CHILDREN AND YOUTH DEATHS IN NOVA SCOTIA FROM 1998 TO 2005

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NELS | Network for End of Life Studies
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Introduction

With support from a Canadian Institutes of Health Research (CIHR) Interdisciplinary Capacity Enhancement (ICE) grant (#HOA-80067), the Network for End of Life Studies (NELS) is investigating end of life care for persons dying of chronic diseases with a focus on vulnerable populations. Phase One is an analysis of Nova Scotia Vital Statistics (NSVS) death certificate data. Subsequent phases are planned involving the linkage of NSVS data to administrative data from various sources including disease registries, palliative care program (PCP) databases, the CIHI discharge abstract database, and physician billings.

By virtue of their dependency state and stage of development, children are a vulnerable population. Children with chronic terminal illness are at an increased level of vulnerability and therefore attention needs to be placed on the adequacy of their end of life care. Palliative care for infants, children and youth in Nova Scotia is provided through the Pediatric Palliative Care Service at the IWK Health Centre.

Previous work has involved a literature review to identify the key components of quality perinatal and pediatric end of life care (Widger and Wilkins, 2004). Dooley (2007) examined end of life care data available for the infant, child and youth population in Nova Scotia. Trevor Dummer and Louise Parker have funding from the Nova Scotia Health Research Foundation (NSHRF) to evaluate death registrations in NS and assess the completeness of mortality data.

NELS ICE wishes to build on this work to develop pediatric cancer and non-cancer end of life surveillance reporting. The goal is to monitor outcomes by establishing population based indicators of quality end of life care relevant to infants, children, and youth. A series of reports have been completed by NELS ICE describing persons dying from specific chronic diseases in Nova Scotia in the adult population. This report is unique in comparison to other reports in that it strictly focuses on **children and youth deaths**.

Purpose

The purposes of this report are to:

- share a synthesis of findings from a descriptive analysis of vital statistics data;
- enter into dialogues with persons interested in building research and surveillance to review and improve the end of life care available to children and youth with chronic terminal illness; and,
- begin to identify and examine disparities in health service use at end of life for children and youth, a vulnerable group at risk for reduced access to quality end of life care.

Methods

Study Subjects: The study population is all Nova Scotia residents who died from January 1, 1998 to December 31, 2005 (N = 63,431). These decedents were identified from the Nova Scotia Vital Statistics death certificate database maintained by the Population Health Research Unit (PHRU) at Dalhousie University. Descriptive findings were prepared using data recorded on the provincial death certificates. Among these 63,431 decedents, 724 (1.1%) were under age 20 at the time of death.

Classification of Deaths: The World Health Organization's International Classification of Diseases (ICD) is used to assign a code for each cause of death listed on the death certificate. From 1979 to 1999, causes of death were coded using the ninth revision of ICD (ICD-9). Since January 1, 2000, causes of death have been coded using the tenth revision of ICD (ICD-10).

Underlying Cause of Death: There can be up to 13 causes of death listed on the death certificate. When only one cause of death is recorded, this cause of death is selected as the underlying cause. When more than one cause of death is recorded, the underlying cause is identified using a set of rules developed by the World Health Organization (Statistics Canada, 2005). The underlying cause of death is defined by Statistics Canada (2007) as "(a) the disease or injury which initiated the train of morbid events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury."

Results

Among those under age 20, there are more deaths reported in males than females. The number of children and youth deaths remained fairly constant from 1998 to 2005 (Table 1). The highest numbers of deaths are observed in infants under 1 year of age and adolescents between the ages of 15 and 19 (Table 2).

A mean of 2.4 causes of death are recorded per decedent in those under age 20. Major underlying causes of death in infants, children and youth include external causes of morbidity and mortality (accidents, injuries and poisonings), conditions originating in the perinatal period, and, congenital malformations, deformations and chromosomal abnormalities (Figure 1). A listing of the ICD-9 and ICD-10 codes can be found in the Appendix. There were seven decedents under age 1 who did not have any causes of death recorded on their death certificate.

Table 1: Children and youth deaths (age < 20), by sex and year, 1998-2005.

	1998	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**TOTAL**
Male	64	49	57	55	53	64	56	47	**445**
Female	44	33	37	34	33	32	38	28	**279**
Total	108	82	94	89	86	96	94	75	**724**

Table 2: Children and youth deaths (age < 20), by age and sex, 1998-2005.

Age (years)	**Male**	**Female**	**Total**
< 1	184	136	320
1 – 4	37	24	61
5 – 9	29	24	53
10 – 14	41	29	70
15 – 19	154	66	220

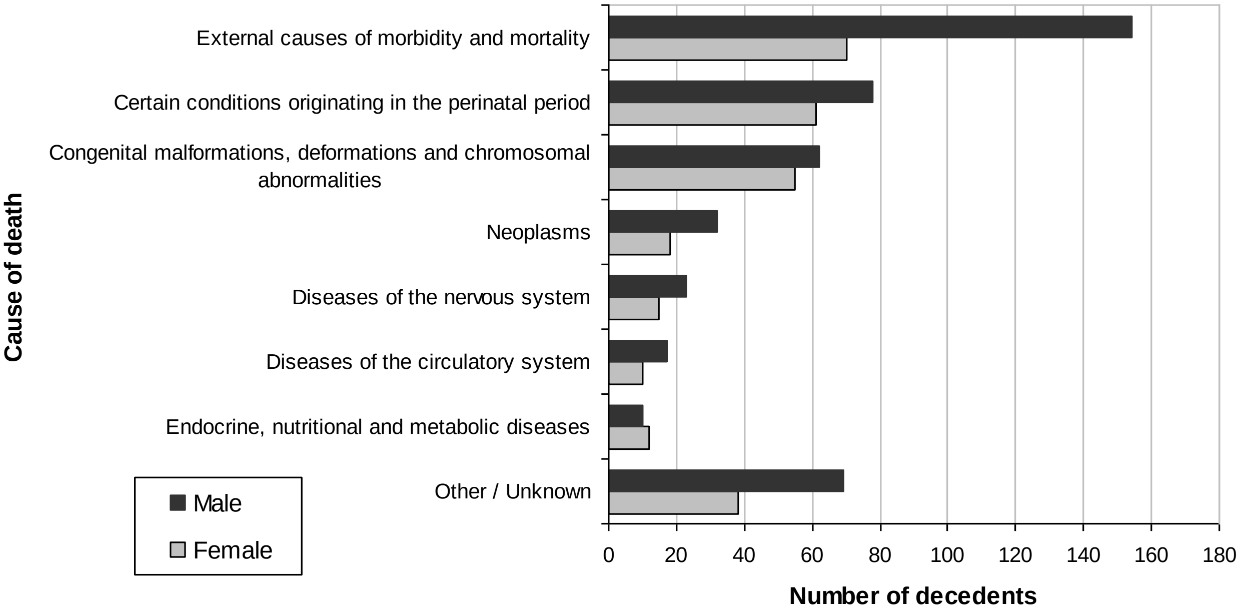

Figure 1: Major underlying causes of death for children and youth (age < 20), 1998-2005 (n = 724).

The vital statistics data obtained from PHRU includes hospital of death information. As age increases, the percentage of hospital deaths tends to decrease with 89% dying in hospital among those under 1 year, and 46% dying in hospital among those aged 15 to 19 (Figure 2). The IWK Health Centre and the former Grace Maternity and IWK hospitals were recorded as the place of death for approximately two-thirds of all infant, children and youth in-hospital deaths.

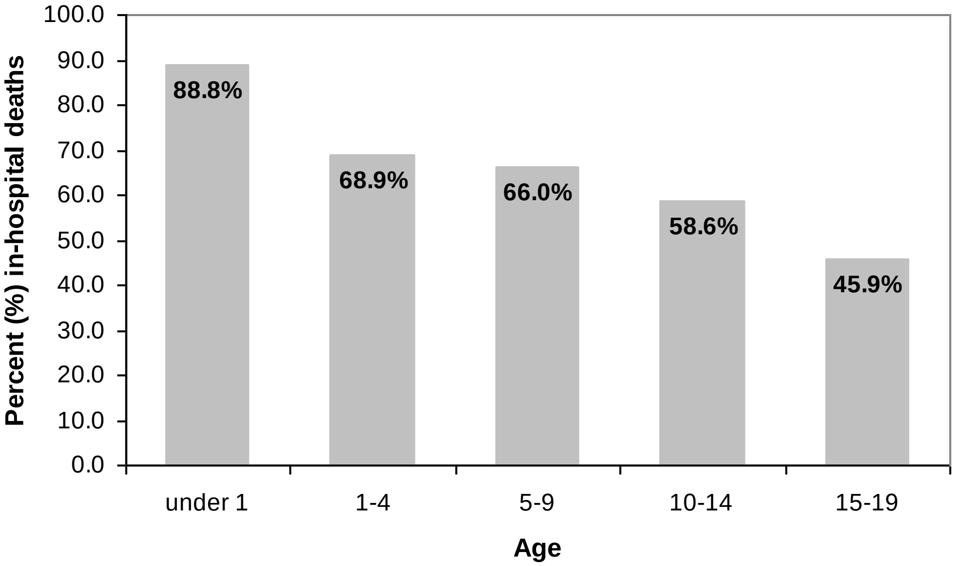

Figure 2: Percentage of in-hospital deaths for children and youth (age < 20), by age group, Nova Scotia, 1998-2005 (n = 724).

Next Steps

A meeting is scheduled for February 24th with members of the IWK Pediatric Palliative Care Service, NELS ICE team members and others interested in pediatric palliative and end of life database development. NELS ICE wishes to learn about the types of data currently being collected at the IWK and what is available in electronic clinical and administrative databases. We would like to do an inventory of the datasets used at the IWK similar to the one already completed for the palliative care programs in the seven district health authorities outside Capital Health and Cape Breton (Kapra, 2008).

The following next steps are planned or are in progress:

1) Multivariate modelling of predictors of dying in hospital (i.e., **further analysis**).

2) Production and sharing of comparable reports starting with cancer, chronic obstructive pulmonary disease, congestive heart failure, renal disease, and deaths among children and youth (i.e., **networking**).

3) Discussion with researchers, graduate students, clinical residents, and others who may be interested in working with NELS ICE to use these data to submit manuscripts for peer review publication, and/or new research grant proposals (i.e., **building research capacity**).

4) Sharing these and other data as they emerge with persons involved in providing and planning palliative and end of life care (i.e., providing data for dialogue to help with **improving care**).

5) Identifying potential inequities in the delivery of end of life care with the aim of improving care for persons who may have inadequate access to quality care (i.e., **overcoming disparities**).

Conclusion

Conclusions cannot be reached from the data reported herein. Many hypotheses can be presented for the findings reported. An adequate literature review has not been carried out as yet to provide a context for these observations. These data are being shared because they have not been previously available, and the goal of NELS ICE is to build research and surveillance capacity to help improve care for vulnerable populations. The provision and discussion of these data provide a forum for this development.

We recognize that the number of children dying each year in Nova Scotia is limited for enabling extensive statistical analysis. Population based demographic, clinical and service information related to all infant, children and youth deaths in Nova Scotia will be examined in extant administrative databases. These data and associated work-in-progress conceptual frameworks will be a template to enable research collaboration with the other Atlantic provinces, across

Canada, and with international colleagues to develop pediatric cancer and non-cancer end of life surveillance reporting, enable new analytic palliative care research, and the design of innovative intervention studies.

The intent of NELS ICE is to provide capacity for interdisciplinary research development to improve care at the end of life for vulnerable populations. The development and dissemination of these data is one aspect of this capacity development. NELS ICE funding is limited. Therefore, other partners and resources are needed to be able to build upon this initial base of progress being made by the NELS ICE team. **You are being provided with this report with the hope that you and your colleagues may find these data of use, and that you will be part of this further building process.**

References

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Appendix

Underlying causes of death for children and youth (age < 20) and their corresponding International Classification of Disease (ICD) codes

Disease	**ICD-9**	**ICD-10**
Neoplasms	140-239	C00-D48
Endocrine, nutritional and metabolic diseases	240-279	E00-E90
Diseases of the nervous system	320-359	G00-G99
Diseases of the circulatory system	390-459	I00-I99
Certain conditions originating in the perinatal period	760-779	P00-P96
Congenital malformations, deformations and chromosomal abnormalities	740-759	Q00-Q99
External causes of morbidity and mortality (accidents, injuries and poisonings)	E800-E999	V01-Y98
Other – includes the following disease groups:		
Certain infectious and parasitic diseases	001-139	A00-B99
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	280-289	D50-D89
Diseases of the respiratory system	460-519	J00-J99
Diseases of the digestive system	520-579	K00-K93
Diseases of the skin and subcutaneous tissue	680-709	L00-L99
Diseases of the musculoskeletal system and connective tissue	710-739	M00-M99
Diseases of the genitourinary system	580-629	N00-N99
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (includes sudden death)	780-799	R00-R99