Infant, Child and Youth Mortality and End of Life Care in Nova Scotia

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Introduction

For children and youth, the transition to the end of life can come tragically early. Equitable, quality end of life care for terminally ill children and their families is needed during this difficult period. Little is known about children and youth that may benefit from palliative care services in Nova Scotia.

Objective

To identify extant sources of registration, demographic and clinical information on pediatric and youth mortality (age 0-24 years) in Nova Scotia between 1997 and 2007.

Methods

Three approaches to identify data:

- Physicians and researchers working in areas relevant to pediatric and youth deaths were queried
- Provincial and national resources for information on child and youth death in the province were assessed
- Six pediatric oncology charts were purposively sampled from the Pediatric Oncology/Hematology database of the IWK Health Centre and reviewed to assess the availability and utility of information on the end-of-life period (6 weeks prior to death)

Context

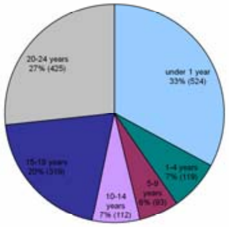
- 1592 deaths in 0-24 age group between 1994 and 2004 (2% of annual deaths in Nova Scotia); 524 were infant deaths with the largest proportion under 1 day old
- 63% of deaths occurred in males, greatest discrepancy in oldest age groups
- mortality rate decreased over time period

Death rate per 1000 population by sex, 0-24 years

Sex	1996	1997	1998	1999	2000	2001	2002	2003	2004
Males	0.63	0.58	0.67	0.54	0.62	0.53	0.51	0.59	0.56
Females	0.43	0.38	0.41	0.31	0.34	0.31	0.30	0.34	0.35
Both	0.53	0.48	0.54	0.42	0.48	0.42	0.41	0.47	0.45

Source: CANSIM, Statistics Canada

Deaths by age, 1994-2004 (n=1592)



Deaths by age and sex, 1994-2004

Age in years	Male	Female	Male:Female
< 1	295	229	1.29
1-14	186	138	1.34
15-24	524	220	2.38
Total	1005	587	1.71

Source: CANSIM, Statistics Canada

Death rate per 1000 population by age as a percentage of 1994 rate

Age in years	Sex	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
< 1	**M**	100	83	87	70	60	78	83	97	90	121	87
	F	100	78	97	76	93	52	81	88	45	62	62
1-4	**M**	100	67	100	67	100	33	133	67	100	133	100
	F	100	33	33	67	50	17	33	17	33	33	50
5-9	**M**	100	33	133	67	67	67	67	33	67	0	33
	F	100	50	50	50	100	50	50	0	100	50	50
10-14	**M**	100	67	67	67	100	33	33	33	67	67	33
	F	100	200	100	0	200	100	100	0	200	100	200
15-19	**M**	100	100	83	133	133	83	83	100	67	100	117
	F	100	300	300	500	200	400	300	400	400	300	300
20-24	**M**	100	83	67	67	92	75	92	58	50	50	67
	F	100	75	125	75	100	100	100	50	50	100	75

Source: CANSIM, Statistics Canada

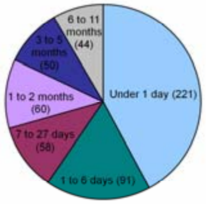
Context (cont'd)

Infant deaths by age over time

Age Group	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
under 1 day	27	21	24	17	13	14	22	30	15	21	17
1-27 days	18	2	13	17	19	12	9	8	8	14	11
1-5 months	14	8	18	8	11	8	10	11	9	6	7
6-11 months	8	3	4	2	1	4	4	1	4	8	5
Total	67	52	59	44	44	38	45	50	36	49	40

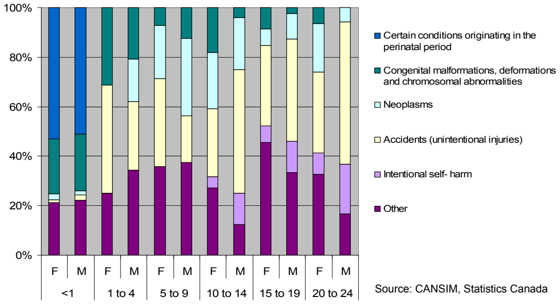
Source: CANSIM, Statistics Canada

Infant deaths by age group, 1994-2004 (n=524)



Source: CANSIM, Statistics Canada

Deaths by age in years, sex and cause, 2000-2004



Source: CANSIM, Statistics Canada

Information available from clinical and administrative databases

Extant Databases	Dates	Deaths	Variables	Access
Nova Scotia Cancer Registry	1969-current	<10 deaths/yr	Demographic, insurance, diagnosing and referring hospitals, physicians, pathology reports, treatment, extent of disease at diagnosis, metastases, date and cause of death from Vital Statistics	Research ethics board and Surveillance & Epidemiology Unit, Cancer Care Nova Scotia approval
Pediatric Hematology/ Oncology, IWK	1970s-current	~12 deaths/yr	Patient demographics, history, family members, treatment protocol, long-term follow-up	Data access application and approval
Perinatal Epidemiology Research Unit	1988-current	~50 deaths/ yr	Extensive clinical information	Reproductive Care Program Access Committee approval
Pediatric Palliative Care Service, IWK	1998-current	166 deaths (Jan. 2000 – present)	Clinical, referral, family, and other extensive information on death	Has not been used for research purposes
Cystic Fibrosis Clinic, IWK	1950s-current	Highly variable ~4 -5 deaths/yr	Clinical, treatment and encounter; unique data on medication	Not accessible

Results

Clinical and Administrative Databases

Strengths

- Overall appears to have high level of quality and completeness
- Clinically rich
- Generally electronic; exception is cystic fibrosis clinic
- Patients often followed over long period of time

Challenges

- Generally not used for research purposes; may be limited access
- Often small numbers of individuals
- Point at which care is best transitioned to adult service is unclear

Chart Review

- Extensive information available on those who died of cancer in the IWK Health Centre on:
  - -symptoms
  - -physician consults
  - -therapeutic interventions
  - -end-of-life discussions and decisions
- Information on those who died at home or out-of-province was less complete and reliable
- Medication information difficult to abstract due to lack of standardized recording; General disarray of chart challenging
- Discussions and decisions regarding end-of-life may occur prior to the 6 week interval before death
- Cause of death difficult to determine; no consistent source of information

Key Findings

- Clinical databases typically developed to support clinical care and may be of limited utility for equity of access to end-of-life care research
- Age to transition from pediatric services to adult services is ill-defined
- National and provincial publications and publicly available data are of limited utility for equity of access to end-of-life care research
- Abstraction of information on end-of-life from medical charts is complex and time-consuming
- Information on cause of death in medical charts is varied
- Limiting chart audit period to 6 week interval prior to death did not always capture discussions and key variables regarding end-of-life decisions

Next Step

- Share findings with stakeholders and set priorities for innovative research capacity development related to equity in access to care for vulnerable populations at end of life

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