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Comprehensive hospice palliative care delivery and impact on end-of-life care, and family satisfaction with care in Sudbury, Ontario 2012-2015: A propensity score matched retrospective observational study using administrative data

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SITE DIRECTOR, ICES NORTH



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ICES is a not-for-profit research institute encompassing a community of research, data and clinical experts, and a secure and accessible array of Ontario's health-related data.

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Our mission is research excellence resulting in trusted evidence that makes policy better, health care stronger and people healthier.

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Our vision is to be a world-leading research institute where data and discovery improve health and health care.

ICES VALUES

- **Excellence** — demonstrated by the quality, innovation and rigour of our work
- **Integrity** — expressed through independence, transparency and impartiality
- **Relevance** — by providing high-value, timely results that are responsive to health priorities
- **Collaboration** — through effective partnerships, accessible data and a spirit of openness
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International research collaboration publishes guidelines in The Lancet on the use of Indigenous health data

An international team of researchers led by ICES have published governance guidelines in The Lancet for the use of Indigenous health data.

Types of ICES data

ICES holds several kinds of data in the following categories:

1. HEALTH SERVICES ADMINISTRATIVE DATA

- Physician billings
- Prescription drug claims for those 65 and older
- Inpatient hospital discharges
- Emergency and ambulatory care visits
- Home care and rehabilitation claims
- Long-term care visits

2. PEOPLE AND GEOGRAPHY

- Population estimates
- Canada census profiles
- Death records
- All Ontarians eligible for health care benefits

3. SPECIAL COLLECTIONS

- Registries (cancer, stroke, cardiac care)
- First Nations and Métis
- Developmental disabilities
- Federal Immigration Information

4. DERIVED CONDITIONS

- Diabetes
- Hypertension
- Chronic obstructive pulmonary disease (COPD)
- Asthma
- Acute myocardial infarction
- Congestive heart failure
- Inflammatory bowel disease

5. SURVEY DATA

- Health Surveys

6. CLINICAL DATA

- Patient information collected with consent in primary clinical studies
- Supplementary clinical data from individual hospitals and other institutions

7. CHART ABSTRACTION DATA

- Information on processes and quality of care collected directly from patients' charts

Limitations:

- 1) Not designed with research in mind but routinely collected information
- 2) Limited clinical information, no test results, proxy measures often used
- 3) Data lag
- 4) Data somewhat remuneration dependent



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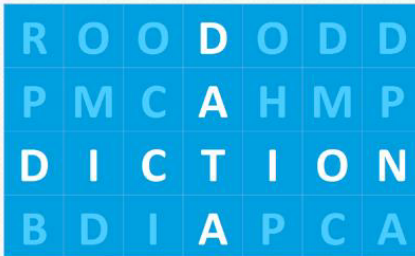
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ICES Data Dictionary

Key to the knowledge produced at ICES is our ability to anonymous health information on an individual patient basis, using unique ICES privacy and confidentiality of health information. ICES data can be in combinations of patient identifiers, physician identifiers, dates, and s allows researchers to obtain a more comprehensive view of specific could be achieved with unlinked data.

For a list of the ICES Data Repository datasets, including detailed d variables and their values, access the [ICES Data Dictionary](#).

				CCC Assessments from December 2006 Home Care Assessments from March 2010 LTC Assessments from August 2005	
ICES-derived Cohorts	Yes	HYPER	Ontario Hypertension dataset	Diagnosed cases 1988-Apr 2016 (Last update: Apr 11, 2017)	Annual
Facilities	No	INST	Information about Ontario health care institutions funded by the Ministry of Health and Long-Term Care (MOHLTC) Including: ACUTE_BEDS, AMININST, MNS, INSTNUM, HOSP_DB	ACUTE_BEDS upto Fiscal year 2015/16 HOSP_DB Up to March 2011; AMININST Up to Fiscal year 2014/15; INSTNUM up to Jul 2016; MNS up to Fiscal Year 2015/16; (Last update date of INSTNUM: Feb 28, 2017 Last update date of MNS: Nov 22, 2016 Last update date of AMININST: May 25, 2016)	Annual
Care Providers	No	IPDB	ICES Physician Database (annual demographics, specialization and workload)	1992 - 2013 (Last Updated Date: Sep 14, 2015)	Annual
Coding & Geography	No	LHIN	Lookup tables for LHIN (Local Health Integration Network) Including: DALHIN, HOSPDALHIN, LHIN_INFO, PC_SUBLHIN, RC_LHIN	March 2009	Varies
Health Services	Yes	LOC	Levels of Care Classification System (for Long-Term Care)	1997 to 2006	No Update
Social	No	MCSS	Ministry of Community and Social Services	The range of main data set is up to fiscal 2009/10. (Last updated: Dec 1st, 2016)	TBA
Financial	No	MIS	Management Information System (Financial and statistical data for the entire hospital sector)	1994/95 - 2012/13	Annual
ICES-derived Cohorts	Yes	MOMBABY	Ontar		
Health Services	Yes	NACRS	Natio		
Health Services	Yes	NACRSQ	Quar		
Acquired Cohorts / Registries	Yes	NDFP	New		
Surveys	No	NLSCY	Natio		
Health Services	Yes	NMS	Narco		
Surveys	Yes	NPHS	Natio		
Health Services	Yes	NRS	Natio		
Acquired Cohorts / Registries	Yes	OBSP	Ontar		
ICES-derived Cohorts	Yes	OCCC	Ontar		

Library: NACRS



Search



The NACRS library contains 6 sets of data, Please select from the following.

ALL DATASETS IN THE LIBRARY

a. NACRSyyyy: National Ambulatory Care Reporting System

CEDISCODE

DX10CODE1FREQ

DX10CODEANYFREQ

FIX_TRANS

NACRS Key

ICES CORE Data Repository: Coded and Linkable



Provider/ Facilities

Physicians
Hospitals
Complex care
Long-term
care homes
Home care



Real-time

Health
Outcomes for
Better
Information
Care (nursing
home)
Implantable
Cardiac
Defibrillators



Health Service Encounters

Physician
claims
Hospital
discharge
abstracts
Emergency
visits
Ontario Drug
Benefit claims
Narcotics
Monitoring
System
Home care
Rehab
Long-term care



People & Geography

*People in
Ontario eligible
for health care
since 1985*

*Unique
individual
ICES Key
Number (IKN)
used for linking
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sets*

Demographics

Deaths

Census



Special Collections*

Disease
registries (ex.
cancer, stroke,
cardiac,
perinatal)

HIV clinics

Immigration

First Nation

Métis

Social
Assistance

Disabilities

Early
Development
Instrument

* Special
governance



Derived Chronic Conditions

*Using routine
ICES data*

Diabetes

Respiratory
problems (ex.
Asthma, chronic
obstructive
pulmonary
disease)

Cardiac
problems (ex.
heart attacks,
hypertension)

Schizophrenia

Many others



Project Specific Research Data

Linked
data set



Comprehensive hospice palliative care delivery and impact on end-of-life care, and family satisfaction with care in Sudbury, Ontario 2012-2015: A propensity score matched retrospective observational study using administrative data

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Barbara Ballantyne, Palliative Symptom Management Clinic

Stacey Santi, Epidemiology HSNRI

Peggy Meigs, Epidemiology HSNRI

Craig Earle, Canadian Partnership Against Cancer

Mark Hartman, HSN/HSNRI

Introduction

For cancer patients facing a terminal illness, a hospice palliative care (HPC) approach is an important component of quality care and can offer many benefits to patients and their families

- Pain and symptom management
- Coordination of care
- Improved quality of life and family caregiver satisfaction

There may also be substantial benefits to the health system that may include decreased use of potentially aggressive end-of-life care, that is often not the wish of patients, and is costly to the health system

The Symptom Management Program (SMP) at the Northeast Cancer Centre of Health Sciences North is an ambulatory program that uses a HPC approach for cancer patients with terminal disease.

Purpose

- **Determine the associations between delivery of comprehensive HPC and the use of potentially aggressive end-of-life care in the last month of life, and place of death, when compared to a matched cohort of palliative patients who reside within the Greater Sudbury and District;**
- **Assess family caregiver satisfaction with advanced cancer care delivered through the SMP**

Methods

Design and Setting

Retrospective study of palliative care decedents enrolled in the Symptom Management Program (SMP)

The SMP

- Ambulatory program that uses an HPC approach for cancer patients with terminal disease 100-120 active patients per year
- Receives about 350 referrals per year
- Majority of people who attend reside in Greater Sudbury or District
- Began operation in 2011

Data Sources

- SMP cohort defined from medical records at the North East Regional Cancer Program of HSN (2012-2015)
- Data sharing agreement allowed us to share the roster with ICES
- Data linkages with administrative data allowed us to define a number of study outcomes, and as the source for a matched control series
- RPDB, OCR, OHIP, CIHI NACRS, DAD
- Potential controls were defined from group of decedent residents of same area, diagnosed with cancer, deceased, had lived 30 days from diagnoses to death, who died within 2012-2015, were not identified as SMP

ICES CORE Data Repository: Coded and Linkable



Provider/ Facilities

Physicians
Hospitals
Complex care
Long-term
care homes
Home care



Real-time

Health
Outcomes for
Better
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Defibrillators



Health Service Encounters

Physician
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Cardiac
problems (ex.
heart attacks,
hypertension)

Schizophrenia

Many others



*Project
Specific
Research
Data*

Linked
data set

FAMCARE Scale-Measuring Satisfaction with Care

- **The FAMCARE Scale is a tool used to measure family satisfaction with advanced cancer care. It measures different areas of care such as availability of care, physical patient care, psychosocial care, and information giving. The original scale is a “20-item Likert-type scale measuring the degree to which family members are content with the health care provider behaviours directed toward to patient and themselves” (Kristjanson, 1993, p. 696).**
- **The FAMCARE Scale can be given to family members while a patient is receiving palliative care or at some point after a patient’s death.**
- **The FAMCARE Scale is a validated instrument and it is used in such places as North America, Australia, Europe, and Canada.**

Statistical Analyses

Patient characteristics between treatment group (SMP) and control group (Non-SMP) were assessed using standardized differences

- Unadjusted and propensity score-matched analyses defined proportions, used to calculate absolute risk reduction (ARR), number needed to treat (NNT) and relative risk (RR)
 - Logistic regression used to define propensity scores with treatment as outcome and all covariates as independent measures; treatment group was matched to controls (greedy matching) using a caliper width (0.05) times the standard deviation of the logit propensity scores
 - Standardized differences were calculated before and after matching
 - Paired analyses to assess
- For FAMCARE questionnaire, scored following recommendations of the author

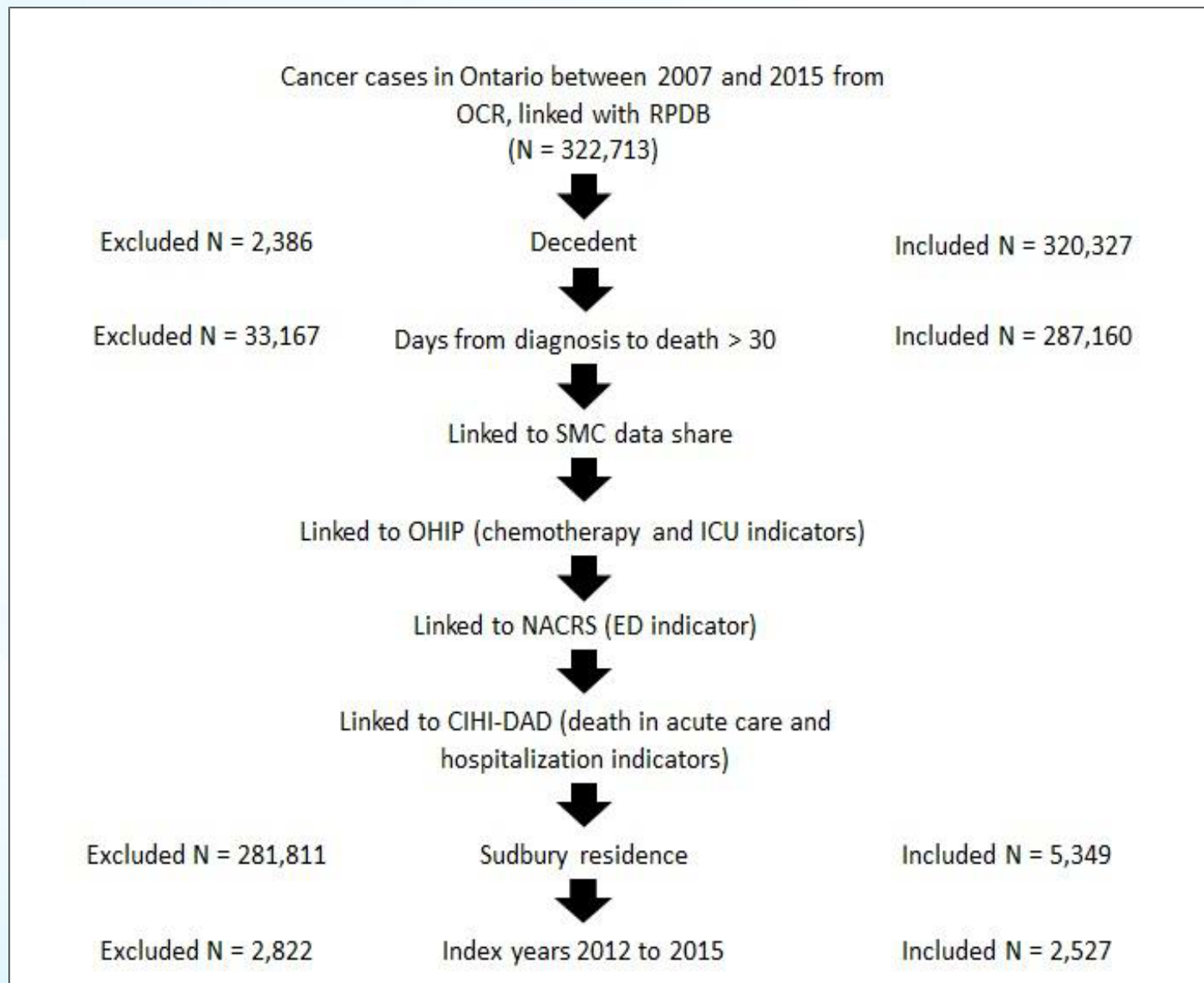


Fig. 1. Flow chart outlining data build including linkages

Results

Table 1. Frequencies, descriptive statistics, and standardized differences (d) of each covariate before and after propensity score matching in palliative patients who received hospice palliative care from the SMP and those who did not.

Covariate	Before Matching			After Matching		
	Non-SMP n = 1,613	SMP n = 914	d	Non-SMP n = 754	SMP n = 754	d
Age Group – n (%)			0.58			0.08
< 55	68 (4.22)	101 (11.05)		58 (7.69)	69 (9.15)	
55-64	180 (11.16)	204 (22.32)		131 (17.37)	145 (19.23)	
65-74	356 (22.07)	283 (30.96)		234 (31.03)	234 (31.03)	
75+	1,009 (62.55)	326 (35.67)		331 (43.90)	306 (40.58)	
Sex – n (%)			0.05			0.00
Male	926 (57.41)	504 (55.14)		431 (57.16)	431 (57.16)	
Female	687 (42.59)	410 (44.86)		323 (42.84)	323 (42.84)	
Charlson Index – mean ±SD	3.81 ±2.88	5.23 ±2.82	0.51	4.92 ±2.90	4.91 ±2.83	0.01
Duration of Disease – mean ±SD	6.79 ±6.35	3.45 ±4.39	0.55	3.48 ±4.23	3.79 ±4.64	0.07

Results

Table 1 (con't). Frequencies, descriptive statistics, and standardized differences (d) of each covariate before and after propensity score matching in palliative patients who received hospice palliative care from the SMP and those who did not.

Covariate	Before Matching			After Matching		
	Non-SMP n = 1,613	SMP n = 914	d	Non-SMP n = 754	SMP n = 754	d
Cancer Type – n (%)			0.44			0.07
Breast	142 (8.80)	59 (6.46)		49 (6.50)	48 (6.37)	
Lung	225 (13.95)	264 (28.88)		170 (22.55)	190 (25.20)	
Colorectal	232 (14.38)	96 (10.50)		87 (11.54)	88 (11.67)	
Prostate	253 (15.69)	67 (7.33)		64 (8.49)	65 (8.62)	
Other	761 (47.18)	428 (46.83)		384 (50.93)	363 (48.14)	
Rural – n (%)			0.18			0.01
No	1,397 (86.61)	842 (92.12)		687 (91.11)	688 (91.25)	
Yes	216 (13.39)	72 (7.88)		67 (8.89)	66 (8.75)	
Income Quintile – n (%)			0.14			0.06
1 (lowest)	443 (27.46)	208 (22.76)		165 (21.88)	185 (24.54)	
2	324 (20.09)	188 (20.57)		163 (21.62)	159 (21.09)	
3	269 (16.68)	185 (20.24)		149 (19.76)	143 (18.97)	
4	327 (20.27)	175 (19.15)		147 (19.50)	140 (18.57)	
5	250 (15.50)	158 (17.29)		130 (17.24)	127 (16.84)	
Index Year – n (%)			0.15			0.02
2012	407 (25.23)	190 (20.79)		166 (22.02)	165 (21.88)	
2013	436 (27.03)	232 (25.38)		210 (27.85)	203 (26.92)	
2014	397 (24.61)	228 (24.95)		183 (24.27)	188 (24.93)	
2015	373 (23.12)	264 (28.88)		195 (25.86)	198 (26.26)	

Results

Table 2. Study outcomes of the use of aggressive end-of-life care in patients who participated in SMP and those with a palliative designation but did not receive HPC.

Outcome	p*	SMP %	Non-SMP %	ARR % (95% CI)	NNT (95% CI)	RR (95% CI)
Hospitalization	0.04	4.77	7.56	2.79 (2.76-2.82)	35.84 (35.45-36.25)	0.63 (0.42-0.95)
Emergency Department	0.03	9.42	13.13	3.71 (3.66-3.76)	26.95 (26.57-27.35)	0.72 (0.53-0.97)
Chemotherapy	0.20	1.46	2.52	-	-	-
Intensive Care Unit	<0.001	1.06	12.20	11.14 (11.11-11.17)	8.98 (8.95-9.00)	0.09 (0.04-0.18)
Any AEoLC	<0.001	12.47	25.20	12.73 (12.65-12.81)	7.86 (7.81-7.91)	0.50 (0.39-0.62)
Death in Acute Care	<0.001	24.14	44.03	19.89 (19.78-20.00)	5.03 (5.00-5.06)	0.55 (0.47-0.64)

Results

Table 3. Descriptive statistics and results for FAMCARE scales completed by family members of patients who received hospice palliative care treatment from SMP (n=96).

Scale (#items/score max)	Overall mean ±SD (n = 96)	Aggressive End-of-Life Care (Any) mean ±SD		p*	Death in Acute Care mean ±SD		p*
		No (n = 86)	Yes (n = 10)		No (n = 68)	Yes (n = 28)	
Total (20/100 max)	85.72 ±11.11	86.50 ±10.93	79.00 ±10.94	0.03	85.22 ±12.09	86.93 ±8.32	0.80
Information Giving (5/25 max)	21.03 ±3.39	21.26 ±3.41	19.10 ±2.60	0.02	20.88 ±3.70	21.39 ±2.50	0.95
Physical Patient Care (7/35)	29.98 ±3.88	30.17 ±3.84	28.30 ±3.97	0.11	29.75 ±4.18	30.54 ±3.01	0.60
Psychosocial Care (4/20)	17.24 ±2.43	17.41 ±2.41	15.80 ±2.15	0.04	17.25 ±2.59	17.21 ±2.03	0.69
Availability of Care (4/20)	17.47 ±2.53	17.66 ±2.40	15.80 ±3.12	0.02	17.34 ±2.80	17.79 ±1.75	0.80

Interpretation

- **3 Key Findings:**

1. Enrolment in the SMP was protective for most measures of potentially aggressive end-of-life care for residents in Greater Sudbury and District

- Risk reductions in ICU admissions
- PC most common reasons for hospital admissions
- 43% higher costs for those managed aggressively

2. Provision of HPC was protective for death in the acute care setting

- While admission to acute care hospital could be appropriate because of disease progression, optimal treatment, or caregiver respite, overuse may signal potential gap in palliative services

3. Family caregiver assessed satisfaction with care appeared high

- Difference in assessed satisfaction with aggressive EOL, not with place of death

Limitations of the study:

- 1. Some variables were not available for analysis**
- 2. System level measures—appropriateness or quality**
- 3. HPC in controls**
- 4. FAMCARE generalizability**

Funding Statement/ICES Disclaimer

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