

End-of-Life Population Study Methods

Grace M. Johnston, MHSA, PhD,¹ Frederick I. Burge, MD, MSc,²
Chris J. Boyd, MSc,³ Maureen MacIntyre, BScN, MHSA⁴

Palliation is the relief of suffering and improvement in the quality of life for persons living with or dying from advanced illness, and for the bereaved.¹ The Special Senate Report "Of Life and Death"² and its recent update³ call for greater action in Canada to meet these needs. While health promotion should span all stages of life,^{4,5} quaternary prevention to reduce end-of-life suffering and promote a good death⁶ has been limited.⁷ Population-based research and information systems are underdeveloped for adequate identification of palliative needs, service provision, and outcomes.⁸⁻¹⁰ This short report provides methodological direction for end-of-life database development and research.

Since more than 90% of palliative care services are devoted to cancer patients,^{11,12} research often focused on this disease. As palliative services become more available to persons dying of other chronic conditions, the methods presented herein can be expanded to non-cancer end-of-life care.

To identify inadequacies in palliative care provision, population-based retrospective studies can be carried out across Canada by learning from progress being made in Nova Scotia (NS). Concurrently, population-based methods must be developed to prospectively identify persons with

palliative care needs and to enable intervention studies.

NS research provides a model for equity studies reporting demographic and service variations in palliative program registration¹² and provision of palliative radiation.¹³ Physician and hospital service utilization is now being investigated.^{14,15} Studies of narcotic analgesic use¹⁶ and nursing workload measures¹⁷ are planned.

For these retrospective studies, the study subjects are all persons dying of cancer. The subjects were identified from the Nova Scotia Cancer Registry that contains provincial Vital Statistics (VS) death registrations. The subjects are an unbiased set of persons likely to have end-of-life needs. The validity of the VS cause of death can be ascertained by comparison to diagnoses recorded in the disease registry.

Canadian provincial/territorial Cancer Registries (CR) identify all persons diagnosed with cancer since 1969¹⁸ from pathology reports, hospital separations and cancer centre visits using International Classification of Disease – Oncology (ICD-O) codes. Vital Statistics (VS) death registrations have ICD-9 cause of death codes. The ICD-9 VS and ICD-O CR codes can be grouped into 10 common categories (Table I).

For NS studies, if a primary cancer site at diagnosis is also recorded as a cause of death, it is assumed that the person would probably require supportive cancer care at the end of life. The extent of agreement between CR and VS cancer sites was ascertained for NS by comparing underlying and other VS cancer causes of death to CR primary cancer(s) at diagnosis. At least one of the cancer causes of death was found as a primary cancer diagnosis for 90.5% of the people dying of cancer. Agreement for

diagnoses microscopically confirmed was similar to those clinically diagnosed.

For the 9.5% in disagreement, anatomically adjacent and metastatic sites, as well as diagnostic uncertainty, were typically involved. The VS cause of death appears plausible given the primary cancer site. Grouped ICD-9 VS cancer cause of death appears to be a valid classification for retrospective study subjects.

Disease registry managers should lead in linking death records to administrative databases for retrospective assessment of palliative care provision. Province-wide, patient-specific profiles of service provision should be generated over time, compared to other geographic areas, and analyzed by sociodemographic determinants such as age, sex, cause of death, urban/rural place of residence, and location of death (hospital, home, nursing home). In all Canadian provinces/territories, hospital and physician services databases exist. In many, palliative radiation, pharmaceutical and home care data are accessible. A major effort is now needed to enable retrospective, end-of-life studies across Canada.

Concurrently, prospective study methods must be developed for the comparison of outcomes from various models of palliative care provision and the evaluation of palliative care interventions. As Canadian cancer registries progress to include stage of disease at diagnosis,¹⁹ consensus should be sought on which markers of disease progression should be added to identify persons likely to require palliative services.

New data collection for prospective studies must be feasible for palliative and home care programs, long term care facilities, and hospitals. Data should be meaningful for planning and policy setting by agencies providing data as well as chronic

1. Associate Professor, School of Health Services Administration, Dalhousie University, and Senior Epidemiologist, Nova Scotia Cancer Registry, Halifax, NS

2. Associate Professor, Department of Family Medicine, Dalhousie University

3. Biostatistician, Nova Scotia Cancer Registry in 1999/2000

4. Director, Nova Scotia Cancer Registry

Correspondence and reprint requests: Dr. Grace Johnston, Associate Professor, School of Health Services Administration, Dalhousie University, 5599 Fenwick St., Halifax, NS, B3H 1R2, Tel: 902-494-1309, E-mail: grace.johnston@dal.ca

TABLE I
Number (and Row Percent) Agreement between Cancer at Diagnosis from Cancer Registry (CR) and Cause of Death from Vital Statistics (VS), Nova Scotia, 1994 to 1998 Deaths

CR CANCER DIAGNOSIS	ICD-0 Codes	VS CANCER CAUSE OF DEATH									
		ENT	GI	Thoracic	Breast	GYN	GU	CNS	Haematological	Other	Unknown Primary
ENT	(140-160)	242 (77.8)	7 (2.2)	30 (9.6)	0 (0.0)	0 (0.0)	2 (0.6)	3 (1.0)	1 (0.3)	17 (5.5)	10 (3.2)
GI	(151-159)	1 (0.0)	2428 (94.3)	25 (1.0)	5 (0.2)	5 (0.2)	9 (0.4)	0 (0.0)	5 (0.2)	18 (0.7)	78 (3.0)
Thoracic	(162-165)	3 (0.1)	11 (0.4)	2590 (95.6)	3 (0.1)	1 (0.0)	8 (0.3)	8 (0.3)	2 (0.1)	14 (0.5)	68 (2.5)
Breast	(174-175)	1 (0.1)	9 (1.0)	11 (1.3)	826 (94.5)	1 (0.1)	0 (0.0)	3 (0.3)	1 (0.1)	4 (0.5)	18 (2.1)
GYN	(180-184)	1 (0.2)	13 (2.9)	5 (1.1)	1 (0.2)	409 (90.1)	1 (0.2)	0 (0.0)	1 (0.2)	6 (1.3)	17 (3.7)
GU	(185-188)	1 (0.1)	28 (2.4)	32 (2.7)	1 (0.1)	2 (0.2)	1085 (91.0)	1 (0.1)	0 (0.0)	9 (0.8)	34 (2.9)
CNS	(191-192)	0 (0.0)	1 (0.5)	1 (0.5)	0 (0.0)	1 (0.5)	0 (0.0)	182 (93.3)	0 (0.0)	8 (4.1)	2 (1.0)
Haematological	(169)	0 (0.0)	3 (1.2)	1 (0.4)	0 (0.0)	0 (0.0)	1 (0.4)	0 (0.0)	235 (92.2)	14 (5.5)	1 (0.4)
Other	(All else)	0 (0.0)	13 (1.6)	12 (1.5)	2 (0.3)	3 (0.4)	4 (0.5)	2 (0.3)	16 (2.0)	716 (90.4)	24 (3.0)
Unknown Primary	(199)	3 (0.5)	156 (25.1)	71 (11.4)	6 (1.0)	12 (1.9)	11 (1.8)	6 (1.0)	0 (0.0)	36 (5.8)	320 (51.5)

disease program managers, drug programs, and clinicians.

In conclusion, the authors recommend that VS cause of death be used to classify persons in retrospective studies of equity in service provision at the end of life to persons dying of cancer across Canada. This method should be used for other chronic diseases such as AIDS, Lou Gerhig's and multiple sclerosis. Concurrently, classification and design issues for prospective studies should be addressed.

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