



Reaping the Benefits of Cancer Registries: Examples from End of Life Studies

Grace Johnston, MHSA, PhD

Professor, School of Health Services

Administration, Dalhousie University, and
Epidemiologist, Surveillance and Epidemiology Unit,
Cancer Care Nova Scotia,
Halifax, Nova Scotia, Canada

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Outline

Beginnings

- Cancer Registry
- Context

Growth

- Linkage to Population Administrative Databases
- Data Quality Assessment
- Expertise and Experiences

Harvest

- Publications
- Research Grants
- New Collegial Relationships



Beginning: Cancer Registry

Cancer Registry data back to 1960's

Death Clearance

Mortality Rates, and
Survival Statistics

Death Certificate Only Rates, and
Mortality to Incidence Ratios

50% of people diagnosed
with cancer die of cancer



Context

Canadian Health Care System

Provincial administered; publicly funded

Hospital care

Fee for service Physician visits

Senate Reports on Care of the Dying, 1995 ...

Limited tertiary hospital based palliative medicine

Virtually no hospice or other community care

Record Linkage

Statistics Canada Mortality Database

Provincial Population Health Research Units

Halifax Palliative Care Program - 1988



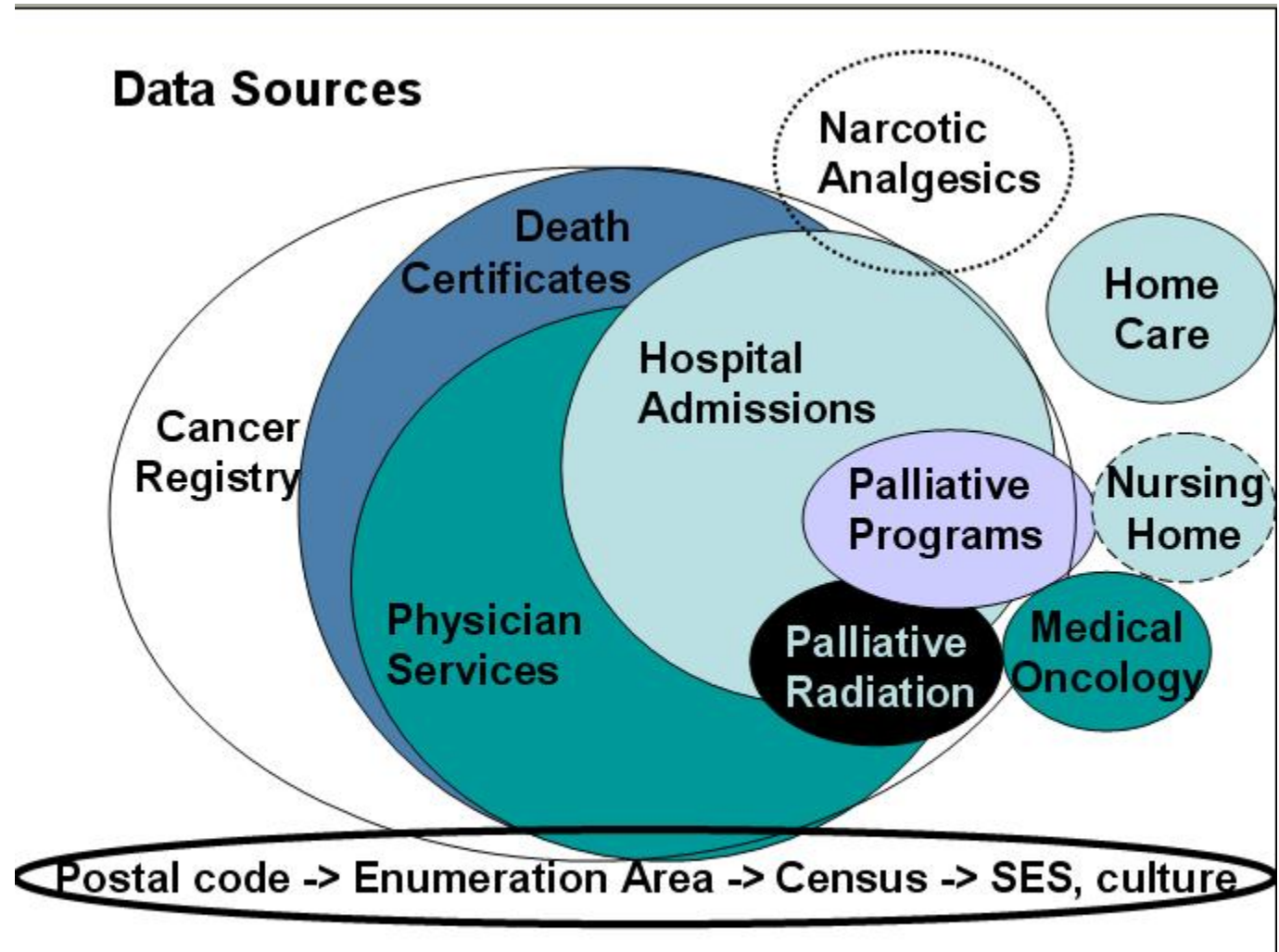
Growth

Linkage to Population
Administrative Databases

Data Quality Assessment

Experiences

Linkage of Cancer Registry Data to Population Based Administrative Databases



Data Quality Framework to assess Administrative Databases being added

Value

Provide checklist for data quality monitoring

Identify time periods and data fields of sufficient quality for reporting

Assist in reconciling data quality problems

Provide a structure for data quality reports

Aid in establishing data quality standards

Concepts

coding constancy	data fields complete
accuracy, reliability	includes all persons
validity, interpreting	includes all services
timely data transfer	reporting constancy



Expertise

For Record Linkage,
Data Quality Assessment,
Statistical Analysis, and
Ongoing Database Updating

R Dewar, B Lawson, C Boyd, N St Jacques,
J Gao, M O'Brien



Expertise

For Interpretation and
Knowledge Translation:

Clinicians from
Family Medicine,
Palliative Care,
Palliative Radiation,
Medical Oncology, and
Pharmacy

F Burge , I Cummings, P McIntyre, D Orychock,
P Joseph, D Rheume, D Rayson, L Broadbent,
E Grunfeld



Personal experiences

Health Services Administration

Family and Friends

Breast Cancer Survivor, and
Dragon Boat Team Member



Harvest

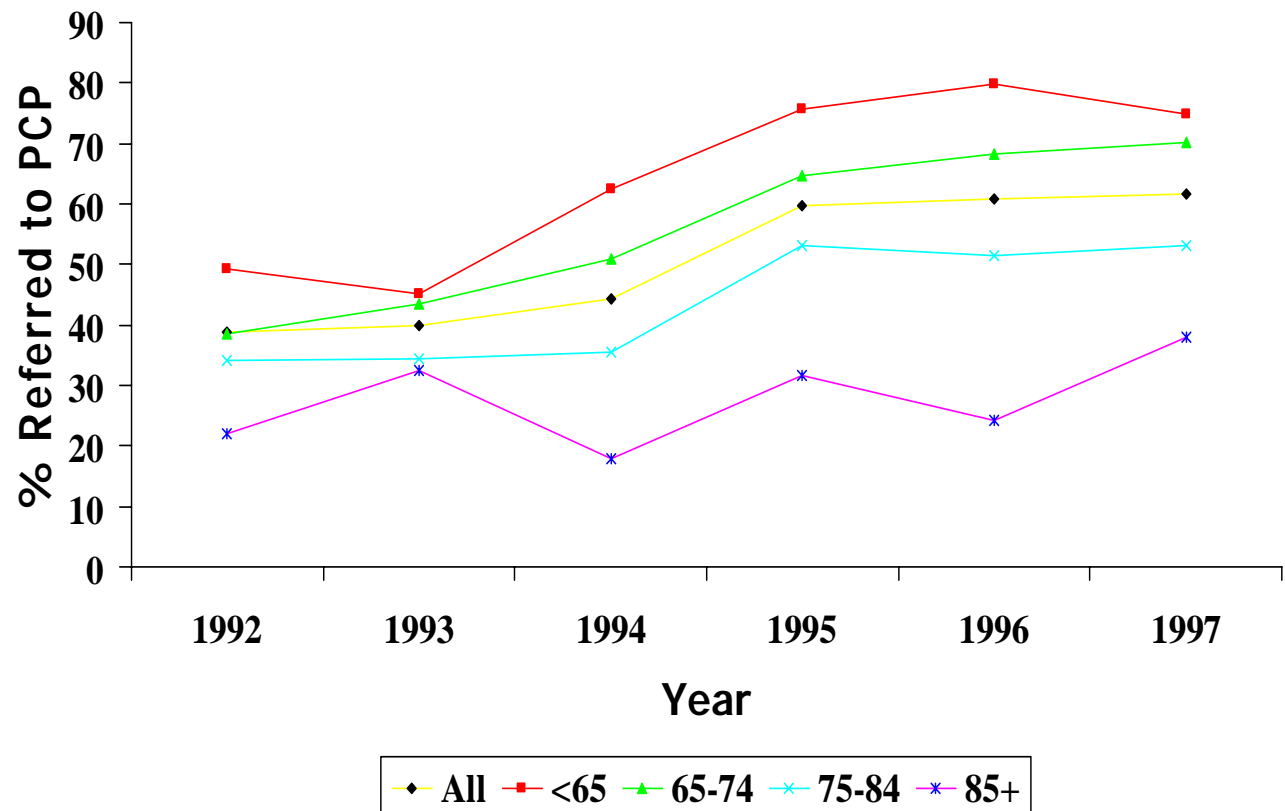
Publications

Research Grants

New Collegial Relationships

Initial publications

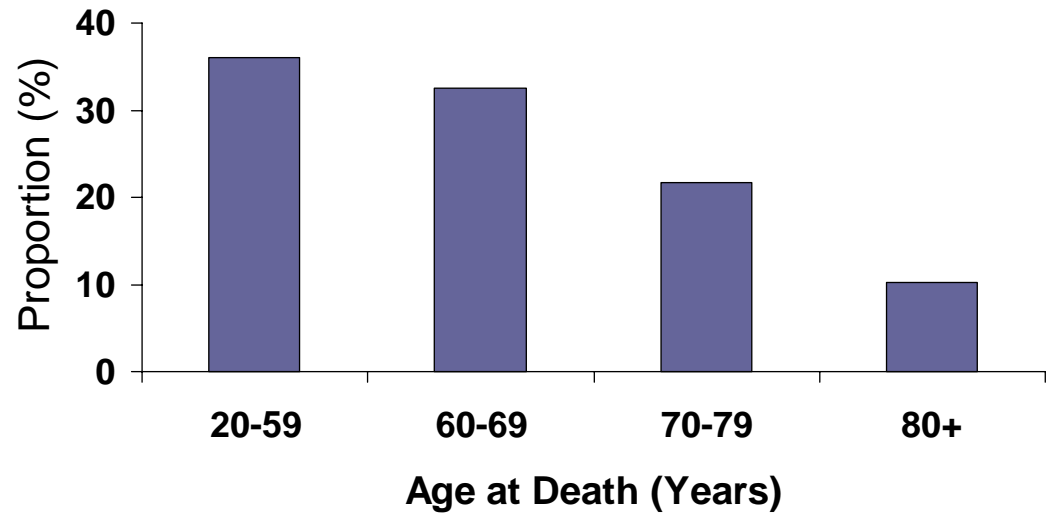
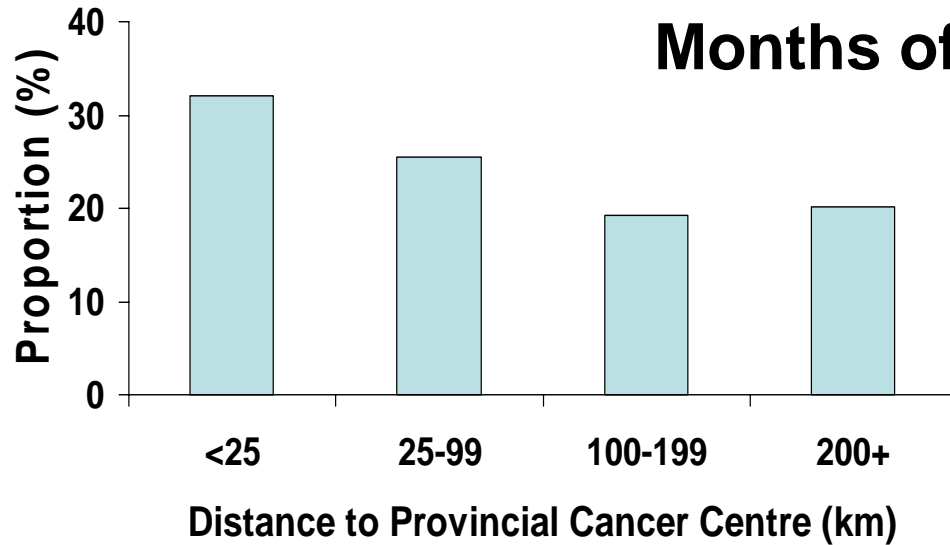
Palliative Care Program Referral by Age, Halifax



Johnston G, Gibbons L, Burge F, Dewar R, Cummings I, Levy I (1998) Need for Palliative Care in Nova Scotia. **Canadian Medical Association Journal** 158(13):1691-8
Burge F, Johnston G, Lawson B, Dewar R, Cummings I (2002) Population Based Trends in Referral of the Elderly to a Comprehensive Palliative Care Program. **Palliative Medicine** 16:255-256



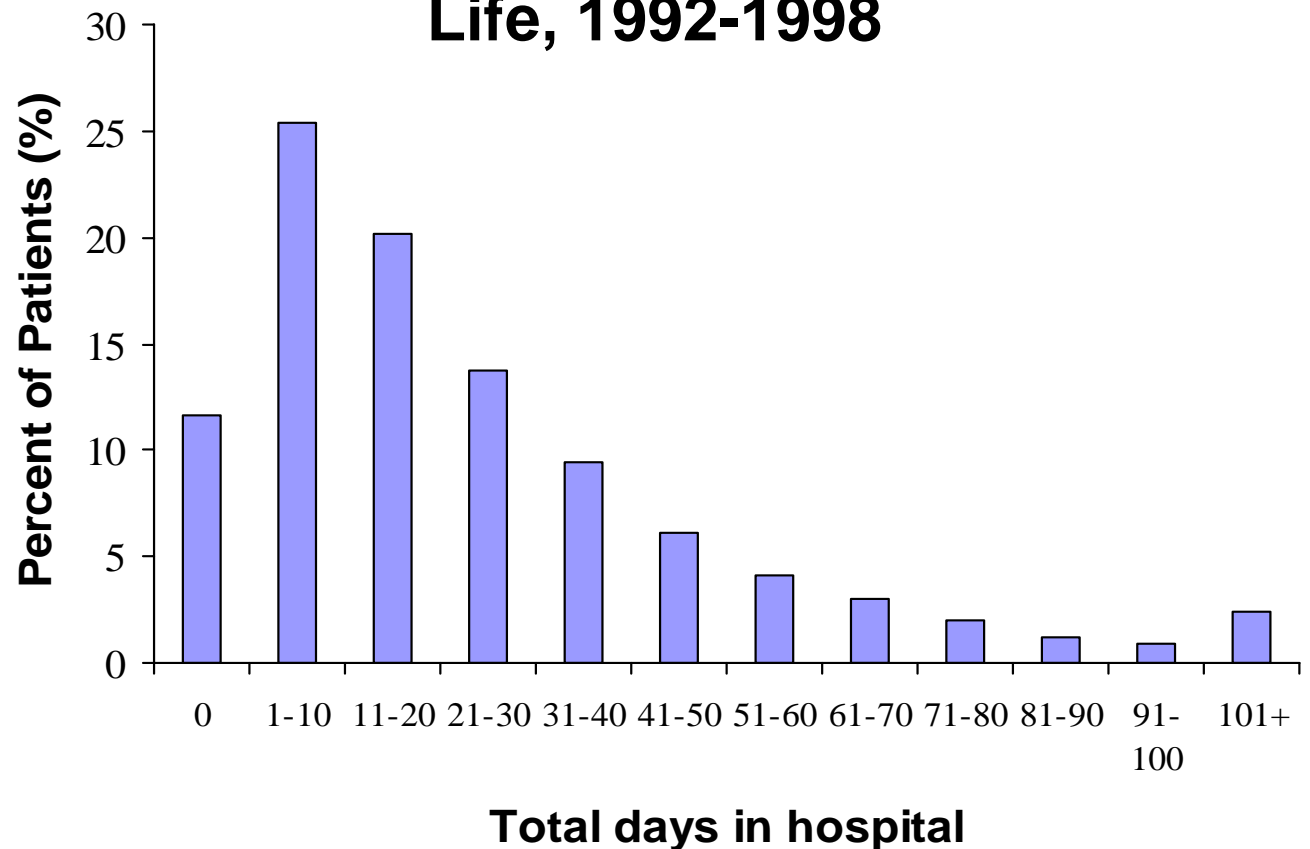
Palliative Radiation in Last Nine Months of Life, 1994-1998



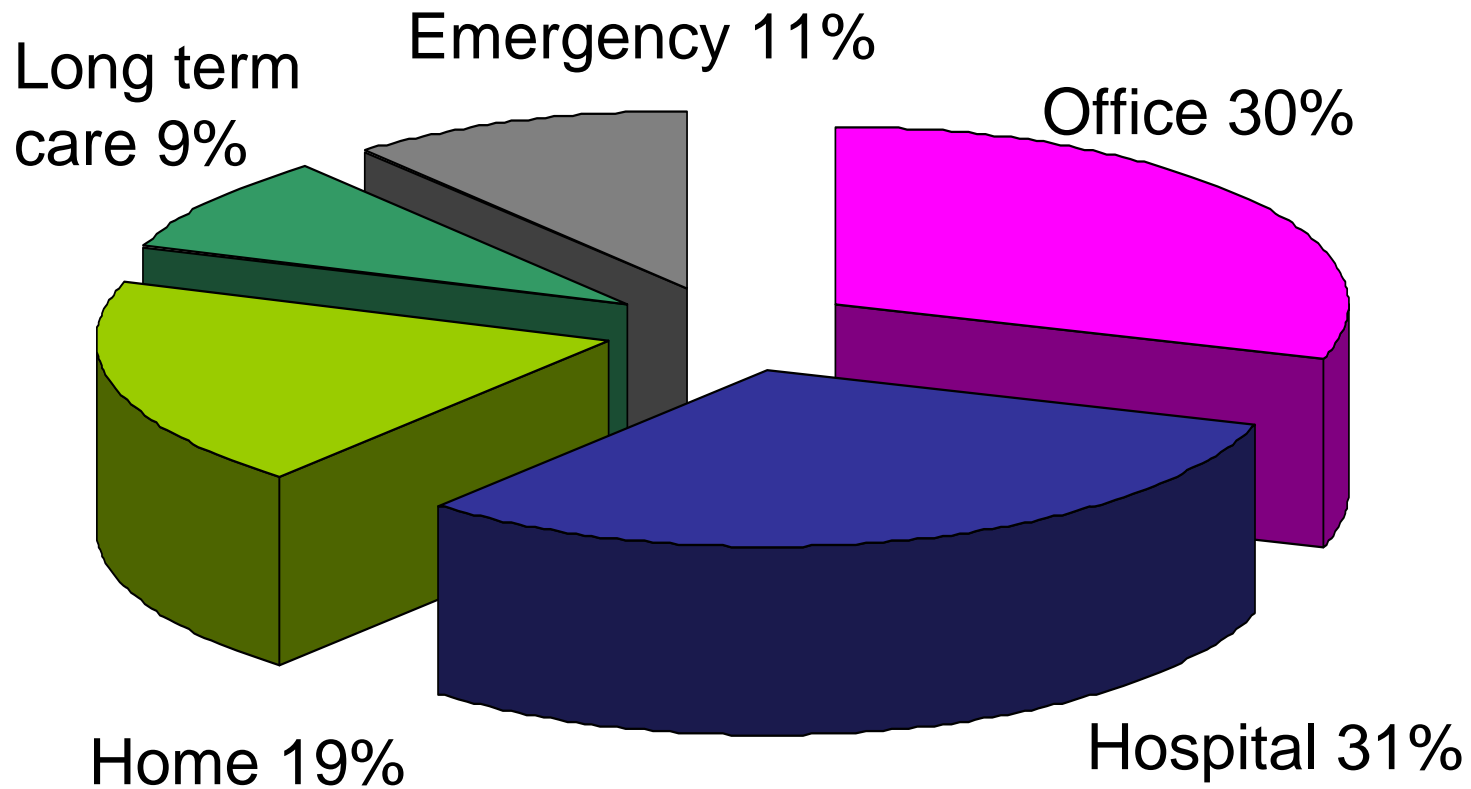
Johnston G, Boyd C, Joseph P, MacIntyre M (2001) Variation in Delivery of Palliative Radiotherapy to Persons Dying of Cancer In Nova Scotia, 1994 to 1998. **Journal of Clinical Oncology** 19(14): 3323-3332

Canadian Institutes for Health Research (CIHR) Operating Grant

Hospital Days in Last Six Months of Life, 1992-1998

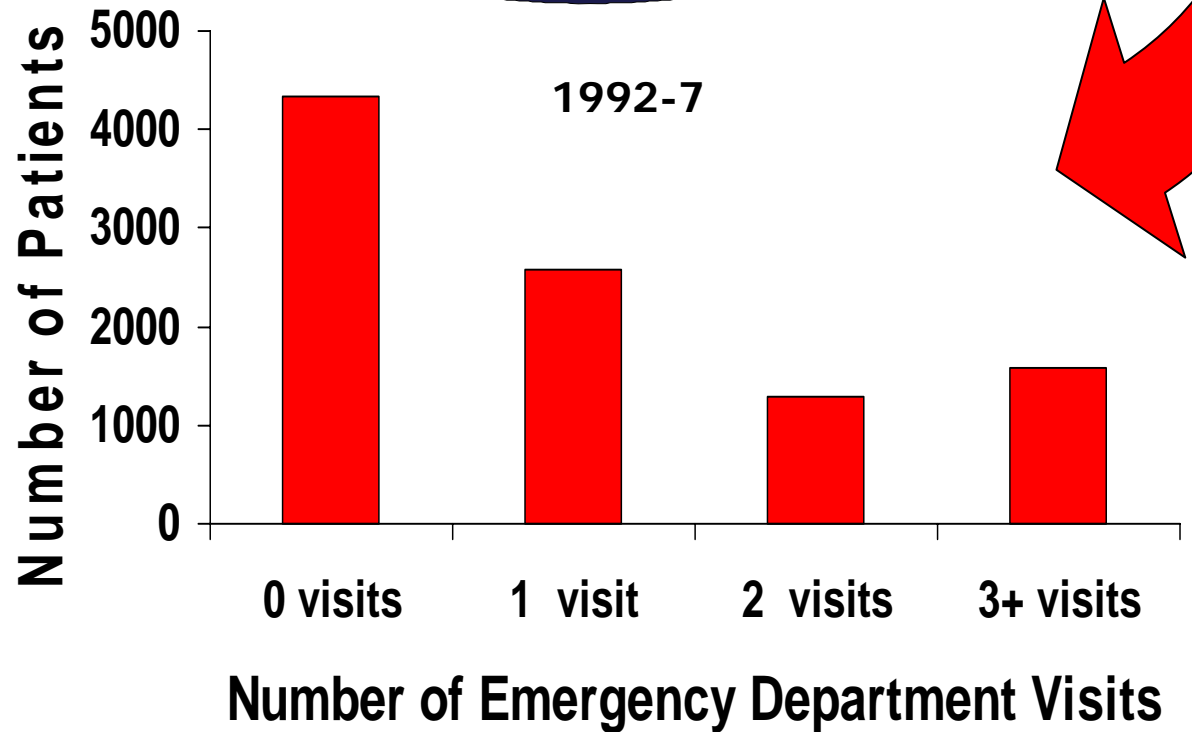
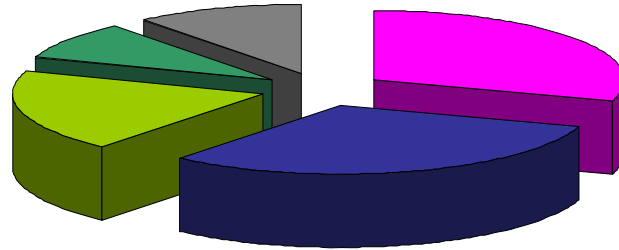


Family Physician Visits in last six months of life, 1995





Emergency Dept Visits 11%



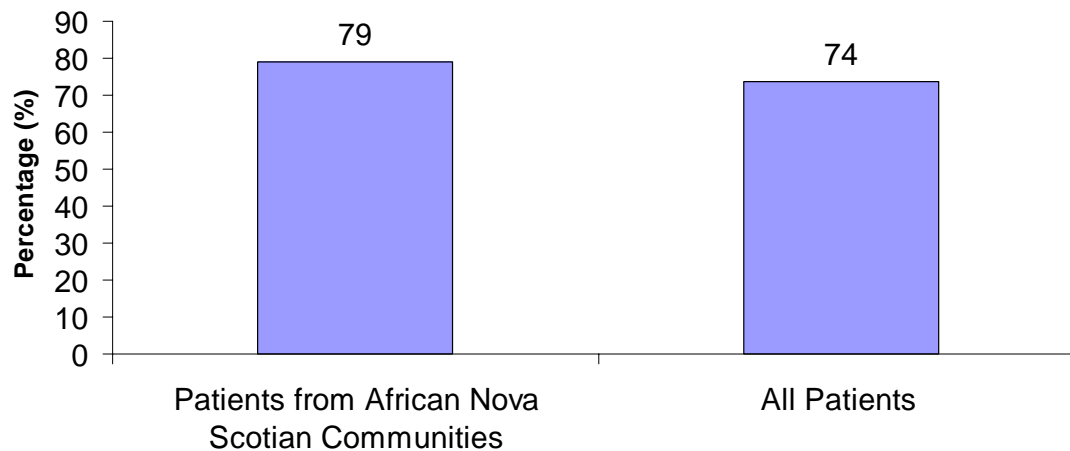
Burge F, Lawson B, Johnston G. (2003) Family Physician Continuity of Care and Emergency Department Use in End-of-Life Cancer Care. **Medical Care** 41(8):992-1001

CIHR Grant New Emerging Team (NET)

British Columbia, Saskatchewan, and Nova Scotia

Cultural indicators

**Referral to Palliative Care Program, Halifax and
Cape Breton 1998-2003**



Postal code at Death > Census Area > Census > SES, Culture



CIHR Interdisciplinary Capacity Enhancement (ICE) Grant for Equity in Access to End of Life Care for Vulnerable Populations

- 1 **Surveillance System and Report of inequity in quality care**
- 2 **Defining vulnerable populations at end of life: Ethical Analysis**
- 3 **Quality pediatric terminal care and vulnerabilities**
- 4 **African Canadians and End-of-Life Care**
- 5 **Attaining a better understanding of gender and age at end of life**
- 6 **Quality end of life cancer care for vulnerable elderly**
- 7 **Community based quality care at end of life with COPD**
- 8 **Canadian Compassionate Care Benefit: Is it working?**

Interactions with other Canadian Colleagues

Study Subjects

Definitions of EOL study subjects vary. Further dialogue on inclusion, uncertain and exclusion criteria is required.

Persons with cancer as primary cause of death

Persons with cancer as another cause of death

Persons who had a cancer diagnosis but not cause of death

Grunfeld 2004

Cancer diagnosis in Cancer Registry prior to death certificate (DC) linkage

Johnston 1998, 2001
Burge 2002, 2003

All persons dying of cancer who could benefit by receiving palliative care

DC follow back identified (DCI) new cancer case, eg clinical diagnoses in long term care facilities. Majority >80 years

Persons dying of cancer

Persons with cancer who died of other chronic disease eg Alzheimer's COPD, stroke,

Died of cancer treatment

Gagnon 2005

Death Certificate Only (DCO) case: date of diagnosis is date of death

Quality Care Indicators

Place of Death for women dying of breast cancer, 1998-2002,

E Grunfeld et al, 2006

Indicator	Statistic description	Nova Scotia	Ontario
Place of death	In hospital	63.4%	52.9%

Burge F, Lawson B, Johnston G. (2003) Trends in Place of Death of Cancer Patients. **Canadian Medical Assoc Journal** 168(3):265-270

Predictors of Home Death for Adults Dying of Cancer, Nova Scotia, 1994-2003

DEMOGRAPHIC FACTORS	Odds Ratios (95% Confidence Intervals)	
	Crude	Adjusted
Age (20-44 years)		
45-64	1.0 (0.8-1.2)	1.1 (0.9-1.4)
65-74	1.0 (0.8-1.2)	1.2 (1.0-1.4)
75-84	1.3 (1.1-1.5)	1.5 (1.2-1.8)
85+	2.1 (1.7-2.5)	2.3 (1.9-2.8)
Sex (Male)		
Female	1.4 (1.3-1.4)	1.3 (1.2-1.3)
CLINICAL SITUATION		
Time lived after cancer diagnosis (<61 days)		
61-120	2.0 (1.8-2.3)	2.2 (2.0-2.5)
121+	2.6 (2.4-2.8)	2.6 (2.4-2.9)
Tumor group (Lung)		
Breast	1.9 (1.7-2.1)	1.2 (1.0-1.3)
Colorectal	1.6 (1.4-1.7)	1.2 (1.1-1.3)
Prostate	1.6 (1.4-1.8)	1.1 (1.0-1.3)
Other	1.2 (1.1-1.3)	1.0 (0.9-1.1)

Predictors of Home Death for Adults Dying of Cancer, Nova Scotia, 1994-2003

COMMUNITY OF RESIDENCE		
	Odds Ratios (95% Confidence Intervals)	
Region (Halifax County)	Crude	Adjusted
Cape Breton County	0.6 (0.6-0.7)	0.7 (0.6-0.7)
All other counties	0.7 (0.6-0.7)	0.7 (0.7-0.8)
Immigrant (No)		
Yes	1.5 (1.3-1.6)	1.2 (1.1-1.3)
Median Income (\$0-25,499)		
25,500-31,999	0.9 (0.8-1.0)	1.0 (0.9-1.1)
32,000-37,499	0.9 (0.8-1.0)	1.0 (0.9-1.1)
37,500-45,999	0.9 (0.8-1.0)	1.0 (0.9-1.1)
46,000+	1.2 (1.1-1.3)	1.2 (1.1-1.3)
HEALTH SERVICES		
Nursing Home Resident ¹ (No)		
Yes	22.8 (18.1-28.7)	24.0 (18.6-30.9)
Palliative Radiation (No)		
Yes	0.9 (0.8-0.9)	0.9 (0.8-0.9)
Medical Oncology Consultation (No)		
Yes	0.8 (0.8-0.9)	0.9 (0.8-1.0)



Research with other Canadian Colleagues

Costing Palliative Care
in Five Canadian Cities,

S Dumont et al

Investigating Bias in Study Sample Selection,

Compare Study Decedents to

Persons dying of cancer in same time period



Products

Assess Palliative Care Policy and Program

Surveillance Report Card

Research Program

Increased Access to Quality End of life Care



Network for End of Life Studies

Questions?