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Leveraging technology to improve patient care

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Telenursing in Hospice Palliative Care

At home in the night, Susan* is caring for her husband, who has advanced cancer. When Bill* says he is in pain, Susan tries to give him an extra dose of morphine, but he can't swallow it. She is scared and doesn't know what to do. His physician's office is closed and the home health office closed at 9 p.m.

Susan and Bill have been given a phone number for home-based patients with the Fraser Health (FH) Hospice Palliative Care (HPC) program. Feeling desperate and alone, Susan calls. The call is answered by an RN at B.C. NurseLine (BCNL), the provincial 24/7 tele-triage and health information call centre. She listens to Susan's concern about Bill's changing ability to swallow his medications and, after completing an assessment, understands that Bill is in his last days of life, that their goal is for Bill to die at home and that they have a plan in place. Bill's symptoms are changing and Susan does not know what to do. The BCNL nurse recognizes this is a new symptom that requires more than information, reassurance or reinforcement of the care plan, so she contacts the palliative response nurse (PRN) for specialized nursing support.

Meanwhile, a palliative care clinical resource nurse is asleep at home. The nurse is taking her turn as the on-call PRN from 9 p.m. to 8 a.m. She is available to home-based FH HPC program patients and families who require additional palliative support after speaking with a BCNL nurse. Awakened by her cellphone, she receives a brief outline of the assessment from the BCNL nurse. The BCNL nurse returns to Susan, who has been on hold, and tells her that the specialist palliative care nurse will call her within 10 minutes.

The PRN takes a few minutes to look up the patient's information, which a local home care nurse has submitted to the FH HPC database, so that she knows basic information about the patient, his illness, his family and any safety or unusual concerns. The PRN calls Susan and is able to determine Bill's current condition and possible options. As Susan has no alternate morphine preparations for other routes of administration, the PRN directs Susan to crush the morphine tablet and put this in a small amount of yogurt. Bill is able to swallow the medication. While the opioid is taking effect, the PRN continues to reassure Susan, exploring her understanding of normal

*Names have been changed to protect the privacy of the patient and family.

changes as death approaches and what to do when Bill dies, and gently preparing her for the possibility that Bill may die tonight. Bill settles and drifts into a comfortable sleep. The PRN reminds Susan that she can call back to BCNL if she has any questions or needs reassurance during the night.

The local home care nurse arrives in the office in the morning, listens to the phone message from the PRN, reads the notes from BCNL and the PRN and phones Susan. Bill died peacefully in the night, about an hour after the call. The community RN, who has known Susan for the past few weeks, drives to her home for support, to pronounce the death and connect with the physician.

THE NEED FOR AFTER-HOURS SUPPORT FOR DYING PATIENTS

Like Bill, the majority of Canadians report that they wish to die at home (Ipsos-Reid, 2004). It is their families who will provide the majority of their care during their last days and weeks of life (Stajduhar, 2003). These families need support available 24 hours a day. The Canadian Hospice Palliative Care Association (Ferris et al., 2002) and the Canadian Council on Health Services Accreditation (2006) have identified 24/7 access as a standard of HPC.

Yet prior to January 2005, few of the 13 communities in the Fraser Health area — one of the largest health authorities in Canada — had formalized after-hours support. Some home health offices close as early as 4:30 p.m., physician offices close at 6 p.m. and few physician offices have night call groups. The majority of home-based HPC patients were left “on their own” during the night hours. They reported concerns about who to call, and if they felt they could not cope on their own, they had no choice but to go to the local emergency department, which was often overcrowded and unable to meet the needs of this patient population at a difficult time (Roberts, 2003). Since the inception of an after-hours partnership between BCNL and the FH HPC program, all palliative patients and their families can call and speak with an RN after home health and family physician offices are closed.

In this article, we outline how information and communications technology have enabled us to merge the telehealth expertise of BCNL with specialized community-based palliative expertise to achieve after-hours services for home-based HPC patients and their families.

In 2004, Fraser Health identified new funding to develop 24/7 HPC services. However, the logistics and economic feasibility of building an after-hours home HPC service in a large health authority of more than one and a half million people with rural, rural-urban and urban populations was a daunting challenge. At the same time, BCNL, a 24/7 provincial telehealth service, was receiving calls from British Columbians who identified themselves as living with advanced illness and seeking telephone advice. ►



PHOTO KEITH MONTGOMERY, CTS, E-COMM, INC.

B.C. NurseLine's Erin Tobler, RN, BSN, assisting a caller as she uses decision-support software specialized for palliative care.

ABSTRACT

During the last months of life, many people with advanced illness will be living in their homes. Coping with changing symptoms, and ultimately preparing for death, becomes part of daily life. Whether the ill person is at home for days or for months, they depend on family or friends to be primary caregivers, supported by home-based services. However, after physician and home health offices close, many patients and their caregivers are left to cope alone. The authors describe an innovative partnership between B.C. NurseLine (a provincial tele-triage and health information call centre), the British Columbia Ministry of Health and Fraser Health Hospice Palliative Care program that created after-hours access to care for dying patients and their families in one of Canada's largest health authorities. The article outlines how information and communications technology enabled merging the capacity and expertise of B.C. NurseLine with the expertise of specialized community-based palliative care services to achieve outcomes of improved symptom management, decreased visits to emergency rooms and enhanced support for families who are caring for loved ones at home. For nurses caring for home-based patients, there are lessons to be learned about how to maximize technology to create systems that both improve access to care and are sustainable in the future.

KEYWORDS

hospice palliative care, palliative response nurse, telenursing

For people like Susan, on her own at home with her husband the night he died, having access to BCNL and the PRN makes a difference.

AN INNOVATIVE SOLUTION

These practice realities were the impetus for a project between Fraser Health and BCNL, supported by the B.C. Ministry of Health Services, now the B.C. Ministry of Health (MOH). In its end-of-life strategy (2006), the MOH endorsed the need to create round-the-clock patient access to HPC support for all British Columbians. A partnership was formalized to develop Fraser Health's after-hours HPC service link with BCNL. The palliative care enhancements to BCNL were developed so they could be adapted for use if similar relationships developed between BCNL and other health authorities in the future.

By linking with BCNL, the FH HPC program benefited from BCNL's use of information technology and evidence-based, decision-support software. BCNL nurses access the Healthwise Knowledgebase triage protocols and health education information during calls. Therefore, one of the first steps undertaken in the palliative project was a joint review of the relevant decision-support software topics and call processes. Specialized content was developed to enhance the existing triage and health information to support decision-making specific for the palliative care needs of patients enrolled in the FH HPC program. Together, BCNL and Fraser Health developed a modified call process to meet the unique needs of these palliative patients and provide them, whenever possible, with an alternative to seeking care in emergency departments after hours.

BCNL then established a designated telephone line for home-based patients enrolled in the FH HPC program. Patients were given a special BCNL phone number to call. These calls have a specific identification on the BCNL phone call display. Modified protocols and processes are used to manage these calls since the callers are known to be people with advanced illness who are anticipated to be within their last months of life and receiving service in the FH HPC program. In addition, triage outcomes were modified so that when a patient's situation warrants the need for additional palliative support, he or she is linked to the PRN rather than being directed to an emergency department or a physician. A specialized education session about hospice palliative care and the revised processes to link with Fraser Health, online learning and lead resource nurses were key aspects of supporting the BCNL nurses as they took on this enhanced role.

Patients in FH HPC receiving home-based care are given a contact sheet that outlines the home health office number, regular home health office hours and the BCNL telephone number to call between 9 p.m. and 8 a.m. The patient's home care nurse has peace of mind knowing that the patient has someone to call in the night. By completing a data sheet with basic information about a patient and family, along with safety information, the home care nurse is able to assist the PRN to manage a call in the night.

It was evident early in the project that the palliative response role required specialized palliative care and community nursing knowledge and skills. Therefore, RNs with advanced expertise in HPC were hired to provide support to HPC health-care providers during the day and to take a rotation of being on call at night. The PRN has the specialized knowledge of HPC necessary to problem solve when the existing plan does not meet the patient's needs, or when the caller's level of distress requires further support.

To aid in the after-hours response, the PRN needed access to basic patient information. This has been achieved by creating a computer software system using a database, standardized across the health authority for all HPC patients. The PRN can access this information from home during the night through a remote secure computer access link. An HPC specialist physician and a clinical nurse specialist (CNS) are on call to support HPC needs across the broader program and are available as backup to the PRN.

Creation of secure systems for information transfer between BCNL nurses and the FH HPC program enabled the partners to become a virtual team. BCNL creates confidential electronic health records for all interactions with callers. Information gathered during calls with FH HPC patients is communicated to a single home health office. This patient information is then forwarded to the appropriate home health office to notify a home care nurse that a patient from their office has contacted BCNL during the night. Information provided includes the patient's concerns at the time of the call, the BCNL assessment and recommendations and the degree of urgency for the home care nurse to contact the patient.

POSITIVE OUTCOMES FOR PATIENTS, FAMILIES AND THE HEALTH SYSTEM

There are approximately 750 home-based HPC patients at any one time who have the after-hours phone number. From January 2005 to December 2006, 498 calls were received from these patients and families. BCNL provided the needed support on 49 per cent (244) of these calls, with the remaining 51 per cent (254) of callers transferred from BCNL to the PRN.

Management of symptoms such as pain, delirium, nausea and shortness of breath was the reason for the majority of calls transferred to the PRN. Another 20 per cent of the transferred calls related to a significant change in the patient's condition, reflecting a time of transition. In these situations, a more specialized skill is required to direct the family. This changing nature of advanced illness emphasizes the importance of a 24/7 resource for family caregivers.

In 80 per cent of the calls referred to the PRN, the direction, advice and support provided met the needs of the family. In the other 20 per cent,

the nurse connected with a physician or CNS to seek advice or new orders. With this support, 231 of these 254 patients (91 per cent) were able to stay home through the night. Twenty-four hours after the call, most patients remained at home, or had died at home. Of the calls received by the PRN, only 23 of the 254 callers (nine per cent) had gone to emergency departments that night or within the next 24 hours.

Because BCNL is able to manage the first level of triage and support within its current infrastructure and link FH HPC callers with specialist hospice palliative care nurses only when needed, the demand on after-hours service has been reduced by 50 per cent. Calls from home-based HPC patients can therefore be managed by one nurse on call after hours, rather than having additional nurses hired to work during the late evening and night to respond to calls throughout the health authority. Only six PRN home visits have been made in the two years of this after-hours service. The partnership has capitalized on available technology enabling Fraser Health to expand services and increase access to HPC with minimal additional resources as well as provided BCNL with augmented service response for FH HPC callers.

For people like Susan, on her own at home with her husband the night he died, having access to BCNL and the PRN makes a difference. "The PRN was a lifeline for me," Susan explains. "She calmed me down so I didn't get panicky and gave me medical advice so I could help my husband be comfortable. Knowing there was a person I could talk to was incredibly valuable."

SHARING THE PROJECT NATIONALLY

The infrastructure developed in this partnership between Fraser Health, the MOH and BCNL was the first Canadian HPC telenursing after-hours service (Pallium, 2005). Subsequently, the Pallium Project, a federal primary care initiative focused on facilitating improved access, enhanced quality and additional system capacity for hospice palliative and end-of-life care, brought together the key players of this foundational work with HPC leaders in Western Canada. The outcomes of the telenursing venture culminated in a framework

document for use by other B.C. health authorities and Canadian provinces that provides detailed instruction on how to set up such a service (Pallium, 2005).

LESSONS LEARNED

There were many lessons learned from this telehealth partnership. We learned that help in the night for patients and families established with an HPC home care program can be provided effectively by telehealth with appropriate decision-making support. Telehealth nurses providing enhanced palliative care support for callers facing end-of-life issues sometimes require emotional support themselves. HPC services need to develop direct access to palliative care units at night as an alternative to emergency admissions, because even with after-hours telehealth services there are patients who can no longer manage at home through the night. Finally, we have learned that through partnership and maximizing communication and information technology, we can enhance care delivery systems to improve access to care in a way that is sustainable in the future. ■

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