

Dying at home

Experience of the Verdun local community service centre

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Abstract

Objective To demonstrate that it is possible for a team of palliative care nurses in an urban centre to care for more than 50% of their terminally ill patients at home until they die, and that medical care delivered in the home is a determining factor in death at home versus death in a hospital.

Design Analysis of place of death of terminally ill patients who died in 2012 and 2013 (N=212) and who had been cared for by palliative care nurses, by type of medical care.

Setting The centre local de services communautaires (CLSC) in Verdun, Que, an urban neighbourhood in southwest Montreal.

Participants A total of 212 terminally ill patients.

Main outcome measures Rate of deaths at home.

Results Of the 212 patients cared for at home by palliative care nurses, 56.6% died at home; 62.6% received medical home care from CLSC physicians, compared with 5.0% who did not receive medical home care from any physician.

Conclusion Combined with a straightforward restructuring of the nursing care delivered by CLSCs, development of medical services delivered in the home would enable the more than 50% of terminally ill patients in Quebec who are cared for by CLSCs to die at home—something that most of them wish for.

EDITOR'S KEY POINTS

- A minority of terminally ill patients in Quebec die at home; most are placed in long-term care centres or hospitalized in short-term care units.
- This study shows that it is possible to integrate nurses who exclusively practise palliative care into home care teams so that patients at the end of life, especially cancer patients, are able to remain at home while they also receive home care from physicians.
- Quebec's family physicians are not interested in making housecalls; this is a substantial obstacle to keeping end-of-life patients in the home. If this trend is to be reversed, family physicians should be encouraged to incorporate housecalls, in particular palliative care housecalls, into their practices.

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Many articles have been published about the factors that influence the possibility of dying at home for terminally ill patients. When brought together, these factors create a “complete” team of palliative home care professionals, with nursing and medical expertise in palliative home care, 24-hour access to nursing and medical care, access to social workers and occupational therapists able to work with palliative care patients in the home, and home supports, as needed.^{1,2} The centre local de services communautaires (CLSC) in Verdun, Que, created such a team.

Quebec has a vast network of CLSCs that offer general nursing care; the services of social workers, occupational therapists, and physiotherapists; and various forms of practical support in the home. Very few CLSCs offer dedicated palliative nursing care and even fewer offer medical care in the home to terminally ill patients, in spite of the fact that most of these patients want to remain at home and that access to a palliative home care team reduces hospitalizations and in-hospital deaths of terminally ill patients while providing comparable quality of care.³

METHODS

This study involves terminally ill patients who were cared for in 2012 and 2013 by a team of palliative care nurses from the CLSC in Verdun, an urban neighbourhood in southwest Montreal. Patients who wanted to remain at home could request these services themselves. They could also be referred by a hospital or a primary care physician. All of the patients assigned to the CLSC palliative care nurses were included in the study, without exception (Table 1).

All but 8 of the 212 patients had cancer. This is not surprising; it is easier to deliver palliative care in the home to terminally ill cancer patients because cancer follows a more linear course, and end of life is easier to detect in patients with cancer than in patients with other terminal conditions that generally follow a longer course, with fewer predictable episodes of acute decompensation that are also more difficult to distinguish from imminent end of life.⁴

Rate of home death was chosen as the key indicator for our study; in spite of this indicator’s limitations, it has been recognized as an indicator of the quality of work of palliative home care teams.⁵ Patients who did not have family physicians (ie, most patients) were cared for at home by CLSC physicians. Several patients who had family physicians who were not affiliated with the CLSC did not receive home visits from their physicians.

RESULTS

Most of the patients were cared for by CLSC physicians (171 out of 212; 80.7%) (Table 2). Of these patients, 107

Table 1. Characteristics of patients cared for at home by palliative care nurses from the Verdun CLSC in 2012 and 2013: N=212.

CHARACTERISTICS	PATIENTS, %
Sex	
• Female	49.5
• Male	50.5
Age at time of death, y	
• <50	2.0
• 50-59	15.0
• 60-69	26.0
• ≥70	57.0
Help in the home from the CLSC	
• Help	54.0
• No help	46.0
Main caregiver for male patients	
• Spouse	43.9
• Child	19.6
• Child and spouse	7.5
• Other	24.3
• None	4.7
Main caregiver for female patients	
• Spouse	23.8
• Child	45.7
• Child and spouse	8.5
• Other	20.1
• None	1.9

CLSC—centre local de services communautaires.

Table 2. Patients cared for by Verdun CLSC palliative care nurses, by type of medical care

PATIENTS	N (%)
Patients cared for at home by nurses	212 (100.0)
• With no physician care in the home	19 (9.0)
• With home care from a physician not affiliated with the CLSC	22 (10.4)
• With home care from an CLSC physician	171 (80.7)
Patients who died at home	120 (100.0)
• With no physician care in the home	1 (0.8)
• With home care from a physician not affiliated with the CLSC	12 (10.0)
• With home care from an CLSC physician	107 (89.2)

CLSC—centre local de services communautaires.

(62.6%) remained at home until they died, compared with 12 of the 22 (54.5%) who had physicians who were not affiliated with the CLSC (Table 3). This yielded a rate of home death of 56.6% for all patients cared for at

home by physicians and by the team of palliative care nurses (Table 4). Of the 19 patients who did not receive home visits from a physician, only 1 was able to die at home, in spite of being cared for by the palliative care nurses (Table 2).

Table 3. Deaths at home for patients cared for by Verdun CLSC palliative care nurses, by type of medical care

PATIENTS	DEATH AT HOME, %
No physician care in the home	5.0
Home care from a physician not affiliated with the CLSC	54.5
Home care from an CLSC physician	62.6

CLSC—centre local de services communautaires.

Table 4. Place of death of patients cared for by palliative care nurses in the home in the Verdun CLSC in 2012 and 2013: N = 212.

PATIENTS	N (%)
At home	120 (56.6)
Elsewhere	92 (43.4)

CLSC—centre local de services communautaires.

DISCUSSION

This study was limited to patients in the CLSC service area who had been diagnosed as being at the end of life and who wanted to remain at home. Most were cancer patients. It included patients already living at home and patients who had returned home after being hospitalized. A minority of terminally ill patients in Quebec die at home; most are placed in long-term care centres or hospitalized in short-term care units. Overall, 71.0% of our patients were referred to us by the palliative care team at Hôpital de Verdun as a result of the coordination of palliative care services at the hospital and at the CLSC that was designed to give priority to discharging patients and enabling them to remain at home.

Barely 9.8% of those in Quebec die of cancer at home, compared with 18% in Alberta, 18% to 28% in the United Kingdom, and 26.5% in France.⁶ The rate of death at home from cancer in our region has increased substantially since 2009, when our service was first introduced. In 2009, 14% of patients who died of cancer in the Verdun CLSC service area died at home; in 2010, this percentage had increased to 15.8%. In 2001, it was 17%. (In 2011, the rate of home death for the Montreal metropolitan area, which includes Verdun, was 12.8%).⁶⁻¹⁰

In our estimation, the Quebec data reflect the lack of structured palliative home care and medical home care. Home care nurses from CLSCs cannot care for end-of-life patients alone, particularly in the advanced stages of

illness. These medically unstable patients require the same level of care they would have if they were hospitalized.

Nurses delivering palliative care in the home must have special expertise; they care for these patients alone, every day. The CLSCs do not generally recruit nurses with formal training in palliative care; we assigned all of these patients to the same group of nurses, enabling them to amass clinical experience. The increase in staffing costs was minimal because the focus was on re-assigning patients to these nurses.

Nurses and physicians delivering palliative care in the home must anticipate the problems typically associated with end of life with various terminal conditions. They must prepare the patient's family and also anticipate when medications need to be ordered from the community pharmacy. The ability to anticipate these problems and to organize care in the home are key aspects of their expertise. Physicians are only able to visit their patients once or twice a week; however, they must answer calls from the palliative care nurses quickly and prescribe medications that can be administered in the event of an emergency or deterioration in patients' conditions. Nurses must be able to assess patients (questionnaire and physical examination) when the physicians are not there to detect problems and quickly organize care. Nurses train family members to administer medications. Despite their best efforts to organize care and anticipate needs, not all terminally ill patients can remain at home and avoid hospitalization. However, a rate of home death of 50% of end-of-life patients cared for by a complete palliative home care team is indicative of excellence.

In addition to meeting the wishes of most patients, palliative home care can be delivered at roughly the same cost as care in a long-term care centre and at a substantially lower cost than care in a hospital.¹¹ The role of the physician in palliative care delivered in the home is well described in care models used in France, Belgium, and the United Kingdom.^{12,13} As our study reveals, care delivered in the home by a physician essentially enables these patients to die at home.

Family physicians in Quebec make very few housecalls; we believe that this explains the very low percentage of cancer patients in Quebec who die at home (9.8%) and the very high percentage of cancer patients in Quebec who die in a hospital (70.1%).¹⁴ This choice of medical practice differs from that of several western primary health care systems in which housecalls to end-of-life patients are encouraged, not only because this is what patients want, but because it has been demonstrated that it results in savings to the health care system.¹⁵

Family physicians find this type of medical practice unattractive for a variety of reasons. These include unattractive remuneration and practice conditions, stronger encouragement to practise in a hospital setting, and a

lack of training in palliative home care for young family physicians. In 2003, Quebec's Conseil de la santé et du bien-être voiced concern over the declining rate of family physician housecalls which, it believed, led to higher rates of hospitalization at the end of life. Owing to a lack of end-of-life palliative care services in the community, dying patients had to be hospitalized. This situation was, according to the Conseil de la santé et du bien-être, a substantial obstacle to the delivery of end-of-life care in the home.¹⁶

Research could be conducted on ways to remunerate the delivery of palliative care in the home by physicians. This is a demanding medical practice requiring continuous availability in a setting that lacks most of the usual medical equipment; it involves complex and unstable cases that require frequent and often unscheduled visits. Because of this, it will be necessary to find modes of remuneration capable of attracting and retaining physicians—this, at a time when Quebec already has a severe shortage of primary care physicians.

Conclusion

It will never be possible for all terminally ill patients to remain at home until they die. However, this is what most terminally ill patients actually want. Our data show that it is possible to integrate nurses who practise palliative care exclusively into CLSC home care teams so that patients at end of life, especially cancer patients, are able to remain at home while also receiving home care from physicians. These CLSCs should receive a mandate to offer complete palliative care services, delivered by teams of nurses with expertise in palliative care and by physicians who make housecalls and who, ideally, have experience in the delivery of palliative care in the home.

Quebec's family physicians are not interested in making housecalls; this is a substantial obstacle to maintaining end-of-life patients in the home. The current trend in Quebec is for patients to die in hospitals, at great cost to the system. If we are to reverse this trend, we need to encourage family physicians to incorporate housecalls, in particular, palliative care housecalls, into their practices.



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Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

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