Re-examining the Definition of Location of Death in Health Services Research

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INTRODUCTION

Location of death in end-of-life health services research is typically defined using death certificate (DC) information (1–3). We wondered whether the traditional DC definition of “hospital death,” particularly for cancer patients, masks the extent of community-based care in the Canadian province of Nova Scotia. Although most people approaching the end of life express the desire to die out-of-hospital, traditional estimates indicate that very few do (4–7): estimates are that in Nova Scotia, 74 percent of cancer patients between 1992 and 1997 died in hospital (1).

For health services research, it is important to understand that the final location of death is not necessarily the location of care during most of the end of life. Are people arriving in hospital during the very last days of their lives, their final terminal period, to die? If so, then it could lead to the assumption that they received more end-of-life hospital care than they actually did and mask the fact that many of them were able to stay out of the hospital and receive community-based care until their very last days. In this short report, we look at the location of death of adults who died of cancer as determined by DC information and as determined by provincial hospital discharge summaries, and we compare the results.

METHOD

Subjects included all adult Nova Scotians over seventeen years of age who died of cancer between January 1, 1998 and December 31, 2003, as identified with DC information (8, 9); a pathological confirmation of cancer was done through the provincial cancer registry.

Location of death was defined in two ways: traditionally, based on each subject’s DC records and categorized as either a hospital or out-of-hospital death; and in a redefined way, based on individual-level information associated with the same subjects taken from the provincial discharge abstract database (DAD). Using DAD information, the location of death was recategorized in three ways: as a hospital death (death occurred in hospital and the decedent was admitted four or more days prior to death); as a final terminal care hospital death (death occurred in hospital and the decedent was admitted less than four days prior to

death); or as an out-of-hospital death (the decedent was not a hospital in-patient on the day of death).

RESULTS

Table 1 summarizes the demographic characteristics of the 14,426 adult Nova Scotians who died due to cancer during the study years. During their last six months of life, 13.6 percent were never admitted to hospital, while 56 percent spent 14 days or less as a hospital in-patient.

DC information indicated that 72 percent died in hospital (Table 2). However, DAD information indicated that 68 percent were hospital in-patients on their day of death. This discrepancy could be due to several factors. DC coding of location of death is very inclusive — it counts as hospital deaths those of people who are dead on arrival at hospital, deaths occurring in emergency departments, and hospital deaths among Nova Scotia residents who die out of province. DAD information includes only patients who are admitted to hospital and are provincial residents (10). Of particular interest in this report are decedents who were in-patients on their death date. Of this group, 17 percent were admitted to hospital during the last three days of their lives: 2.7 percent on the same day, 5.4 percent one day prior to death, 4.9 percent two days prior, and 3.9 percent three days prior. DAD information indicates that 49 percent of cancer decedents either died out-of-hospital or arrived during their final terminal days. Fifty-one percent of decedents had been inpatients for four or more days prior to their deaths.

DISCUSSION

Even though the majority of cancer decedents were in hospital on their death date, a large proportion remained in the community until their very last days. The traditional DC definition suggests that 72 percent of them died in hospital, a proportion similar to that reported previously in Nova Scotia (1). However, of the 72 percent, 22 percent were not hospital in-patients on their date of death and remained in the community or were admitted to hospital less than four days before they died. Others report similar increases in hospital admissions in the final terminal period (11, 12).

If we consider these final terminal care hospital deaths as primarily out-of-hospital because the decedents were cared for in the community, then 51 percent of Nova Scotia cancer deaths — those of people who were in hospital four days or more prior to dying — would be defined as hospital deaths. This reduction in the proportion of deaths reported as occurring in hospital is an acknowledgement that a greater proportion of people are being cared for in the community until the very last days of their lives. Remaining in the community until one is close to death is not uncommon. In a study investigating care and location of death preferences over time, Agar et al. (13) noted a trend among patients approaching death to change their preference from care in the community to in care in hospital or hospice. They suggest that a patient's preferred place of care and preferred location of death are not necessarily the same — these preferences are two separate questions.

Our redefinition of location of death based on hospital discharge summaries has major health service implications. A greater proportion of people are cared for in the community until their very last days than traditional DC estimates imply. This suggests a need for greater development, support, and evaluation of community-based health services for the dying. In addition, the fact that a substantial number of people (17 percent) required hospital admission fewer than four days before death deserves research attention. Family or other care providers may have decided that the hospital should be the final terminal care site; or maybe the dying person's urgent needs during those last three days could only be met in hospital, not at home. Once the reasons for hospitalization in the final three days are clarified, home-based care programs could be altered to help reduce preventable admissions.

CONCLUSION

In summary, the traditional DC definition of a hospital death appears to mask the extent of care provided in the community. Although the majority of cancer patients are in hospital on the day of their death, a large proportion of them are not admitted until their final terminal days, and they receive the majority of their end-of-life care in the community.

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References

1. Burge F, Lawson B, Johnston G. Trends in the place of death of cancer patients, 1992–1997. *CMAJ*. 2003; 168(3):265–270. [PubMed: 12566330]
2. Davies E, Linklater KM, Jack RH, et al. How is place of death from cancer changing and what affects it? Analysis of cancer registration and service data. *Br J Cancer*. 2006; 95(5):593–600. [PubMed: 16909139]
3. McNamara B, Rosenwax L. Factors affecting place of death in Western Australia. *Health Place*. 2007; 13(2):356–367. [PubMed: 16735136]
4. Beccaro M, Costantini M, Giorgi Rossi P, et al. Actual and preferred place of death of cancer patients: results from the Italian survey of the dying of cancer (ISDOC). *J Epidemiol Community Health*. 2006; 60(5):412–416. [PubMed: 16614331]
5. Tiernan E, O'Connor M, O'Siorain, et al. A prospective study of preferred versus actual place of death among patients referred to a palliative care home-care service. *Ir Med J*. 2002; 95(8):232–235. [PubMed: 12405498]
6. Townsend J, Frank AO, Fermont D, et al. Terminal cancer care and patients' preference for place of death: a prospective study. *BMJ*. 1990; 301(6749):415–417. [PubMed: 1967134]
7. McWhinney IR, Bass MJ, Orr V. Factors associated with location of death (home or hospital) of patients referred to a palliative care team. *CMAJ*. 1995; 152(3):361–367. [PubMed: 7530164]
8. Centers for Disease Control and Prevention (CDCP). International Classification of Diseases, Ninth Revision (ICD-9). Atlanta: CDCP; 2009.
9. Centers for Disease Control and Prevention (CDCP). International Classification of Diseases, Tenth Revision (ICD-10). Atlanta: CDCP; 2010.
10. Neutel CI, Bishop ML, Harper SD, et al. Proportion of cancer deaths occurring in hospital, Canada, 1994–2000. *Can J Public Health*. 2005; 96(4):264–268. [PubMed: 16625792]
11. Van den Block L, Deschepper R, Bilsen J, et al. Transitions between care settings at the end of life in Belgium. *JAMA*. 2007; 298(14):1638–1639. [PubMed: 17925515]

12. Van den Block L, Deschepper R, Drieskens K, et al. Hospitalisations at the end of life: using a sentinel surveillance network to study hospital use and associated patient, disease and healthcare factors. *BMC Health Serv Res.* 2007; 7:69. [PubMed: 17488520]
13. Agar M, Currow DC, Shelby-James TM, et al. Preference for place of care and place of death in palliative care: are these different questions? *Palliat Med.* 2008; 22(7):787–795. [PubMed: 18755830]

Table 1

Nova Scotia Cancer Decedent Demographics, 1998–2003 (n=14,426)

Characteristic	Number of patients (%)
Sex	
female	6,702 (46.5)
male	7,724 (53.5)
Age (years)	
<55	1,513 (10.5)
55–64	2,228 (15.4)
65–74	3,394 (23.5)
75–84	4,472 (31.0)
85+	2,819 (19.5)
mean (standard deviation)	72.0 (12.9)
median (range)	74 (18–103)
Year of death	
1998	2,301 (16.0)
1999	2,298 (15.9)
2000	2,409 (16.7)
2001	2,401 (16.6)
2002	2,488 (17.3)
2003	2,529 (17.5)
Cancer cause of death	
breast	1,015 (7.0)
lung	3,749 (26.0)
colorectal	1,328 (9.2)
gastrointestinal/other	2,190 (15.2)
prostate	846 (5.9)
genitourinary/other	677 (4.7)
gynecologic	548 (3.8)
hematological	1,019 (7.1)
other	1,043 (7.2)
unknown primary	2,011 (13.9)
In-patient length of stay *	
0 days	1,961 (13.6)
1–14 days	4,701 (32.6)
15–31 days	3,593 (24.9)
32+ days	4,170 (28.9)
mean (standard deviation)	25.8 (30.1)
median (range)	17 (0–183)

* Total during last six months of life.

Table 2

Location of Death Using Traditional Death Certificate Information and Hospital Discharge Abstract Data
(n=14,426)

Data source	Frequency (%)	
	by subgroup	overall
<i>Death certificate (DC)</i>		
out of hospital		3,804 (26.4)
hospital		10,376 (71.9)
not known		246 (1.7)
<i>Hospital discharge abstract data (DAD)</i>		
<i>out of hospital death</i> (not in hospital on death date)		4,617 (32.0)
<i>final terminal care hospital death</i> (admitted 0–3 days prior to death)		2,447 (17.0)
admitted on death date	384 (2.7)	
admitted 1 day prior to death	784 (5.4)	
admitted 2 days prior to death	711 (4.9)	
admitted 3 days prior to death	568 (3.9)	
<i>hospital death</i> (admitted 4 or more days prior to death)		7,362 (51.0)
admitted 4–7 days prior to death	1,719 (11.9)	
admitted 8+ days prior to death	5,643 (39.1)	