

## **Do We All Want to Die at Home?**

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Palliative care reports on home care continually repeat the dogma that most patients and their families would prefer a home death, and that to a large extent this can be solved by increasing health care supervision in the home (1, 2). Our Regional Palliative Care Program in Edmonton has been operating for the last five years. The 24 hour access offered by the Palliative Home Care Nursing Program is now supplemented by 24 hour access to specialist palliative care physicians and nurses. However data of cancer patients dying at home in our region, has remained static at around the 20% figure for all cancer patients dying in our region. It is worth comparing recent reports from England and Sweden to publications in the Spring issue of the Journal of Palliative Care that originate from Edmonton (3, 4).

Grande et al (1) note that in England and Wales in 1995 26% of cancer deaths occurred in patients homes. They report that in their area a hospital in the home program was set up to provide nursing care for up to 24 hours a day for as long as two weeks. This care is provided by qualified nurses or nursing auxiliaries. This was in addition to standard care available in the area which includes support from family physicians, a variety of district nursing services, evening district nursing, social services and a flexible care nursing service. Twenty five (58%) of patients receiving standard care died at home, compared to 124 (67%) of patients allocated to the hospital in the home program. There was no statistical difference, leaving the authors to conclude that terminally ill patients allocated to hospital at home were no more likely to die there than patients receiving extended care.

In the Swedish study by Rosenquist et al (2) 108 cancer patients dying within a twelve month period in their area made up the study group. The hospital based home care program provides 24 hour access to doctors and nurses for health care advice. Forty people (37%) of the total cancer population died in their own homes, and another 11% were considered appropriate for end of life home care. The authors conclude that offering qualified medical care and psychosocial support on a 24 hour basis, can result in 40 to 50% of home care deaths being a realistic goal.

Those of us working in palliative care in Edmonton believe that our Home Care Program and the Regional Palliative Care Program work very hard together in attempting to facilitate end of life care in the home for as long as possible, and for as many patients and families that wish for this care. However inappropriate comparisons may be drawn between the more than 50% of home care deaths reported by others. Obvious errors in this comparison would be the failure of some reports to take into account what percentage of cancer patients in an entire region that are truly dying at home, rather than the percentage of home care patients dying at home. In addition in a relatively small geographic area (2), more problematic cancer patients may have been hospitalized and died in other tertiary referral regions. A further important difference would be social demographic variables in the family support available to patients.

The reports by our Edmonton group are timely and helpful in understanding the limitations of what we can achieve with palliative home care, as well as developing a better understanding of how we could demonstrate the effectiveness of the home care we do provide. Cantwell et al used a questionnaire to understand the viability of home death in patients seen by the Regional Palliative Care Program (3). The desire for a home death by the patient and caregiver, support of a family physician, and presence of more than one caregiver were all significantly associated with a home death. Analysis demonstrated that a desire for home death by both the patient and caregiver were the main predictive factors in determining the likelihood of a home death. The Palliative Care Program at the Royal Alexandra Hospital (4) initiated a prospective study to identify factors hindering home discharge for 100 consecutive patients who did not require ongoing acute care or referral to the tertiary palliative care unit. Patients with better cognition and functional ability were more likely to go home, as were patients who were married, and younger. In the patient group admitted to a hospice, 24% of patients and 7% of families would have preferred a home discharge. Increased physical support at home was identified as a factor that could have facilitated a home discharge for these patients. The conclusion was that unless patients are able to identify the front door of the hospital and ambulate independently to the exit, they are unlikely to return home, as most will lack sufficient support. As funding for 24 hour home care for prolonged periods of time is likely the only way in which many of these patients could be assured a home death, we can anticipate the economic restraints are unlikely to make this a realistic option.

Those wishing to understand the historical backdrop to home deaths in Canada may wish to read a recent report by Smith & Nickel (5). This report was part of a larger study on the history of palliative care and dying in 20th century Canada, and highlighted the parallel in the history of birthing and dying as this moved from home to the hospital in Canada during the 20th century. The report demonstrates that the availability of paid and unpaid female caregivers was a key factor that resulted in the shift in location of death to hospitals, much as it was for birth.

It is to our advantage to understand the limitations of other reports apparently highlighting extremely high rates of home cancer deaths in other settings. Further we need to continue to document our own results, and the limitations of our ability to dramatically impact on the percentage of palliative care home deaths in Edmonton. Those of us involved in caring for patients at home are well aware of the fact that patients and families often change their opinion of their ability to manage at home, as the physical and psychological pressures mount in the face of progressive disease. Personally I have no doubt that we have been successful in the Edmonton region in enabling patients to remain at home for longer periods of time, with resulting shorter admissions for end of life care in acute care hospitals or palliative care units. Unfortunately this is one area that we have not been successful in capturing sufficient data to be able to demonstrate this shift effectively. However we do have sufficient evidence to document that within the resources available to assist patients and families in the home, we are providing the care that most want at the time that they want it. We are fortunate that we are able to provide the option of admission to the hospice in-patient units. We will need to continue to monitor the care we provide to ensure that we are meeting the needs of our community for both home and in-patient end of life care.

**References:**

1. Grande GE, Todd CJ, Barclay SI, et al. Does hospital at home for palliative care facilitate death at home? Randomised controlled trial. *BMJ* 1999; 319:1472-1475.
2. Rosenquist A, Bergman K, Strang P. Optimizing hospital-based home care for dying cancer patients: A population-based study. *Palliative Medicine* 1999; 13:393-397.
3. Cantwell P, Turco S, Brenneis C, et al. Predictors of home death in palliative care cancer patients. *J of Palliative Care* 2000; 16(1):23-28.
4. Fainsinger RL, deMoissac D, Cole J, et al. Home versus hospice in-patient care: Discharge characteristics of palliative care patients in an acute care hospital. *J of Palliative Care* 2000; 16(1):29-34.
5. Smith SL, Nickel DD. From home to hospital: Parallels in birthing and dying in twentieth-century Canada. *Canadian Bulletin of Medical History* 1999; 16(1):49- 64.