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*Vulnerable Populations at
End-of-Life: An Ethical Analysis*

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N E L S

Network for End of Life Studies

Interdisciplinary Capacity Enhancement (ICE) For Vulnerable Populations Research Frameworks and Methods for the Study of Population Access to Quality Palliative Care

Vulnerable populations are at risk for unequal opportunity to achieve optimal health as a consequence of inadequate access to resources. End of life is a time of vulnerability for all persons with chronic terminal disease. However, sub-groups within our society can be multiply disadvantaged.

The purpose of the Nova Scotia NELS/ICE is to enhance research to improve access to care for vulnerable populations at end of life.

Our conceptual frameworks include Asada's measurement of inequity¹ (Figure 1) Andersen's access to care² (Figure 2), and Baquet's research process³ (Figure 3). Asada's steps for measuring health inequity are:

- 1) defining when a health distribution becomes inequitable,
- 2) deciding measurement strategies, and
- 3) quantifying health inequity. Empirical analyses are complemented by qualitative studies to provide an understanding of care received by vulnerable populations.

Multivariate quantitative methods using linked administrative databases (Figure 4) identify population based patterns and predictors of quality end of life care provided to persons with chronic terminal disease. In Nova Scotia, 23,730 adults died of cancer from 1994 to 2003; only 27% died at home⁴ which is the preferred place of death for most people. Among the 3000 persons dying of congestive heart failure that we studied, 33% were nursing home residents, a minimally researched population. Figures 5 and 6 show the age distribution of selected causes of death from chronic disease in Nova Scotia.

With a CIHR funded ICE Grant "Reducing Health Disparities and Promoting Equity for Vulnerable Populations: Identification, Explication, and Applications of Research for Vulnerable Populations at End of Life," our NELS will support 1) training of graduate students and post doctoral fellows, 2) pilot projects to develop new research proposals, and 3) further development of surveillance systems to monitor equity in access to end of life care.

We aim to work locally, nationally, and globally to build palliative care and end-of-life research that is translated into knowledge, policies and practices that improve the lives of all at end of life.

REFERENCES:

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2. **Andersen RM.** Revisiting the behavioural model and access to medical care: does it matter? *J Health Soc Behav* 1995;36(March):1-10.
3. **Baquet C, Hammond C, Commiskey M, Brooks S, Mullins D.** Health disparities research - a model for conducting research on cancer disparities: Characterization and reduction. *Journal Assoc Acad Minor Phys* 2002; 13(2):33-40.
4. **Burge F, Lawson B, Johnston G.** Trends in the place of death of cancer patients, 1992-1997. *CMAJ* 2003; 168(3):265-70.

Figure 1: Terminology

Within a population of concern (e.g., country, county), among the unit of analysis (individual or group):

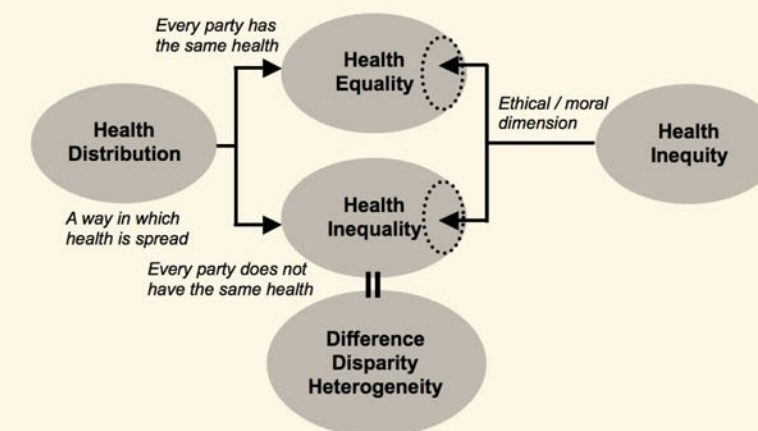


Figure 2: Andersen model of health service use as applied by NELS investigators to quantitative analyses of predictors of care at end of life using population-based linked administrative databases

HEALTH SYSTEM	PREDISPOSING DEMOGRAPHICS	ENABLING RESOURCES	INDICATORS OF NEED	TREATMENT	OUTCOMES
Geographic area • County • Rural/urban • Distance to care	• Age • Sex • Community - Ethnicity/race - Language - Migration - Family structure	• Palliative care • Home care • Nursing home • Family physician continuity • Community - Income - Education - Employed	• Terminal chronic disease • Type of disease and co-morbidity • Time from disease diagnosis to death	• Systemic therapy • Palliation radiation • Surgery • Narcotic analgesics • Intensive care	Quality of life • Home death • Limited time in hospital Quality Care • Low use of emergency department

Figure 3: Research Framework for our Network of End of Life Studies

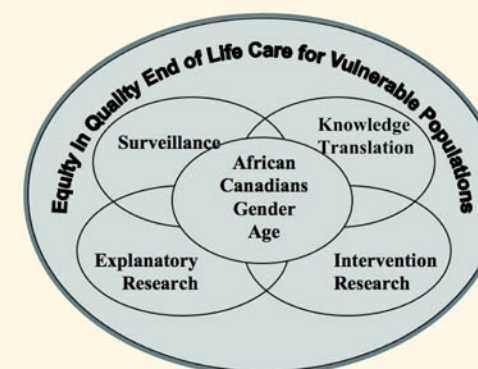


Figure 5: Main chronic disease deaths, Nova Scotia, 2004

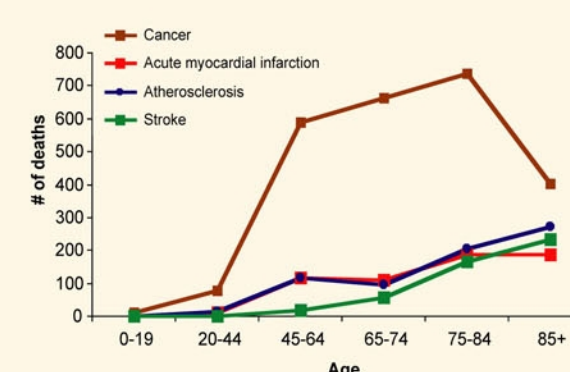


Figure 4: Linked administrative databases

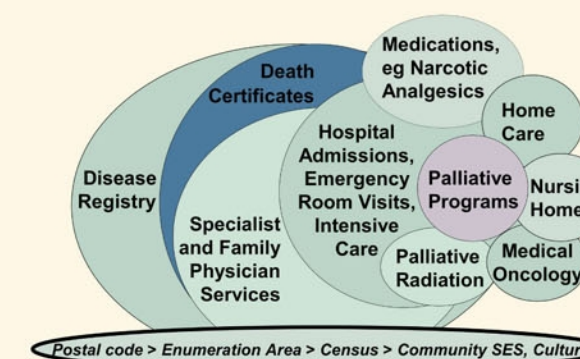


Figure 6: Other chronic disease deaths, Nova Scotia, 2004

