share their stories and add anything that was not captured in the focus group discussion. Hospice Peterborough recruited the participants by letter using a purposive sample of volunteers or participants in the Hospice’s various programs. In total, 40 volunteers and 89 caregivers were invited to participate with 27 completing the telephone survey (9 volunteers; 19 caregivers), 39 attending the focus groups (18 volunteers; 21 caregivers) and 12 submitting narrative diaries (3 volunteers; 9 caregivers). The participants were mostly older adult women, either client service volunteers or bereaved caregivers who had accessed Hospice Peterborough services within the last two years.

Findings from the telephone survey revealed the key challenges facing volunteers (i.e., emotional support, communication, education) and caregivers (i.e., communication, emotional support, health system, fatigue). Although caregiving is emotionally draining for both groups and requires social support and positive coping strategies, volunteers as compared to caregivers are not immersed in the caregiving situation 24 hours a day and were able to practice self-care and health promoting behaviours and have a greater perceived sense of control of their situation. During four focus group sessions, the Continued on page 12.
participants ranked their challenges, brainstormed potential solutions and further analyzed their strategies for importance and resource availability. Examples of the types of strategies identified by the volunteers included professional support similar to an employee assistance program; more follow-up communication by Hospice staff; and more workshops and training opportunities. Examples of the types of strategies identified by the caregivers included establishment of a 24/7 telephone support line; more respite services; and increased awareness of Hospice services and programs. The importance of addressing the challenges and support strategies was validated in the analysis of the narrative diaries, through which the participants’ own words illuminated the experiences of volunteering and caregiving in the hospice sector. For instance, as a volunteer wrote, “This young family, particularly this young woman, captured my heart, with her love, her bravery and her determination. I have grieved her death, but do not regret knowing her and sharing part of her journey...Thanks for allowing me to share. It has been therapeutic writing this story.” Such excerpts reveal the empowering nature of CBPR.

The project concluded with an information session for participants and stakeholders, through which the volunteers and caregivers validated the findings and were encouraged that their ideas were coming to fruition by some of the programming changes at Hospice Peterborough. For example, caregiver support groups are now facilitated twice a month and a package to promote Hospice Peterborough for potential clients and caregivers has been created and distributed widely. The CBPR approach was not only empowering to those involved, but could be transferable to other health and social care organizations with a volunteer pool to support their clients in a community-based setting, particularly those dealing with chronic conditions cared for in the community. The outcomes of this project will be of particular interest to community health and social care researchers working with vulnerable populations in areas where social exclusion and diminished social support are challenges for sustaining volunteers and informal caregivers.

Email Ann MacLeod at annmacleod@trentu.ca for cited references.

“Thanks for allowing me to share. It has been therapeutic writing this story.”