NELS
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, subgroups 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 inequity (Figure 1) Andersen’s access to care (Figure 2), and Baquett’s research process (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 home 4 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: