End of Life Care in Nova Scotia

Surveillance Report

Network for End of Life Studies (NELS)
Interdisciplinary Capacity Enhancement (ICE)
Dalhousie University

Recommended citation:

NELS ICE. (2008) End of Life Care in Nova Scotia Surveillance Report.

Network for End of Life Studies (NELS) Interdisciplinary Capacity Enhancement (ICE),

Dalhousie University, Halifax, Nova Scotia, Canada.

ISBN 978-0-7703-0565-9

"Soft release" versions of this report have been available on this NELS website from September 2007 onward. After a formal stakeholder review process and input in June 2008, the final report was posted on this website in September 2008 and officially released on October 1, 2008. The "Listening to Stakeholders" report from thr June 2008 meeting is also available on the NELS website.

DISCLAIMER

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The Network for End of Life Studies (NELS) Interdisciplinary Capacity Enhancement (ICE) research team acknowledges the valuable contributions of many individuals and organizations who made this report possible. We would like to thank particularly the Canadian Institutes of Health Research (CIHR) for providing the base funding for the initiative (HOA 80067). Other contributing organizations include: the Dalhousie University Faculties of Medicine and Health Professions; Capital District Health Authority, Nova Scotia; Cancer Care Nova Scotia; Nova Scotia Vital Statistics; the IWK Health Centre; and the Palliative Care Secretariat of the Government of Canada. Individual contributors beyond the NELS ICE team members listed below are named in Appendix 1.

The NELS ICE research team worked together to develop the content of this report. For this report to be worthwhile, we would now value the review and use of this work by clinical care providers, decision-makers, advocates for end of life care and vulnerable populations, and researchers.

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EXECUTIVE SUMMARY

The last few months of a person's life are often associated with an increased need for and utilization of health services, resulting in substantial health care costs. Ideally, the focus is on quality of life and supportive care. Public opinion surveys in 2000 and 2003 show that 80% of Nova Scotians believe that it is critically important to have access to palliative and supportive care close to home. Fewer than 20% are completely satisfied with current practice. In a 2007 oncology survey, 26% of patients indicated that they wanted but did not receive information on palliative care. Given an aging population, provision of quality care at end of life is an increasing concern.

The Network for End of Life Studies (NELS) aims to enhance the capacity for end of life research and its application in order to reduce inequities and improve care. The Canadian Institutes for Health Research (CIHR) provided NELS with a five year Interdisciplinary Capacity Enhancement (ICE) grant through which a surveillance system to identify populations that are vulnerable at end of life is beginning to be developed. This work demonstrates the ability to build an end of life care surveillance system that is population-based, grounded in standardized definitions, and attempts to identify inequities. This is the first NELS ICE population-based surveillance report on health system care for those dying of chronic terminal conditions in Nova Scotia.

While all persons are vulnerable at the end of life, some subgroups face additional challenges in accessing appropriate care. The NELS team values equity and therefore endeavours to determine what is just in the context of service needs, disparities, options, and what is viable to publicly finance. End of life care for children and youth is examined, as well as the elderly, urban-rural differences and associations with community of residence. The historic issues facing African Canadians residing in Nova Scotia are featured.

This report translates knowledge emerging from Nova Scotia-based end of life care research into policy relevant language in the context of education and community understanding. It also raises awareness regarding the expected increase in the number of deaths from chronic conditions due to the aging population. This information is intended to assist in making evidence-based decisions with regard to end of life care.

This report provides measures of inequality related to physician, hospital and other care accessed in the last months of life to persons dying of cancer and congestive heart failure. Over the coming years the NELS team proposes to:

- move from measures of inequality to measures of inequity by incorporating considerations of justice;
- move beyond indicators of care received to measures of quality of care;
- extend research to chronic conditions beyond cancer, which to date has been the primary focus of palliative care programs; and,
- enhance our understanding of the roles and services of long-term care facilities, home care, emergency departments, and intensive care, across all ages.

This report outlines what is known and what is not yet known. The recommendations relate to building the surveillance and research infrastructure to provide the evidence needed by decision-makers to develop policies and interventions to improve access and equity in publicly funded quality end of life care.

KEY MESSAGES:

1. In 2004, there were 8166 deaths in Nova Scotia. Fifty-eight percent of these deaths were due to major chronic diseases with a potential need for end of life care: cancer, chronic ischemic heart disease (IHD), stroke, chronic obstructive pulmonary disease (COPD), diabetes mellitus, congestive heart failure (CHF) and renal failure. On average, nearly 13 of the approximate 22 deaths each day in Nova Scotia in 2004 were attributed to these diseases.
2. Nova Scotia has an aging population. In 2001, 14% of the population was 65 years or older. By the year 2020, the percentage of older persons is expected to increase to approximately 21.6% of the population. Correspondingly, the percentage of younger persons, who will be caregivers of the dying elderly, will decline.
3. The use of palliative care programs in Halifax and Sydney for persons dying of cancer is high (70-80%) compared to norms reported elsewhere. Comparative data are unavailable as yet for other regions of Nova Scotia.
4. Older persons appear less likely to receive specialized palliative services at end of life. Urban-rural differences exist. There are associations between care received and average neighbourhood household income and community culture.
5. Historically, most persons referred to palliative care were dying of cancer.
6. Challenges facing individuals dying of diseases other than cancer, including chronic obstructive pulmonary disease (COPD) and congestive heart failure (CHF), need attention.
7. Deaths from COPD are expected to increase rapidly, with Nova Scotia COPD deaths increasing to 770 per year in 2020, up from 447 in 2004.
8. The family physician and long-term care facilities have a more extensive role for persons dying of congestive heart failure, in comparison to cancer.
9. While differences exist among people of African descent in terms of cultural beliefs regarding death and dying, and gender roles in caregiving, there is a general expectation that family members will assume the primary caregiving role for chronic and terminal illness, and that this care will be in the home setting.
10. End of life issues in children require separate attention as their needs differ due to their range of diseases and changing developmental requirements.
11. End of life care research methods pioneered in Nova Scotia continue to expand with numerous new methodological developments including quality care indicators, ecological measures of deprivation, community culture, population-based methods, and database development projects, moving beyond cancer, prospective studies, and measures of equity.
12. There is a lack of consensus on:
    - what is quality care at end of life?
    - what outcome measures indicate a good death experience?
    - what are cost effective options to provide quality care at end of life?
    - how to overcome inequities, i.e., unjustifiable inequalities?

This report includes recommendations to build surveillance and research capacity. Generating new knowledge will help answer both current and future questions. By working with district, provincial, national, and international expertise, NELS ICE researchers intend to help provide further methodological insights and information for public and professional dialogue on health system and service review.

1.1. NETWORK FOR END OF LIFE STUDIES

The Network for End of Life Studies (NELS) is a team of Nova Scotia-based researchers working through collaboration to enhance interdisciplinary research capacity and improving end of life care. In 2006, a group of researchers within NELS received funding from the Canadian Institutes of Health Research (CIHR) through a five-year Interdisciplinary Capacity Enhancement (ICE) grant to help build research capacity through a systematic focus on vulnerable populations. The objectives of NELS ICE are to:

1. Develop a system that will enhance identification and surveillance of populations that are vulnerable at end of life.
2. Design and conduct pilot studies to facilitate the development of full research proposals to examine and address vulnerability and inequity in the provision of quality end of life care.
3. Engage in knowledge translation to inform decision-makers, health professionals and researchers on the provision of end of life care in vulnerable populations.
4. Further build an interdisciplinary team of researchers, trainees, health professionals and community partners.

1.2. PROBLEM

Improving care for those most vulnerable at the end of life requires serious attention in Canada and globally. According to Statistics Canada 237,931 people died in Canada in 2006/2007 (Statistics Canada 2007). This represents approximately 652 persons per day. In 2004, there were nearly 240 deaths each day in Canada due to cancer and chronic ischemic heart disease (Statistics Canada 2004a; Statistics Canada 2004c). Almost another 90 persons died each day from stroke, chronic obstructive pulmonary disease and diabetes mellitus (Statistics Canada 2004d; Statistics Canada 2004b).

Among individuals who are terminally ill with cancer, the majority would prefer to die at home (Burge, Lawson, & Johnston 2003b), but only about 30% in Nova Scotia are able to do so (Burge et al. 2003b). A substantial proportion of deaths are in special hospital units (Heyland et al. 2000), often in medical, surgical, transitional or intensive departments, rather than palliative care beds. This gap between preference and practice is generally attributed to inadequate support for community-based end of life care (Davies and Higginson 2004). The number of deaths from chronic disease will increase in the next decades due to the aging population (Saint-Jacques et al. 2002). Nova Scotia is not adequately prepared to address the inevitable demand for end of life care.

Canadians continue to value their health system and expect ready access to excellent care. However, the “provision of end of life care is characterized by uneven access to services, and disruptive, ineffective care leading to substandard outcomes” (Senate Committee of Canada 1995). A follow-up to the 1995 Senate report found little change (Carstairs 2005). Thus, it is a relevant and urgent task to create an ongoing mechanism to report on how well care is being provided at end of life, and specifically to identify groups who are not receiving adequate levels of quality care.

The research team believes that vulnerability at end of life has two dimensions:

- All persons at end of life are at risk. end of life is associated with substantial physical, emotional, and economic burdens which can increase vulnerability for any individual.
- For some, an additional increase in risk is due to their demographic, social and other attributes, the effects of which are not yet fully understood.

Through the release of this and subsequent surveillance reports, NELS ICE plans to help translate the new knowledge emerging from Nova Scotia-based research into policy relevant language and to enable the exchange of insights into addressing problems with an expanding community that has similar concerns.

1.3. CONTEXT

End of life is often a time of considerable health service utilization, substantial service needs, and major health care costs. During this time, there is a focus on quality of life and community-based supportive care rather than on cure or prolonging survival. To date, there is no consensus about indicators to predict when individuals are likely to die from a chronic disease and the associated need to plan for increasing, appropriate supportive care. Typical timelines used in NELS retrospective and other studies have been six and nine months prior to death (Burge et al. 2003b; Institute of Medicine 2001; Johnston et al. 2001a; Johnston et al. 1998).

Public opinion surveys indicate 80% of Nova Scotians believe it is critical to have access to palliative and supportive care that is close to home. Unfortunately, fewer than 20% are completely satisfied. This represents a considerable gap between perceived need and actual service provision (Cancer Care Nova Scotia 2000; Cancer Care Nova Scotia 2003). In a 2007 oncology survey, 26% of patients indicated that they wanted but did not receive information on palliative care (Cancer Care Nova Scotia 2008).

Advances in end of life care have typically focused on cancer although it is increasingly being recognized that end of life care for other terminal disease also requires attention (Rocker 2005). Needs-based rather than disease-based approaches are preferable. Nova Scotia and Canada are not alone in turning their attention to the provision of care for those dying of chronic conditions. Facing the challenges of providing quality care at end of life is a global concern.

Despite the intensity of care at end of life, little research evidence exists about the extent of disparities or inequities in care, and how best to overcome these in order to improve care provision. Figure 1 outlines the framework for examining and measuring inequity that guides the NELS team's research analyses (Asada 2005). Equal as well as unequal distribution of care among groups or individuals can be forms of inequity if the moral and ethical dimensions of varying needs are not met.

Vulnerable populations have been defined as "those at risk at any particular point in time for unequal opportunity to achieve maximum possible health and quality of life because of differences in intrinsic and

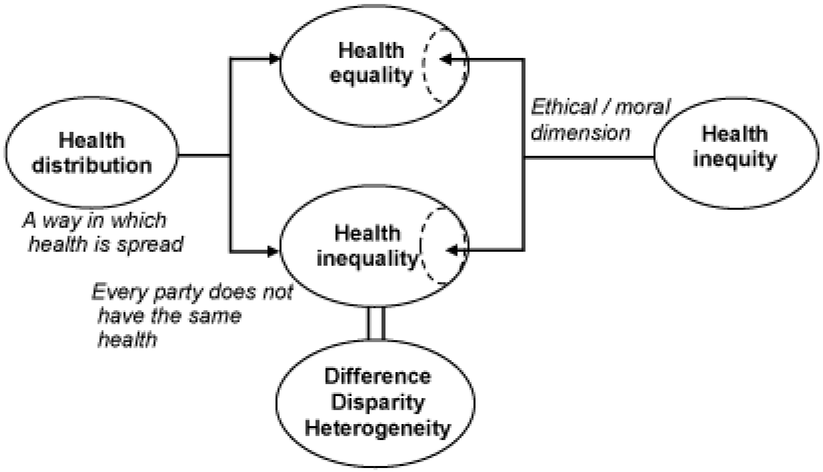

Figure 1: Inequity framework. Source: Asada 2005.

extrinsic resources that are associated with good health" (Danis and Patrick 2002). The substantial physical, psychological, and economic impacts on patients and their families at the end of life (Grunfeld et al. 2004) make them a vulnerable group as the medical and supportive needs of these dying patients and their families are considerable (Canadian Hospice Palliative Care Association 2003a; Rao, Anderson, & Smith 2002). Since all persons must face end of life, everybody becomes vulnerable in this way at some time (Higginson and Koffman 2005; Rao et al. 2002). Therefore, examining vulnerable populations at end of life provides a unique opportunity to recognize "universal vulnerability, the concept of vulnerabilities applies to virtually all persons in the population" (Danis et al. 2002).

While all persons are vulnerable at end of life, some subgroups face multiple disadvantages. Vulnerable subpopulations at end of life are traditionally conceptualized in categories based on gender, age, ethnicity, socio-economic status, and geography (Johnston et al. 2005). Identifying vulnerable populations requires both empirical investigation to identify populations at risk of suffering from poor health and an analysis of the moral claims each of these populations presents (Brock 2002). Vulnerability can be explored in terms of a social dynamic of shared experience linked to the ascription of meaning in people's daily lives as demonstrated by qualitative and naturalistic research approaches. A complex interplay of meanings that represent and shape the individual, and collective experiences at end of life are associated with disparity and inequity (Iwama 2004). Who is most vulnerable and what are their forms of vulnerability? This report provides critical information for identifying vulnerable subpopulations at end of life.

1.4. PURPOSE

The NELS ICE objective is to enhance the capacity for research and its application in order to reduce inequities and improve end of life care. Sustainability of this research is one of the underlying premises and a major surveillance reporting goal. NELS ICE aims to ensure work is both relevant and useful so that it will live on under the mandate of others after the 2011 cessation of ICE funding. The team is working toward this goal by expanding the level of interaction with others in Nova Scotia and beyond.

NELS ICE study activities have been framed based on the four components of Bacquet et al.'s research model (Baquet et al. 2002). Figure 2 illustrates the model's four components: surveillance, explanatory research, intervention or application research, and translation of evidence.

While all four components interconnect, the first and fourth components (surveillance and knowledge translation) have particularly strong cross cutting effects providing the foundation and forum for knowledge synthesis and hypothesis generation, as well as the mobilization of knowledge into practice. This report represents an example of the surveillance and knowledge translation components.

NELS ICE plans are in place to explore a range of potentially vulnerable groups in Nova Scotia beginning with women, children, the elderly, and African Canadians. Other population groups are

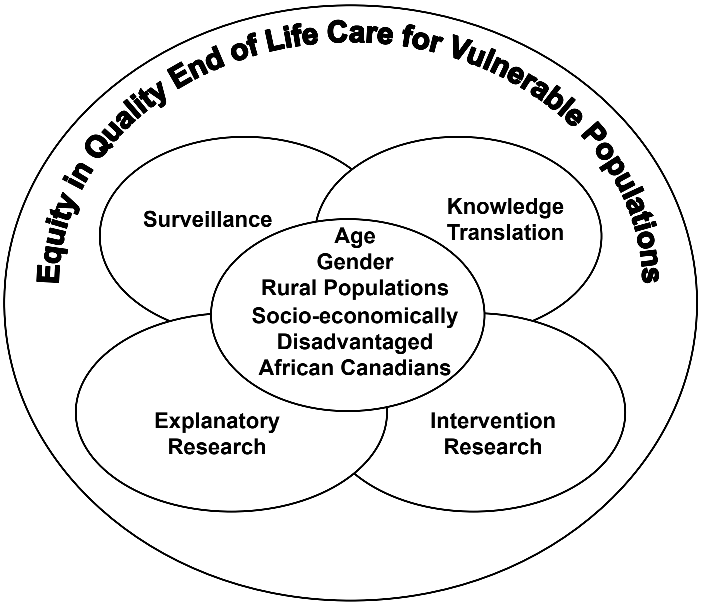

Figure 2: Research framework for the Network for End of Life Studies.
Source: Johnston, Burge, et al. 2007.

also of interest including youth transitioning from children's health services to adult services, men, rural versus urban residents, low socioeconomic status communities, communities with distinct cultural and language factors that influence end of life care needs, and invisible and less visible vulnerable populations including those with disabilities and co-morbidities including conditions such as dementia and deafness. These are early concepts of potentially vulnerable populations. It is anticipated that new concepts and groupings of vulnerable populations will develop as this research evolves.

"Surveillance is the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health" (US Centre for Disease Control 2001). Reducing mortality may be a goal of other types of surveillance reports, but it is not a realistic goal for end of life surveillance since the people of interest have terminal disease. Surveillance data can be used for immediate public health action, program planning and evaluation, and formulating research hypotheses. For example, data from a surveillance system can be used to:

- guide immediate action for cases of public health importance;
- measure the burden of a disease (or other health-related event), including changes in related factors, the identification of populations at high risk, and the identification of new or emerging health concerns;
- monitor trends in the burden of a disease (or other health-related event);
- guide the planning, implementation, and evaluation of programs to prevent and control disease, injury, or adverse exposure;
- evaluate public policy;
- detect changes in health practices and the effects of these changes;
- prioritize the allocation of health resources;
- describe the clinical course of disease; and,
- provide a basis for epidemiologic research (US Centre for Disease Control 2001).

Objectives of NELS ICE within its surveillance component are to define vulnerable populations and to describe the disparities in health services use at end of life. NELS ICE research is focused primarily on Nova Scotia (population 950,000) (Figure 3) but some data and research projects are district-specific due to local issues, e.g., data and service availability. To capitalize on opportunities available for comparative analysis, research studies have commenced with the extramural hospital program in the health area that includes Saint John, New Brunswick.

At present, a population-based surveillance system does not exist with the explicit aim of either identifying vulnerable populations or monitoring inequity in quality end of life care. The objective is to provide a template for consideration in surveillance reports to better understand health care disparities and inequities at end of life among vulnerable populations. This report provides population-based retrospective measures of inequalities in care for cancer and congestive heart failure. Over the coming years, advancements are anticipated by moving from inequality to inequity measures, focusing on quality care, and further extending analyses beyond cancer and from retrospective to prospective studies.

1.5. HOW IS THIS REPORT DIFFERENT?

Numerous documents have been produced locally, nationally, and internationally on palliative and end of life care. Examples of Canadian reports include those of Senator Sharon Carstairs (Carstairs 2000; Carstairs 2005), Canadian Hospice Palliative Care Association (CHPCA) (Canadian Hospice Palliative Care Association 2003a), the Canadian Council on Health Services Accreditation Hospice/Palliative and End of

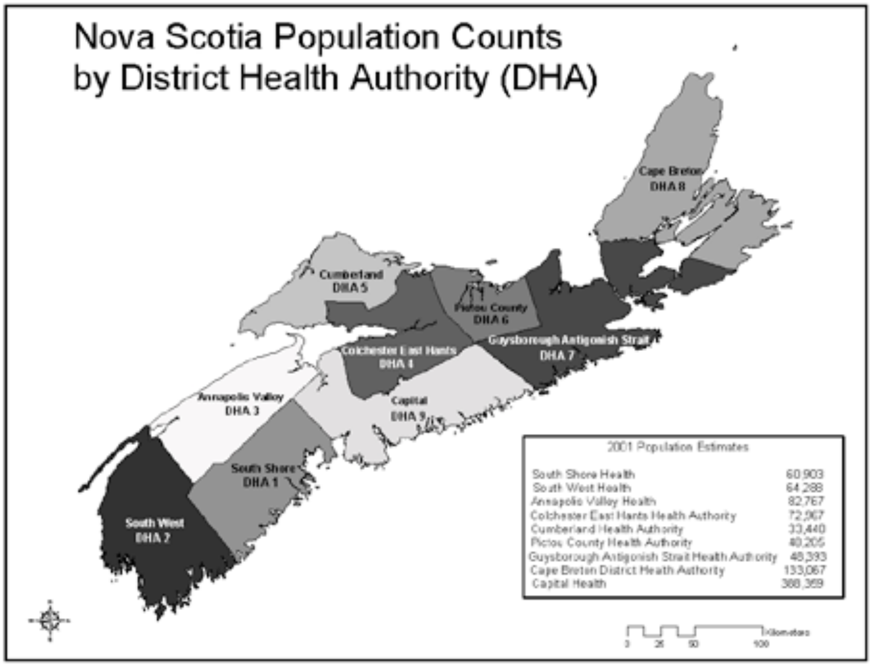

Figure 3: Population counts, by district health authority, Nova Scotia, 2001.
Source: Statistics Canada Table 109-5315.

Life Care Project (Canadian Council on Health Services Accreditation (CCHSA) 2007), the Manitoba Centre for Health Policy Report (Menec et al. 2004) and the Western Canada End of Life Care Project (Canadian Institute for Health Information 2007). The NELS ICE team also values the work that has been carried out internationally including that of the Gold Standards Framework (Thomas 2005) from the United Kingdom, the Project on Death in America (Open Society Institute 1994) and the European Association of Palliative Care's Atlas of Palliative Care in Europe (Centeno et al. 2007). Through advocacy and the delineation of important issues, such work has placed the need for improved end of life care in the spotlight, and provided momentum and direction for positive change in end of life care across the world and in Canada.

NELS ICE work adds to the current body of knowledge by:

- demonstrating population-based end of life surveillance;
- incorporating the development and use of standardized definitions;
- grounding surveillance in the evolution of conceptual frameworks and new research; and,
- helping to identify and address inequities in quality care.

Similarities to the Western Canada End of Life Care Project report exist (Canadian Institute for Health Information 2007), with this report providing an eastern Canadian perspective using comparable and also different health service utilization data. Projections on the burden of dying are presented. Some indicators of quality of care are explored and analyses of potentially vulnerable populations are highlighted, in a context of education and community awareness.

This report does not directly advise on health care and system changes. Rather, the focus is on generating evidence for informed dialogue on appropriate changes to consider.

1.6. CONCEPTUAL FRAMEWORK AND METHODOLOGICAL APPROACH

Over the coming years, NELS ICE surveillance will identify disparities using innovative end of life research methods now under development. Using the expanding NELS team strengths, populations at risk for increased vulnerability and reduced access to quality end of life care will be identified. Population disparities in service utilization at end of life using administrative databases will be described. Measurement of inequity and quality care will occur with attention to primary, oncology, palliative, intensive, and pediatric care for populations at risk of unmet needs. Over time, further investigation of predefined at-risk groups and searches for previously unidentified vulnerable groups will be undertaken.

Health services that will be investigated for inequalities and inequities include homecare, long-term care, family physician care, palliative care, radiation and medical oncology, other specialist physician care, and hospital utilization. Looking beyond these publicly funded, provincially delivered health services is an important as the determinants of quality end of life care include more than the delivery of health care. Inclusion of cost considerations, education and community awareness, and public policy review within and beyond the traditional health sector is proposed, but will be limited to pilot study work given the limits on the ICE funding and mandate. The intent is that ICE pilot and infrastructure building work will prompt and enable new NELS research proposals and funding in the future.

To prepare this inaugural report, literature on indicators of quality care and inequity in end of life care, and systems for monitoring inequity in health care was reviewed. The work-in-progress NELS ICE conceptual framework as shown in Figure 4 (Burge et al. 2007) was developed for framing this report.

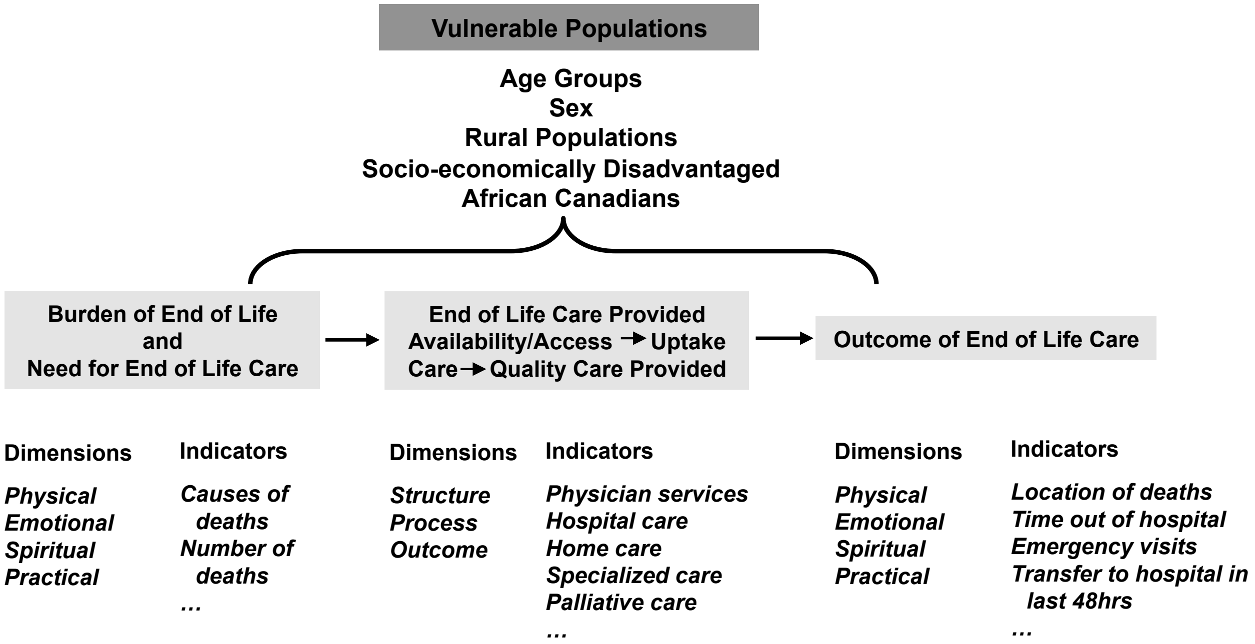

Figure 4: NELS-ICE conceptual framework for measuring health inequity. Source: Burge et al. 2007.

Existing Nova Scotia linked cancer and congestive heart failure end of life data was used to provide examples for this report. An implicit assumption is that useful surveillance measures for planning, program delivery, policy making, and assessment, as well as for building research capacity, will be further developed and sustained by partnerships and/or agencies beyond the ICE team itself which is limited in time and resources. Through dialogue and reflection, this end of life care surveillance work is expected to evolve.

The unique and complementary research strengths of the team are being used, not only to produce this end of life surveillance report, but also to pilot new studies and train a cadre of new researchers in a strong interdisciplinary context. NELS ICE will expand the use of new ecological measures of culture and deprivation, extend the understanding of the role of the long-term care facility and home care, investigate within-hospital service use including the emergency department, intensive care unit, palliative care program and transitional care beds, and use co-morbidity measures in analyses. Over time ethical analysis will be further developed and applied to these surveillance data.

In this report, the data are primarily quantitative. When examining issues of end of life care, much information is qualitative describing in words, or in other forms such as art, the real experiences of individuals with health care systems. Encompassing the various non-numerical ways of knowing is highly valued by the NELS ICE team but not the focus of this report.

Appendix 2 provides an overview of the methods and data sources for the quantitative findings presented in Chapters 2 to 5 of this report. Recommendations for improving the provision of evidence to plan and evaluate end of life care are included throughout and are also presented together in a list at the end of the report.

1.7. OUR AUDIENCE AND CONTRIBUTORS

The NELS ICE mandate includes translating emerging end of life care research knowledge into practice. Translation of new inter-disciplinary conceptualizations and information is a complex process requiring time for meaningful knowledge exchange and actively engaging in dialogue with diverse communities. NELS ICE provides an interface between end of life service provision and research that cross three domains: ethical analysis grounded in social science; quantitative health service analyses using administration and other population datasets; and clinical care including oncology, palliative medicine, family practice, respirology, gerontology, pediatrics, and others (Figure 5). Ideas are being shared with those engaged in understanding and improving end of life care both across Canada and internationally.

By working with chronic disease agencies, government, advocates for at-risk populations, and others whose roles include provision of information to health authorities, it is anticipated that a synthesis of relevant

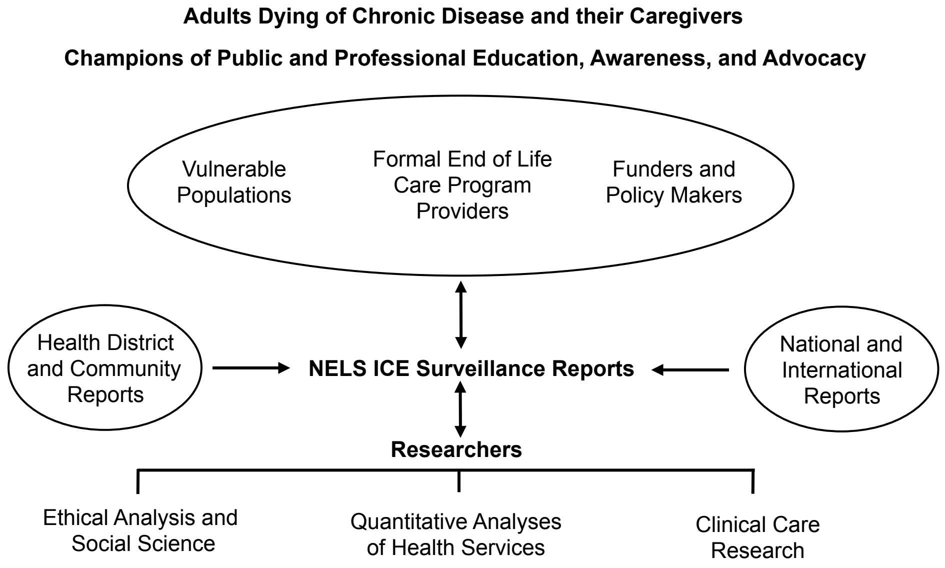

Figure 5: NELS-ICE surveillance report in relation to its contributors and audiences.

information will become available for local needs. At the local level, spokespersons for vulnerable populations, formal care providers, and decision makers who have fiduciary authority are encouraged to work with the information available to plan comprehensive community-based care. The pressing needs that are being faced, the burgeoning technology for information transfer, and the natural experiments at the local and district level can lead to change. Provincial and national plans and champions of public and professional education and advocacy can also increase awareness. Thereby, opportunities for improved access to quality end of life care for all persons dying of chronic diseases become apparent.

1.8. STRENGTHS AND LIMITATIONS

The strengths of NELS ICE emerge from the abilities of the interdisciplinary team members who are knowledgeable in ethics, epidemiology, and clinical practice, combined with the expertise of community and institutional partners. The work being undertaken is innovative, builds on existing expertise, and will increase the depth of understanding. It will explore new forms of end of life care provision by investigating and moving from inequality to inequity measures, from care to quality care measures, from cancer to include other chronic diseases, and from retrospective to prospective population data systems. Various forms of knowledge transfer will be piloted using research and organizational networks, working with varied community groups, and translating research into clinical practice guidelines.

This report represents more than ten years of end of life linked health administration database development in Nova Scotia, which has a manageable size for population studies and supportive culture for this work. The NELS ICE team is networked with cross-Canada and international experts. Unlike research into program–based palliative and hospice care, the work considers all publicly funded care in the last months of life for all persons dying of chronic disease in defined geographic areas. The health services research perspectives being applied include, but also move beyond, palliative medicine and its associated literature.

NELS ICE work has limits in that it needs to focus on the Canadian Institutes of Health Research (CIHR) funded purposes including the development of rigorous and innovative research, and the training of a new cadre of end of life care researchers. To be able to achieve these purposes, the NELS ICE team is focused on equity in the provision of publicly funded end of life care within and beyond the health system. Excluded from the NELS ICE work are privately funded and volunteer care, ethical issues surrounding end of life care beyond equity and vulnerable populations, and a comprehensive analysis of public policy and palliative and end of life care services.

Summaries at the end of chapters help identify information gaps and limitations in the work to date. Over the next years, some of these problems are expected to be addressed locally. Learning will occur by working with people nearby and at a distance that are tackling parallel issues. Through synthesis, the critique of knowledge, creativity, and the piloting of novel approaches, the NELS team can contribute to the improvement of surveillance methods and systems. The goal is to measure not just what is possible to measure, but what is important to measure.

The NELS ICE team aspires to make a positive contribution towards providing evidence for meeting the end of life care needs to be faced in the next decades while recognizing that the challenges ahead require much more than this five-year program of surveillance and research development. The evolution of the NELS ICE conceptual framework for measuring health inequity (Figure 4) is expected to guide future work and thus frames the subsequent chapters of this report.

RECOMMENDATIONS

Recommendation 1: In dialogue with others, continue to refine and develop comprehensive conceptual frameworks that help elucidate dimensions of vulnerability, disparities, and inequities in access to and receipt of quality end of life care.

Recommendation 2: Produce further reports that openly share and critique ideas and examples from research that challenge and extend the way we think about access to quality end of life care.

Recommendation 3: Work with others so that worthwhile aspects of end of life care surveillance, quality indicator reporting, knowledge exchange, and improved access to quality end of life care for vulnerable populations become sustainable.

NELS ICE defines vulnerable populations as "those at risk at any particular point in time for unequal opportunity to achieve maximum possible health and quality of life because of differences in intrinsic and extrinsic resources that are associated with good health" (Danis et al. 2002). Persons needing end of life care are assumed to be vulnerable, but some subgroups may face additional challenges. These vulnerable subpopulations are traditionally conceptualized in categories such as gender, age, ethnicity, socio-economic status, and geography (Johnston et al. 2005).

In future reports, it is hoped that vulnerable subpopulations at end of life will be identified by following the approach of Brock, who argues for both empirical investigation to identify populations at risk of suffering from poor health, and an analysis of the moral claims each of these populations presents (Brock 2002). In this first surveillance report, however, only potential vulnerable populations and their distribution within Nova Scotia are considered. This report focuses on variables included in our CIHR funded ICE proposal. This small step in Nova Scotia moves us closer to determining which populations are most vulnerable at end of life and their specific forms of vulnerability.

There are potentially vulnerable groups that have not been examined, for instance, people who are negatively affected by where they live and invisible populations that do not even appear on the health care radar. In terms of geography, the lack of clear, uniform definitions of urban and rural, and what constitutes a geographic inequity creates difficulty. There are multiple ways of describing rural. These include Census Rural Areas as defined by population size and density, Metropolitan Area and Census Agglomeration Influenced Zones (MIZ), OECD Definitions of Rural, Non-Metropolitan Regions (modified Beale codes) and Rural Postal Codes (du Plessis et al. 2002). Each definition emphasizes different criteria and has different associated thresholds and, as a result, the choice of definition is important (du Plessis et al. 2002).

The issue of invisible vulnerable populations is complex. There is little on this topic and, as with geography, the concept is difficult to define. Furthermore, invisible vulnerable populations are a broad category including, but not limited to the gay, lesbian, bi-sexual, trans-gendered and inter-sex communities; the visual and hearing impaired; the illiterate; the learning disabled; those with various forms of mental illness; persons dealing with substance, physical, or emotional abuse; and the homeless and others. Typically, data do not exist for these complex classifications. Anecdotally, it is known that these populations face significant vulnerability at end of life.

2.1. AGE, SEX AND GENDER

Some people use the words sex and gender interchangeably. These terms are very different conceptually. Their discrepant use can cause confusion and misunderstanding. Sex most commonly refers to the biological condition of being male or female or less commonly, hermaphrodite or neuter. Gender is used in social and cultural contexts to distinguish a social role or personal identity distinct from biological sex. However, since there is a high degree of correspondence between gender and sex, sex to some extent may act as a proxy measure of gender. Both sex and gender can be associated with vulnerability and influence access to end of life services. Population census and administrative health services data include sex but not gender. To date, the social influence of gender on end of life experience has not been a focus of our work.

A person's age may be associated with particular vulnerabilities at end of life. Elderly persons with multiple co-morbidities may be more vulnerable than others who are younger due to their complex health care needs; limitations in mobility, sight and hearing; limited financial resources; and limited social support. At the other end of the age continuum, children and youth are perceived as vulnerable by virtue of their dependency state and stage of development, as well as needs for access to care not typically available from health services designed for adults. The transition from children to adult services may also be associated with increased vulnerability to gaps in care provision.

The 2001 population pyramid and data tables below (Figures 6 and 7, and Tables 1 and 2) that were obtained from the Canadian 2001 Census, show there were slightly more females (468,920) than males (439,085) in Nova Scotia. For every 100 women there were 93.6 men, which is a greater difference than the Canadian average of 100 to 96.1 (Statistics Canada 2001). The median age of the province's population was 38.8 years, an increase of 5.4 years since 1991 (Statistics Canada 2001). By 2006, the median age was 41.0 years and this number is projected to increase further by the year 2020.

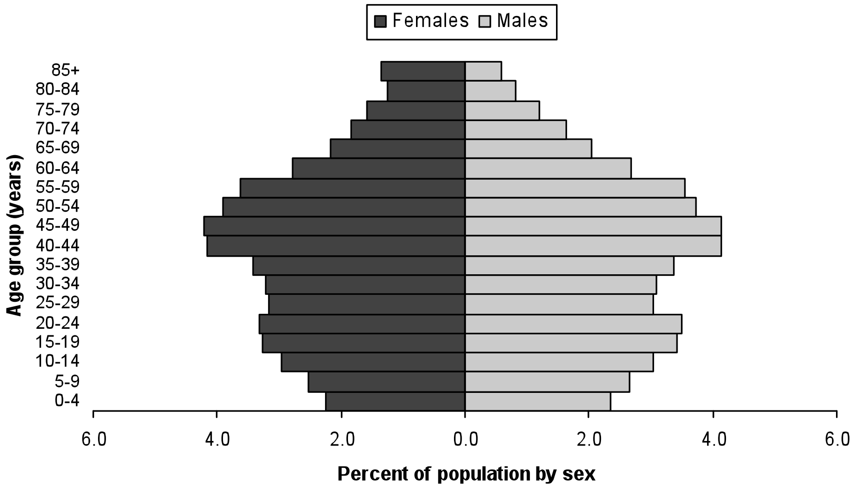

Figure 6: Population pyramid, by five year age categories, Nova Scotia, 2001.
Source: Statistics Canada, Table 109-5315.

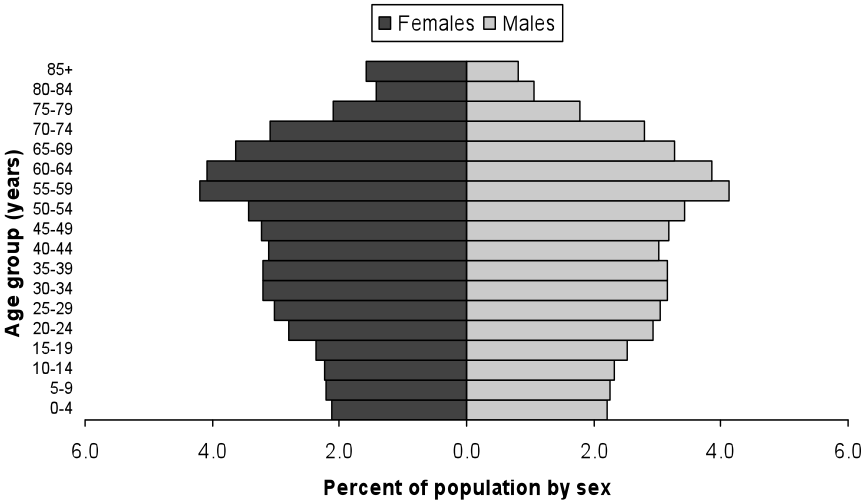

Figure 7: Projected population pyramid, by five year age categories,
Nova Scotia, 2020. Source: Statistics Canada, Table 052-0004.

Table 1: Population counts, by five year age categories, Nova Scotia, 2001.
Source: Statistics Canada, Table 109-5315.

Age Group (Years)	Sex	
	Male	**Female**
0-4	24,325	23,130
5-9	28,385	27,455
10-14	31,455	30,270
15-19	31,560	30,190
20-24	27,365	28,815
25-29	26,000	28,495
30-34	29,265	31,460
35-39	36,685	38,790
40-44	37,435	39,520
45-49	34,625	36,440
50-54	33,210	34,000
55-59	25,335	25,935
60-64	20,215	21,085
65-69	17,355	18,605
70-74	13,810	16,875
75-59	10,660	15,020
80-84	6,840	11,895
85+	4,575	10,935
Total	**439,085**	**468,920**

Table 2: Projected population estimates, by five year age categories, Nova Scotia, 2020.
Source: Statistics Canada, Table 052-0004.

Age Group (Years)	Sex	
	Male	**Female**
0-4	20,900	20,200
5-9	21,400	20,900
10-14	22,100	21,200
15-19	23,900	22,500
20-24	27,700	26,600
25-29	28,900	28,700
30-34	29,900	30,300
35-39	29,900	30,400
40-44	28,600	29,600
45-49	30,100	30,600
50-54	32,500	32,500
55-59	39,200	39,800
60-64	36,500	38,600
65-69	31,100	34,500
70-74	26,500	29,200
75-59	16,900	19,800
80-84	10,000	13,500
85+	7,800	15,000
Total	**463,900**	**483,900**

In 2001 in Nova Scotia, the economically dependent population (under 19 years) accounted for 25% of the overall population, while the labour force (20-64 yrs) and the elderly population (65+ years) were 61% and 14%, respectively. By 2006, population demographics shifted to 22.5% dependents, 62.9% labour force and 14.6% elderly. By 2020, the population under 19 years is expected to further decrease to 18.3% of the population while the labour force drops to 60.2% and the elderly population increases substantially to 21.6%.

A large proportion of the Nova Scotia population will reach retirement age in the next decades. These people are now of an age when mortality rates from chronic disease rise significantly. This state of affairs drives our research and surveillance projects. The growing number of elderly persons approaching end of life will increase Nova Scotia's current challenges in the delivery of quality health care.

Death in children is not common but its impact may be greater due to the effects on the physical, emotional, social and spiritual health of parents, siblings, grandparents and peers (Li et al. 2003; Li et al. 2005). It is also important to look at end of life issues in children separately as their needs may be very different due to their range of diseases and changing developmental requirements (Widger et al. 2007). Because the actual numbers of children and youth dying are small and centralized, pediatric palliative expertise may be limited.

2.2. RACE, ETHNICITY, LANGUAGE AND CULTURE

The concepts of race and ethnicity require clarity. Ethnicity refers to selected cultural and physical characteristics used to classify people into sub-categories that are considered to be distinct from others. This group identity may or may not be associated with common cultural traditions. The concept of ethnicity is multidimensional as it includes aspects such as race, origin or ancestry, identity, language and religion. "Race is a socially constructed taxonomy that groups human populations on the basis of external physical characteristics or geographic origin" (Williams and Warren 1994). The concept of race has little biological meaning but great societal significance. Given its association with racism, race is the most widely used term when referring to aspects of ethnicity, be they race, language, or culture. Language and culture are often seen as subsets of race and ethnicity, although this may not be true. Within this report, ethnicity and language are used to represent ways of subdividing a population and defining vulnerability. The classification of groups by visible minority is used by Statistics Canada in census reporting.

Aboriginal and Aboriginal Identity are Statistics Canada terms used to refer to those persons who self-identified with at least one Aboriginal group or indicated being a Treaty or Registered Indian or a member of an Indian Band or a First Nation. This may not be the most appropriate term to describe this population but, to date, it is the most comprehensive and widely used phrase.

Race, ethnicity, language and culture can be associated with vulnerability at end of life in many ways. Communication styles, language of service, signage, physical design, and form of service-delivery can influence a person's access to health services (Nova Scotia Department of Health 2005). As well, discrimination is a potential issue for those who are visibly diverse, and thus a disincentive to access the health care system.

Within Nova Scotia approximately 6% of the population are reported to be persons from minority groups (Figure 8). African Canadians account for 2% of the population. First Nations/Inuit/Metis (Aboriginal peoples) account for another 2% of the population. Many of these persons reside in or are associated with long standing indigenous communities

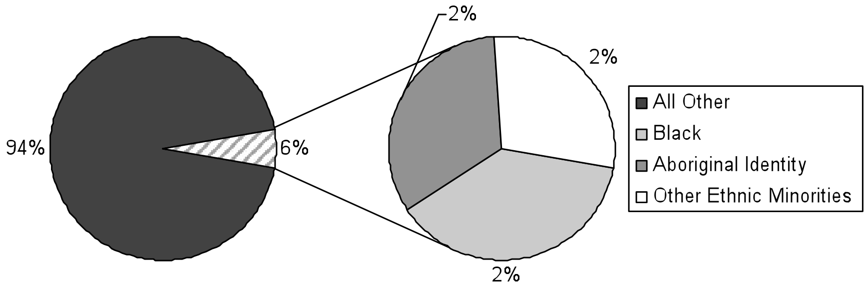

Figure 8: Minorities as a percent of total population, Nova Scotia, 2001.
Source: Statistics Canada, 2001 census data.

Figure 9 maps the distribution of visible minorities within Nova Scotia. Most have settled in two of the nine district health authorities (South West and Capital Health) with 75% of the total visible minority population residing in Capital District Health Authority.

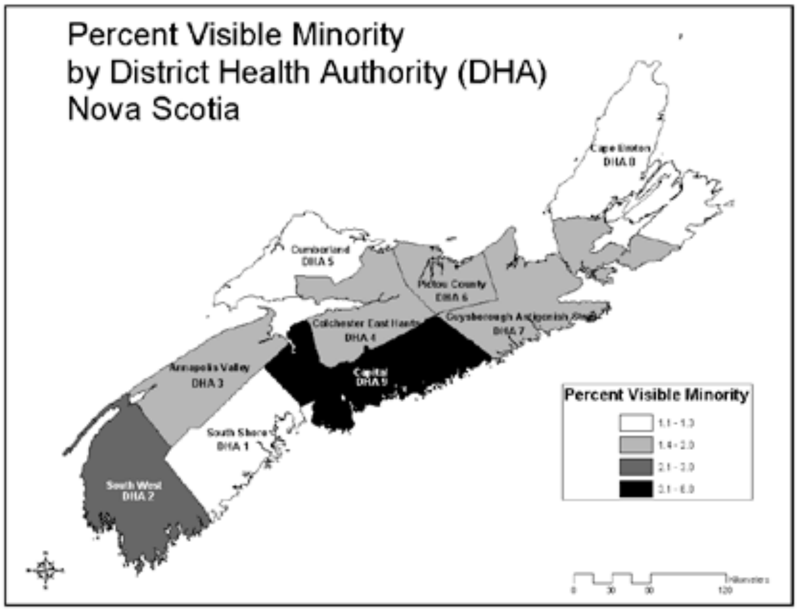

Figure 9: Distribution of visible minority groups, by District Health Authority, Nova Scotia, 2001.
Source: Statistics Canada 2001 census data.

The mother tongue of Nova Scotians is 93.0% English, 3.8% French, 0.3% English or French and a non-official language, and 3.0% neither English nor French (Census Canada 2001). The largest non-English, first language immigrant group speaks Arabic. The extent and patterns of future immigration are unknown but government policy toward increased immigration is evident.

In response to these demographic realities and recommendations from community and academic sectors, the Government of Nova Scotia created the Diversity and Social Inclusion in Primary Health Care Initiative as part of the provincial program of primary health care renewal. One outcome of this initiative is Canada's first guidelines for the culturally competent delivery of primary health care (Nova Scotia Department of Health 2005). Steps taken to address the need for cultural competence included the creation and distribution of "A Cultural Competence Guide for Primary Health Care Professionals in Nova Scotia" which targets management and administrative staff, front-line staff and primary health care providers, and includes tools and resources to assist primary health care professionals in providing culturally competent health care. All district health authorities and the IWK Health Centre were involved in the process. Capital District Health Authority has led the cultural competence training by providing training across its district (Brown and Rhymes 2006).

NELS ICE trainees have begun to explore some of the end of life care issues for selected groups in Nova Scotia. Victor Maddalena's doctoral, and postdoctoral studies which highlight end of life issues in the African Canadian population, are outlined in Chapter 10. Skylan Parker's exploration of end of life issues in Mi'kmaq peoples and Farhana Kanth's examination of the situation for east Indians are available for download from the NELS website at http://www.nels.dal.ca.

2.3. SOCIO-ECONOMIC STATUS

Socio-economic status represents a tangible barrier to quality end of life care as it affects the ability to purchase goods and services, as well as the availability of services within a community and the ability to access services that are far from home. Thus, low socio-economic status may impact individual options for end of life care.

An individual's socioeconomic status is associated with household income, level of education, occupation, and social status in the community. In this section of the report individual income levels will be used when describing socio-economic status.

In 2001, there were 691,585 wage earners in Nova Scotia (Statistics Canada 2001) (Figure 10 and Table 3). Average reported individual income was $25,297 versus the national average of $29,769. Individual earnings for Nova Scotians increased by 17.4% from the 1996 average of $21,552. Over this 5-year period, the median Nova Scotian individual income increased by $2,735 (14.5%) to $18,735.

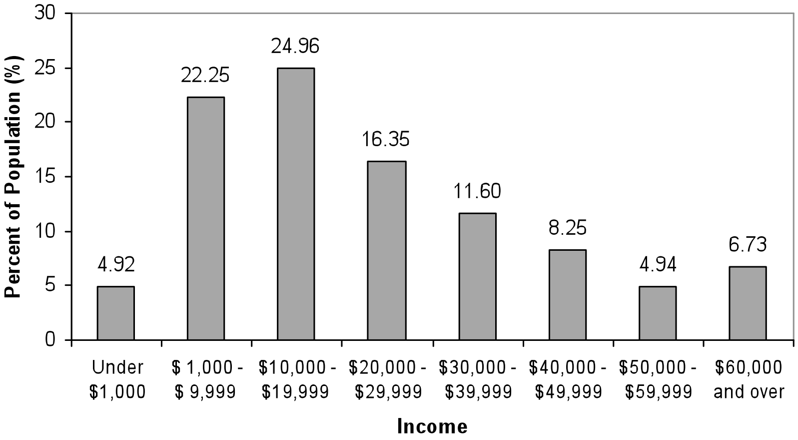

Figure 10: Income level percentage distribution for individuals 15 years of age and older, Nova Scotia, 2001.
Source: Statistics Canada, 2001 census data.

An examination of the median income distribution across Nova Scotia shows variations by District Health Authority with the Capital Health District having the highest median incomes and rural areas, particularly Guysborough Antigonish Straight and South West, having lower incomes (Figure 11).

Caring for the dying at home is the preference of many persons, but this can result in substantial out-of-pocket expenses. This raises the question: what are the implications of a provincial median income that is 15% less than the national average and lower for areas within the province?

Table 3: Population counts for individuals 15 years of age and older, by income level, Nova Scotia, 2001. Source: Statistics Canada, 2001 census data.

Income	**Population**
Under $1,000	34,040
$ 1,000 - $ 2,999	36,245
$ 3,000 - $ 4,999	31,180
$ 5,000 - $ 6,999	33,985
$ 7,000 - $ 9,999	52,440
$10,000 - $11,999	41,480
$12,000 - $14,999	56,740
$15,000 - $19,999	74,425
$20,000 - $24,999	61,690
$25,000 - $29,999	51,370
$30,000 - $34,999	45,655
$35,000 - $39,999	34,570
$40,000 - $44,999	31,940
$45,000 - $49,999	25,115
$50,000 - $59,999	34,190
$60,000 and over	46,515
Total	691,585
Average income	$25,297
Median income	$18,735
Standard error of average income	$82

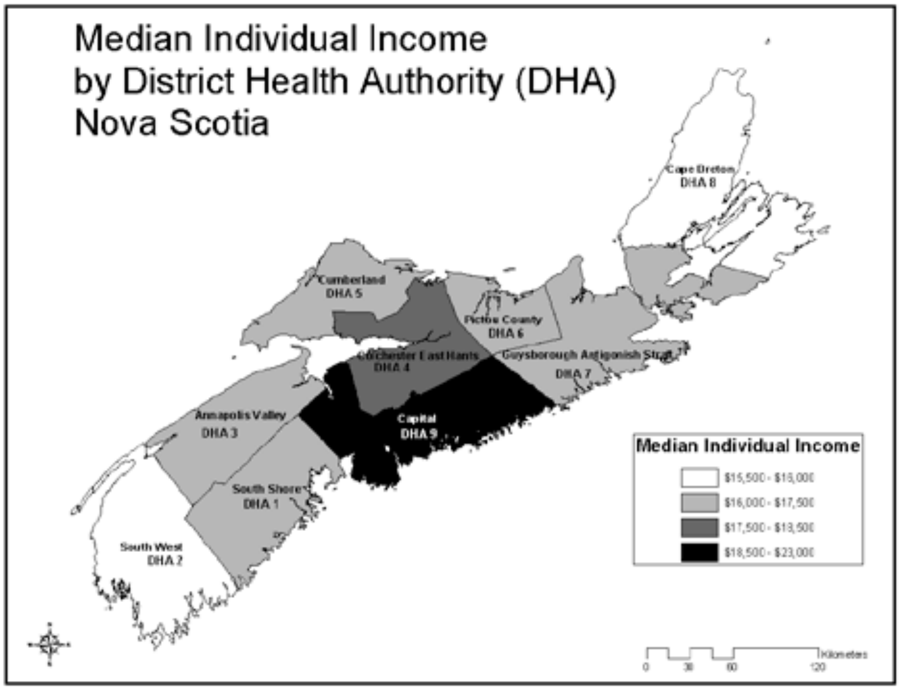

Figure 11: Distribution of income, by District Health Authority, Nova Scotia, 2001. Source: Statistics Canada, 2001 census data.

2.4. SUMMARY

The population of Nova Scotia, and particularly in the Capital Health (Halifax) area, is increasing in cultural diversity. This presents increasing health care delivery challenges and opportunities for meeting diverse needs. Nova Scotia has a growing elderly population, and at the opposite end of the age spectrum, there are a small number of children and young individuals who experience chronic diseases leading to premature death with specialized needs and distinct challenges. There are pockets of low income geographic areas, particularly outside the main urban areas, that are of particular concern.

Geography can affect the ability to access available services. Furthermore, visible and invisible vulnerable populations may not access the health care system due to a fear of real or perceived discrimination. It is hoped that some light will be shed on these issues in future research and reports.

What is known…	Who some of the potential vulnerable populations may be and how they are distributed within Nova Scotia.
What is unknown…	Empirical evidence to support their classification as vulnerable. Definitions and data to describe the distribution of other vulnerabilities.
What we NEED to know…	Burden of death, service use, and outcomes by vulnerability status. A better understanding of which groups are vulnerable but invisible. A systematic ethical framework that identifies vulnerable populations, along with empirical data.

RECOMMENDATIONS

Recommendation 4: Design and carry out population-based studies to better understand the needs of children and youth and the elderly as well as factors associated with sex and gender so that we can better discern where access to quality care may be sub-optimal and interventions can be designed to help improve care at end of life.

Recommendation 5: Improve our ability to identify factors associated with race, ethnicity, language, and culture that may adversely influence end of life care provision or, conversely, learn from these groups about ways and means to potentially improve care for all.

Recommendation 6: Gain a better understanding of the costs associated with end of life care in rural and urban areas with particular attention to persons living in communities where household incomes may compromise access to quality care.

Seven major chronic diseases have been selected to show the magnitude and distribution of causes of death in Nova Scotia: cancer, diabetes mellitus, chronic ischemic heart disease (IHD), congestive heart failure (CHF), cerebrovascular disease (stroke), chronic obstructive pulmonary disease (COPD) and renal failure. The emphasis on chronic disease and projected deaths for future years provides a context for the upcoming chapters on service use.

Vulnerability may be associated with being in certain age or disease groups for which treatment guidelines and access to care may be less available. Examples include deaths in children and youth and deaths from less common chronic conditions, e.g., cystic fibrosis, for which 25 deaths were reported in Nova Scotia between 1999 and 2004. Less common chronic conditions are not featured in this report. The expansion of research and surveillance will enable other chronic conditions and population groups to be studied in the future.

3.1. DEATH IN NOVA SCOTIA

Data for this chapter was obtained from the Vital Statistics Division of Service Nova Scotia and Municipal Relations (SNSMR). Over a 6-year period (1999-2004) 27,301 persons died in Nova Scotia from selected chronic diseases with a potential need for end of life care services (Table 4). In 2004, there were a total of 8166 deaths (Service Nova Scotia and Municipal Relations Vital Statistics 2004) and 58% of these deaths were due to the selected chronic diseases. This means that on average, nearly 13 of the approximate 22 deaths each day in Nova Scotia in 2004, were attributed to these diseases. In terms of the disease-specific deaths between 1999 and 2004, cancer had the highest number of deaths with 14,032. Chronic IHD and stroke accounted for a combined total of 7659 deaths, followed by COPD with 2253 deaths. The number of deaths each year remained relatively constant from 1999 to 2004 for each of the selected chronic diseases (Figure 12).

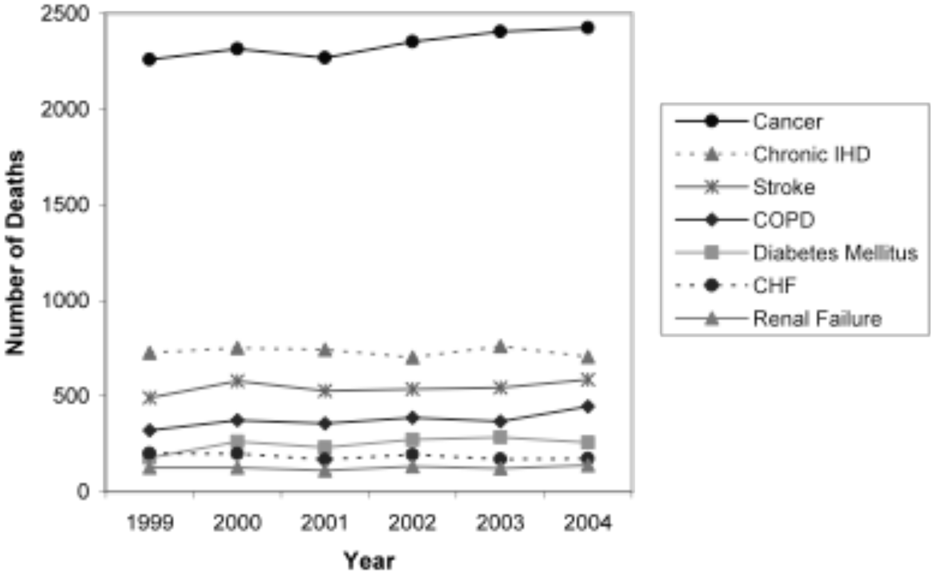

Figure 12: Deaths from selected chronic diseases, by year, Nova Scotia, 1999-2004 (N=27,301).
Source: Vital Statistics, Service Nova Scotia and Municipal Relations.

Table 4: Deaths from selected chronic diseases, by year, Nova Scotia, 1999-2004.
Source: Vital Statistics, Service Nova Scotia and Municipal Relations.

Disease	Sex	Year						
		1999	2000	2001	2002	2003	2004	Total
Malignant neoplasms (cancer)	M	1,222	1,246	1,216	1,235	1,240	1,291	7,450
	F	1,038	1,070	1,053	1,119	1,167	1,135	6,582
	T	2,260	2,316	2,269	2,354	2,407	2,426	14,032
Chronic ischemic heart disease (includes atherosclerotic heart disease)	M	410	403	394	383	402	384	2,376
	F	317	349	350	320	360	321	2,017
	T	727	752	744	703	762	705	4,393
Cerebrovascular disease (stroke)	M	194	204	195	223	228	215	1,259
	F	297	375	332	314	317	372	2,007
	T	491	579	527	537	545	587	3,266
Chronic obstructive pulmonary disease (excluding asthma)	M	186	202	191	218	204	250	1,251
	F	135	172	167	169	164	197	1,004
	T	321	374	358	387	368	447	2,255
Diabetes mellitus	M	90	136	109	135	138	136	744
	F	88	126	123	138	147	122	744
	T	178	262	232	273	285	258	1,488
Congestive heart failure	M	70	74	60	61	61	76	402
	F	131	125	109	133	110	98	706
	T	201	199	169	194	171	174	1,108
Renal failure	M	63	66	45	67	53	79	373
	F	63	61	67	66	69	60	386
	T	126	127	112	133	122	139	759
Total selected chronic diseases	M	2,235	2,331	2,210	2,322	2,326	2,431	13,855
	F	2,069	2,278	2,201	2,259	2,334	2,305	13,446
	T	4,304	4,609	4,411	4,581	4,660	4,736	27,301

The number of deaths from chronic diseases generally increases as age increases. For the chronic diseases analyzed, there were a total of 46 deaths in the 0-19 age group as compared to 8990 in the 75-84 age group (Table 5). After age 85, the death counts for cancer, diabetes mellitus and COPD declined while those for CHF continued to increase. For chronic IHD, stroke and renal failure, the number of deaths after age 85 decreased in males but increased in females (Figures 13-14).

Causes of death are coded using the World Health Organization's International Classification of Diseases (ICD). The ICD codes for the chronic diseases analyzed in this report are outlined in Appendix 2. Prior to the year 2000, 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). Only the underlying cause of death is used in the data presented in this chapter.

Death certificate information is helpful but limited for end of life care planning. Identifying those who require end of life care should involve measures of pain, breathlessness, fatigue, distress, functional status, and other factors, which are not captured by the ICD classification system.

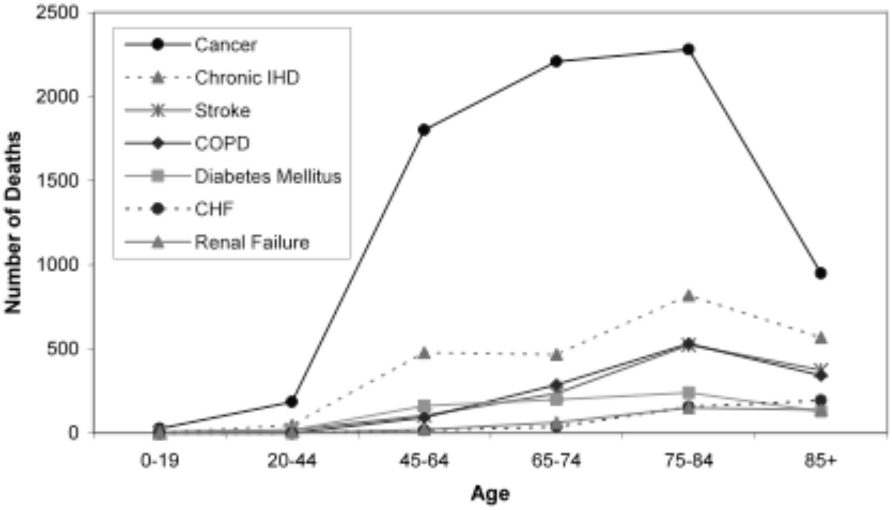

Figure 13: Deaths from selected chronic diseases, by age, males, Nova Scotia, 1999-2004 (N=13,855).
Source: Vital Statistics, Service Nova Scotia and Municipal Relations.

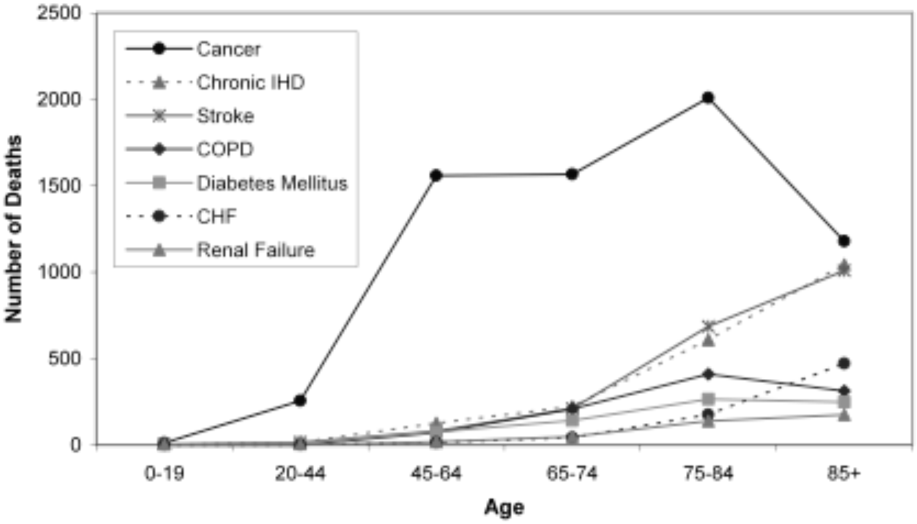

Figure 14: Deaths from selected chronic diseases, by age, females, Nova Scotia, 1999-2004 (N=13,446).
Source: Vital Statistics, Service Nova Scotia and Municipal Relations.

The Gold Standards Framework (GSF) developed within the National Health Service (NHS) in the United Kingdom incorporates clinical indicators at end of life which are of interest to the NELS ICE team. The GSF central team consulted a number of specialist clinical bodies and National Disease Associations to produce a Prognostic Indicator Guidance paper (Gold Standards Framework 2006). The goal is to help clinicians better identify patients with advanced disease in the last months/year of life to improve their assessment and planning for specific care needs.

Table 5: Deaths from selected chronic diseases, by age, Nova Scotia, 1999-2004.
Source: Vital Statistics, Service Nova Scotia and Municipal Relations.

Disease	**Sex**	**Age**					
		0-19	**20-44**	**45-64**	**65-74**	**75-84**	**85+**
Malignant neoplasms (cancer)	M	26	185	1,801	2,208	2,281	949
	F	12	256	1,559	1,567	2,009	1,179
	T	38	441	3,360	3,775	4,290	2,128
Chronic ischemic heart disease (includes atherosclerotic heart disease)	M	–	47	477	467	817	568
	F	–	16	126	222	609	1,044
	T	–	63	603	689	1,426	1,612
Cerebrovascular disease (stroke)	M	4	19	104	235	523	374
	F	4	15	81	211	687	1,009
	T	8	34	185	446	1,210	1,383
Chronic obstructive pulmonary disease (excluding asthma)	M	–	–	92	286	531	342
	F	–	–	71	209	410	312
	T	–	–	163	495	941	654
Diabetes mellitus	M	–	17	161	198	239	128
	F	–	12	77	142	265	248
	T	–	29	238	340	504	376
Congestive heart failure	M	–	–	17	36	155	194
	F	–	–	15	42	176	472
	T	–	–	32	78	331	666
Renal failure	M	–	–	20	63	149	137
	F	–	–	19	49	139	176
	T	–	–	39	112	288	313
Total selected chronic diseases	M	30	268	2,672	3,493	4,695	2,692
	F	16	299	1,948	2,442	4,295	4,440
	T	46	567	4,620	5,935	8,990	7,132

– Fewer than 3 deaths, number suppressed to maintain confidentiality. Therefore, total number of deaths in this table is 11 fewer than in Table 4.

3.2. PROJECTIONS

To forecast the number of deaths up to the year 2020 in Nova Scotia for cancer, COPD and CHF, it was assumed that future trends in age specific death rates would be similar to past trends. Changes as a result of new treatments, risk factor reductions, a major flu pandemic or other factors were not considered. The projections follow the methods in “Understanding Cancer in Nova Scotia: A statistical report by Cancer Care Nova Scotia with a focus on 2000-2004” (Saint-Jacques et al. 2006). The COPD and CHF projections are based on Nova Scotia population data from 1999 to 2004. These projections are limited but provide an indication of what is possible in more extensive future analyses.

3.2.1 Cancer

The cancer projections were previously reported and are based on population data from 1990 to 2005 (Saint-Jacques et al. 2006). Since 1992, cancer mortality rates have declined among males and this downward trend is expected to continue in future years. Cancer mortality rates in females have remained stable over this same period, although it is anticipated that these rates will decline once the mortality rate from lung cancer decreases (Saint-Jacques et al. 2006). However, the number of deaths from cancer will continue to rise each year mainly due to the aging population. The total number of cancer deaths in the province is expected to be 27% higher in 2020 as compared to 2004 (Table 6).

Table 6: Actual and projected annual deaths due to cancer, Nova Scotia.
Source: Vital Statistics, Service Nova Scotia and Municipal Relations.

		Death Counts		
		Females	**Males**	**Total**
Actual	2004	1,280	1,130	2,410
Projected	2010	1,320	1,170	2,490
	2015	1,440	1,260	2,700
	2020	1,640	1,420	3,060

3.2.2 Chronic Obstructive Pulmonary Disease (COPD)

The COPD projections show a trend of increasing death rates in both sexes. A substantial increase of over 70% in the total number of deaths from 2004 to 2020 is predicted (Table 7). The growing COPD burden has been recognized in the literature. In the United States, age standardized death rates for COPD doubled from 1970 to 2002 as a result of the long-term effects of tobacco smoking within an aging population (Jemal et al. 2005). Lacasse, Brooks and Goldstein (1999) anticipated large increases in the number of deaths from COPD over the next decade in Canada, particularly among women (Lacasse, Brooks, & Goldstein 1999). The WHO Global Burden of Disease Project (Buist et al. 2007) estimated that COPD was the fifth leading cause of death worldwide in 2001 and is expected to be the third leading cause by 2020. COPD will be an increasing health issue globally, across Canada and in Nova Scotia.

Table 7: Actual and projected annual deaths due to chronic obstructive pulmonary disease, Nova Scotia.
Source: Vital Statistics, Service Nova Scotia and Municipal Relations.

		Death Counts		
		Females	**Males**	**Total**
Actual	2004	197	250	447
Projected	2010	240	270	510
	2015	300	320	620
	2020	370	400	770

3.2.3 Congestive Heart Failure (CHF)

The CHF projections show that the total number of deaths from 2004 to 2020 will increase by 9%. The number of deaths in males is predicted to increase by 44% in males, and decrease by 18% in females (Table 8). Although the predicted increase in mortality for CHF is not as significant as the increases expected for cancer and COPD, it is a condition that affects a large proportion of the population. In Canada, over 350,000 are affected by CHF and the one year post-diagnosis mortality rate ranges between 25% and 40% (Tsuyuki et al. 2003). CHF is the most common reason for hospitalization in Canada and the mortality rate is much higher in patients over age 65 (Townley and Howlett 2002).

Risk factors for CHF include heart disease, diabetes mellitus, hypertension and obesity. In developed nations, the prevalence of these conditions is already endemic resulting in more cases of CHF being observed (Schocken 2000). The incidence of CHF in Canada has increased in recent years as a result of the aging population and better patient outcomes following myocardial infarction (Johansen et al. 2003). Since myocardial infarction is a major risk factor for CHF and survival rates for myocardial infarction have improved, it is anticipated that the prevalence of CHF will increase in the future (Stewart et al. 2003).

Table 8: Actual and projected annual deaths due to congestive heart failure, Nova Scotia.
Source: Vital Statistics, Service Nova Scotia and Municipal Relations.

		Death Counts		
		Females	**Males**	**Total**
Actual	2004	98	76	174
Projected	2010	90	90	180
	2015	80	100	180
	2020	80	110	190

3.3 SUMMARY

In preparing to care for the dying it is necessary to know the diseases from which they will die. Each disease presents varying mortality burdens with specific health care needs. Even if age specific mortality rates do not increase, death counts are expected to increase in the future due to the aging population. In addition, growing numbers of the aging population have multiple co-morbidities. The increased presence of multiple co-morbidities will play an even greater role in determining the care needed and provided during what may be a much more prolonged and complex dying phase than that to which we have become accustomed.

What is known…	Which chronic diseases are the leading causes of death in Nova Scotia as well as preliminary projections of what the burden of death will look like in the coming years.
What is unknown…	Disease specific mortality information for many vulnerable groups as well as district specific information for planning.
What we NEED to know…	More specific end of life information with additional attention to the needs of vulnerable populations.

RECOMMENDATIONS

Recommendation 7: Expand the clinical breadth of the research team so that we can gain a better understanding of end of life care issues for persons dying of chronic diseases other than cancer and including co-morbidities.

Patterns of health service utilization at the individual, district and provincial levels are complex. They reflect the need for services as well as the availability of health services, human resources, and demographic, economic and other determinants of utilization. This chapter reports examples of publicly funded health services within Nova Scotia that are available to individuals in need of end of life care, followed by brief mention of the need to translate service utilization into costs. Various NELS published papers more extensively report findings (O'Brien et al. 2007; Grunfeld et al. 2006; Lawson et al. 2006; Burge et al. 2005a; Burge, Lawson, & Johnston 2005a; Burge, Lawson, & Johnston 2005b; Burge et al. 2005b; Johnston et al. 2004; Burge et al. 2003c; Burge, Lawson, & Johnston 2003a; Burge et al. 2003b; Johnston and Burge 2002; Burge et al. 2002; Johnston et al. 2001a; Johnston et al. 2001b; Johnston et al. 1998). Rather than a comprehensive analysis, the data herein indicate a range of analyses that are available or possible to produce.

For this report, end of life services include physician services, hospital days, home care, specialized palliative care, long-term care, radiotherapy and medical oncology for cancer patients, and emergency services. Exploration of pharmaceutical use at end of life has been limited. Physician services are subdivided into family physician services (office, home care, long-term care, in- and out-patient hospital care, after-hours care) and specialist physician services. Hospital days can be categorized by number of hospitalizations, length of stays, location of care within the hospital, time spent in hospital within last six months of life, and for those who died in hospital, length of last hospital stay.

Between 1998 and 2000, a Rural Palliative Home Care Model was piloted in the northern health region of Nova Scotia. The purpose was to examine how to overcome barriers to service delivery, integrate palliative home care with other services and in a variety of settings, and support and educate providers (Rural Palliative Home Care Staff and Consultants 2001). The pilot, which was funded by the Federal Health Transition Fund, consisted of the development and evaluation of an Integrated Palliative Care Program in Nova Scotia and Prince Edward Island (Health Canada 1997). Of the seven recommendations laid out in the study's March 2001 report, only three have been partially met. Outstanding recommendations include the establishment of palliative care as a core essential service with 24 hours a day/7 days a week access, where home is identified as the preferred setting.

In 2003, the Capital Health palliative care program became an integrated service with the provincial Continuing Care program providing home care to address the requirements of persons with end of life care needs. Integrated end of life services assist individuals in moving easily to the care settings that best meet their needs. Within the Integrated Palliative Service model, many health care providers work closely together to deliver end of life service, including the option of the primary care team and/or the palliative care consult team following patients at home (Capital Health & Cancer Care Nova Scotia 2005).

This chapter reports on service use. NELS ICE recognizes the lack of data for determining need for services at end of life beyond the general statements in Chapter 1.

4.1. CARE AVAILABLE

Describing the availability of end of life care in Nova Scotia is complicated. Multiple sectors, including primary health care, deliver end of life care. Providers include family doctors; home care services via Nova Scotia Department of Health Continuing Care Services, municipal government, private and non-profit groups; various specialist services including oncology, congestive heart failure clinics and dialysis programs; and long-term care facilities, hospitals and palliative care services in each of the nine district health authorities (DHAs). There is no provincial standard of what constitutes a palliative care program and associated services. However, many organizations and individuals are working collaboratively to describe available services in each health district, and to advocate for the need for equitable access to palliative care. The Nova Scotia Hospice Palliative Care Association (NSHPCA) has an advocacy campaign for access to palliative care services (Nova Scotia Hospice Palliative Care Association (NSHPCA) 2007) and the Government of Nova Scotia has initiatives through its continuing care strategy (Nova Scotia Department of Health 2007a).

Palliative services are available with varying degrees of integration throughout the nine DHAs and the IWK Health Centre for children in Halifax. Figure 3 identifies the DHAs. Each had at least one palliative care initiative when this description was prepared in 2007. The programs vary in terms of their professional and volunteer components. All have palliative care physicians and palliative care consultant nurses, and there is a clinical nurse specialist at the IWK. Only Capital Health, Cape Breton and Pictou feature dedicated palliative care beds. All but one DHA have a full- or part-time Palliative Care Manager. Four DHAs have designated home care coordinators. Across the province, services of other funded palliative caregivers, such as social work, pharmacy, and rehabilitation therapy, are limited. Availability of the palliative care team on a 24/7 basis is offered in three of the districts (Guysborough Antigonish Strait, Cape Breton, and Capital Health).

A service supporting palliative care that has been in place for a number of years is Cancer Patient Navigation (CPN). In 2001, Cancer Care Nova Scotia implemented a CPN program to help patients and families deal with the serious social, emotional, informational, financial and logistical challenges faced by a cancer patient. The cancer patient navigator, a specialized oncology nurse, can assist patients through the complex cancer system, improving access to care, better co-ordinating services and addressing a range of supportive care needs. They can make care possible closer to home by ensuring early access to supportive and palliative care, volunteer and other supports in home communities. South Shore Health, South West Health, Annapolis Valley Health, Pictou Health, and Guysborough Antigonish Strait Health have full time navigators. The remaining four health districts have identified the need for navigators.

An example of the national interest in improving end of life care is the May 2006 release of hospice palliative and end of life care standards by the Canadian Council on Health Services Accreditation (Canadian Council on Health Services Accreditation (CCHSA) 2007). These standards offer an accreditation program for hospice organizations and a core set of performance measures or indicators. CCHSA is accredited by the International Society for Quality in Health Care.

4.2. UTILIZATION BY PERSONS DYING OF CANCER

For over 10 years, health administrative databases have been linked to identify health service use in the last months of life for adults dying of cancer and, to a limited extent, for persons dying of congestive heart failure (Section 4.3). Appendix 2 of this report provides an overview of the development of these data. The distribution of cancer decedents by age and sex was previously provided in Tables 4 and 5, and Figures 12, 13 and 14 in Chapter 3: Burden of Death and Dying.

4.2.1.Physician Services

From 1998 to 2003, a total of 560,245 family physician and speciality physician visits were identified for 14,426 adults dying of cancer during their last 6 months of life (Figure 15). These persons saw a physician on average 38.8 times (median 32), with the distribution of the number of visits given in Tables 9 and 10. The majority (58.9%) of visits were with a family physician. Of the physician visits, 3.5% were provided in the emergency department.

Table 9: Number of physician visits in the last 6 months of life for adults dying of cancer, Nova Scotia, 1998-2003 (N=14,426).

Number of physician visits	Frequency (%)
0-19	3,874 (26.9)
20-34	3,894 (27.0)
35-49	2,820 (19.6)
50+	3,838 (26.6)

Table 10: Mean and median number of physician visits in the last 6 months of life for adults dying of cancer, by visit type, Nova Scotia, 1998-2003 (N=14,426).

Visit Type	Mean (SD)	Median
All physician visits		
All visits	38.8 (28.9)	32
Emergency department	1.4 (1.9)	1
Family physician visits		
All visits	22.9 (21.4)	16
Specialty physician visits		
All visits	16.0 (19.6)	10

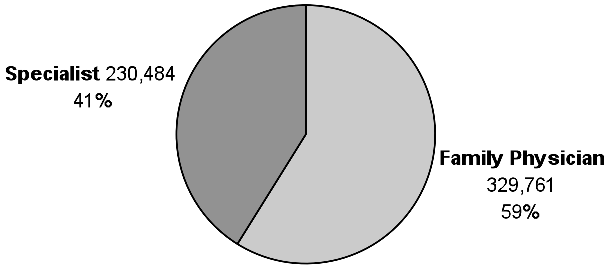

Figure 15: Physician services utilized in last 6 months of life by adults dying of cancer, Nova Scotia, 1998-2003 (N=14,426).

4.2.2. Hospital Services

Of the 14,426 adults who died of cancer between 1998 and 2003, 86.4% were admitted to hospital within their last six months of life. Approximately a third (32.6%) spent between 1 and 14 days in a hospital, 28.9% were hospitalized for more than 31 days (Table 11).

Table 11: Inpatient length of stay in the last 6 months of life for adults dying of cancer, Nova Scotia, 1998-2003 (N=14,426).

Inpatient length of stay (days)	Frequency (%)
0	1,961 (13.6)
1-14	4,701 (32.6)
15-31	3,593 (24.9)
32+	4,170 (28.9)

4.2.3. Homecare Services

Provincial home care services were expanded in the past decade and organized through Single Entry Access (SEA). Minimum data set (MDS) collection at the time of SEA assessment was implemented and data collection began in 2003. NELS linked dataset development was the first research to use these new data. Table 12 shows that in 2003 over 70% of the adults dying of cancer in Nova Scotia used some form of homecare services in their last 6-months of life.

Table 12: Homecare service utilization in last 6 months of life by adults dying of cancer, Nova Scotia, 2003 (N=2,529).

Homecare	Frequency (%)
Yes	1,785 (70.6)
No	744 (29.4)

4.2.4. Palliative Care Services

Palliative care programs in Nova Scotia are designed primarily to provide consultation, rather than to directly deliver day-to-day care at end of life. There are no free standing community hospice facilities in Nova Scotia. The majority of clients referred to the palliative care programs are dying of cancer. Palliative care is available across Nova Scotia, but palliative care program data are not as yet available in a provincial database.

For a number of years, NELS research has involved linking and analyzing palliative care registration data from the palliative care program of the Capital District Health Authority in Halifax which formally began in 1988 (Burge et al. 2002; Johnston et al. 1998). Only persons assessed and registered are included in this database. In 2003, the Capital Health program became an integrated service with the provincial Continuing Care program which provides home care to address the needs of all persons requiring end of life care.

Recently, NELS began working with palliative care program data from Cape Breton. The Cape Breton program also began in 1988, but the database for this program was only initiated in 1994-5. In the Cape Breton database, all persons referred to the service are recorded on their date of referral which on average is believed to be about one day before the date of assessment by the palliative care service. Given this anomaly, for ease of reading, the term enrollment is used for both the Capital Health and Cape Breton reporting purposes.

Among adults dying of cancer, palliative care enrollment rates increase for the period 1996-2005 for Halifax County, with the rate levelling off at about 70% from 1998-2003, and then rising to about 80% in 2005. In Cape Breton, enrollment rates rose steadily over the period examined, also levelling off at approximately 80% in 2005 (Figure 16). For other chronic diseases, enrollment rates have not as yet been calculated but they are much lower.

Urban areas show a much higher palliative care enrollment rate than their rural counterparts, and their rates increased over this 10-year period (Figure 17). The enrollment rate in rural areas climbed steadily for the first half of this period, peaking at 72.3% in 1998. After this, however, the rate began to decline and settled at 43.8% in 2005. Exploring the reasons for these trends is important in shaping the understanding of service delivery to different regions in the province. One factor relates to policies on the maximum distance palliative care consultants travel to make home visits. Due to limitations in data availability, an analysis of access to palliative care across Nova Scotia is not possible at this time.

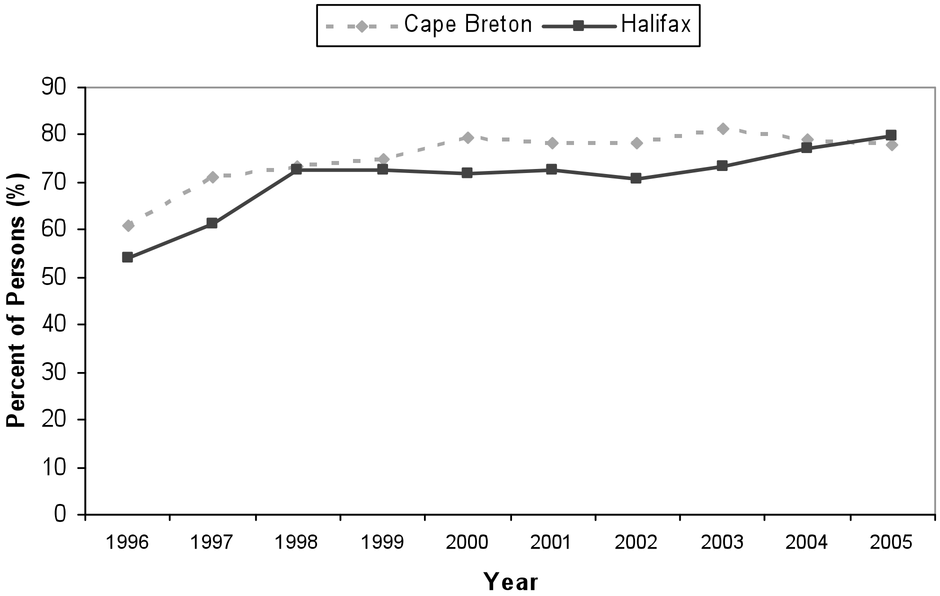

Figure 16: Trends in palliative care program enrollment rates for adults dying of cancer, Halifax and Cape Breton counties, Nova Scotia, 1996-2005 (N=10,227).

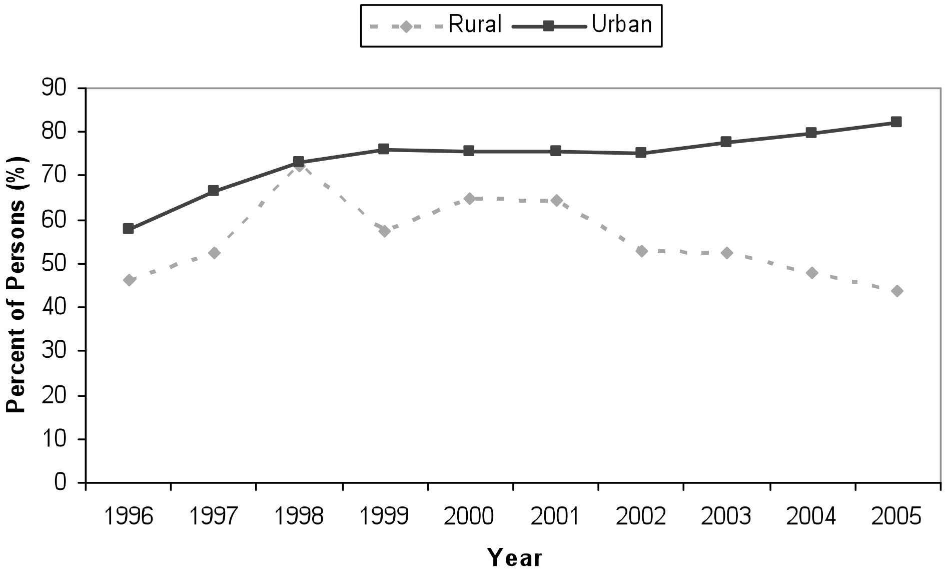

Figure 17: Trends in palliative care enrollment rates for adults dying of cancer, by urban/rural classification, Halifax and Cape Breton counties, Nova Scotia, 1996-2005 (N=10,227).

4.2.5. Long-term Care Services

There is no provincial database identifying residents of long-term care facilities. However, long-term care facilities are identified as the place as residence and place of death on the Vital Statistics death certificates. Using this information, an algorithm was developed to identify persons who were long-term care facility residents at the time of death (Cancer Care Nova Scotia 2005).

Figure 18 shows that, predictably, as age increases, so does the use of long-term care facilities. This increased from 2-3% for both women and men dying of cancer aged 20-64, to 23% in women and 16% in men in the 85 and older group. Women outnumber men in the use of long-term care facilities at all ages. The rate of use of long-term care services by those who died of cancer remained fairly steady over the period 2000-2005, at 6-8%.

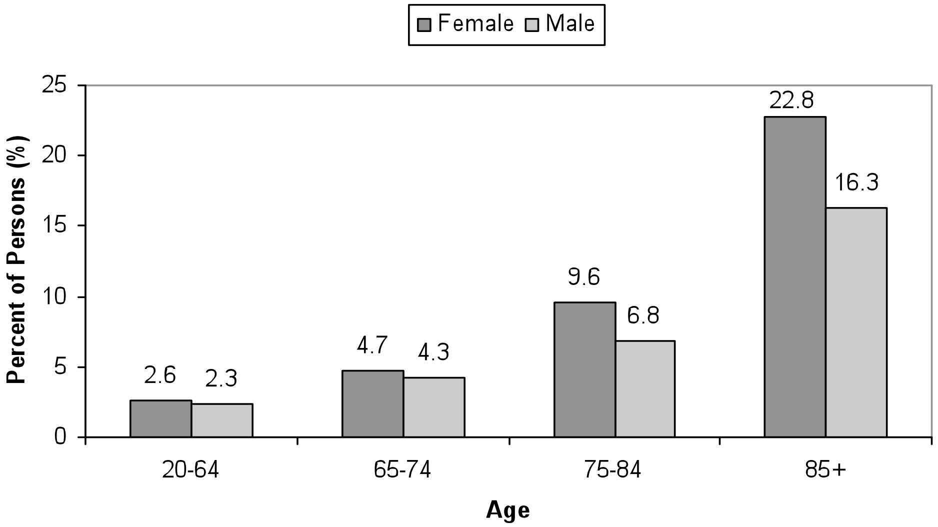

Figure 18: Adults dying of cancer who were long term care residents at time of death, by age and sex, Nova Scotia, 2000-2005 (N=13,711).

4.2.6. Palliative Radiation Services

The methods used to identify predictors of palliative radiation at end of life for adults dying of cancer in Nova Scotia are published (Johnston et al. 2001a). Postal codes of residence at death were used to generate an ecological measure of the socioeconomic status; median household incomes for neighbourhoods are ranked into quintiles.

Figure 19 shows that adults are somewhat more likely to receive palliative radiation if they are from the highest income quintile. As the neighbourhood median household income increases, the rate of utilization of palliative radiation therapy increases, from approximately 27.7% in the lowest income neighbourhood to about 33.8% in the highest.

These univariate analyses need to be interpreted in the context of a more complex picture. Palliative radiation services are less likely to be used by persons living further from the two urban radiation treatment facilities, and are more likely to be received by younger persons. Persons in urban areas have, on average, higher incomes and younger populations than rural areas. However, even in multivariate analyses, there appeared to be a statistically significant association between living in a higher socioeconomic status community of residence and consultation for palliative radiation treatment.

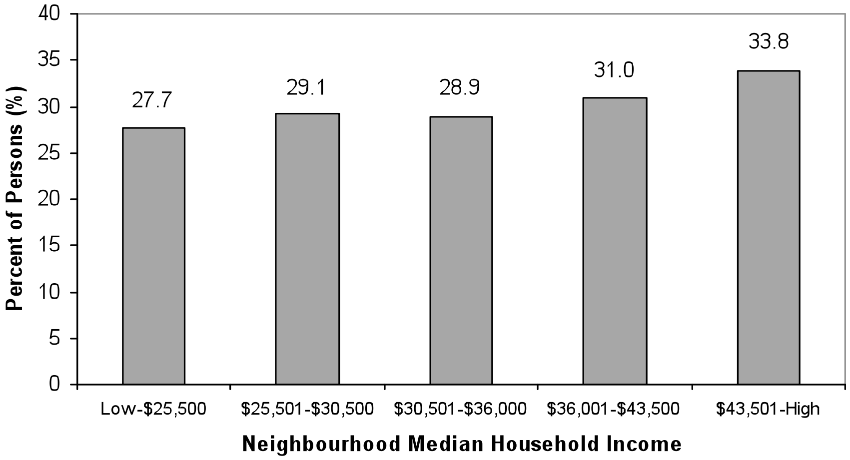

Figure 19: Palliative radiation therapy utilization by adults dying of cancer, by neighbourhood income, Nova Scotia, 2000-2005 (N=13,095).

4.2.7. Medical Oncology Services

Medical oncologists who provide specialist chemotherapy and other systemic therapy consultation and care for adults are located in the cancer centres in Halifax and Cape Breton. More recently they provide satellite clinics in other areas across the province. Their service data have been linked to persons dying of cancer. Medical oncologist consultation data are complete for the province. However, chemotherapy and other systemic therapy can be delivered by surgeons and other physicians. Therefore, the available records of delivery of systemic and chemotherapy across the province may be incomplete. The increasing numbers of randomized controlled trials for new drugs that prolong and improve quality of life may be an important factor in the options available for delivery of end of life care in the years ahead, but are not currently a major factor.

Table 13 shows that 14% of persons dying of cancer in Nova Scotia (1998-2003) received a medical oncology consultation in their last 12 months of life. Medical oncology consultation in the last 12 months of life by median household income of one's community of residence (Figure 20) shows that the highest income bracket has higher utilization (~18%) than other groups (~11-13%).

Table 13: Medical oncology consultation in the last 12 months of life for adults dying of cancer, Nova Scotia, 1998-2003 (N=14,426).

At least one oncology visit	Frequency (%)
No	12,372 (85.8)
Yes	2,054 (14.2)

As analyses are developed to investigate end of life care for persons dying of diseases beyond cancer, the intent would be to examine the distribution of specialized disease, palliative and other end of life care. To date, we have some limited data on congestive heart failure.

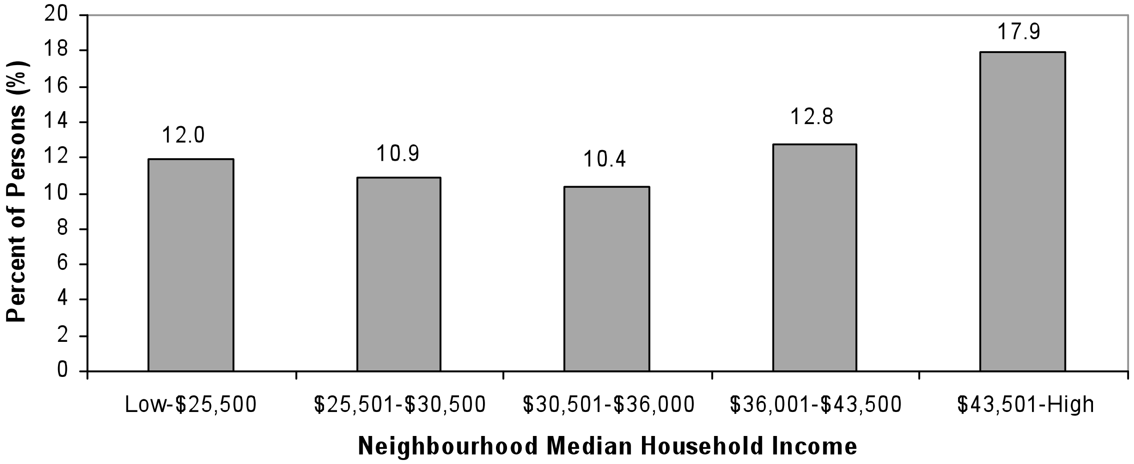

Figure 20: Medical oncology consultation in the last 12 months of life for adults dying of cancer, by median household income, Nova Scotia, 2000-2005 (N=13,201).

4.3. UTILIZATION BY PERSONS DYING OF CONGESTIVE HEART FAILURE

Congestive heart failure (CHF) costs the Canadian healthcare system approximately $1 billion annually; 70% - 80% of this is hospital costs (Townley et al. 2002). CHF is a progressive disease, and its terminal stages are not as predictable as cancer (Townley et al. 2002). Those dying of CHF often have symptoms that go untreated at end of life. For this and other reasons, persons with CHF would likely benefit from palliative care services (Workman 2003). Unfortunately, palliative care is limited for persons with this disease. While much is known about its stages and progression, end of life care in this population has not been thoroughly examined.

As our research team moves beyond cancer to examine end of life issues in other disease populations, examining trends and patterns in health services utilization by those dying of CHF becomes a priority and can provide an opportunity to further study equity in end of life care for vulnerable populations. In the following analyses, the study population consists of those individuals who had CHF as the immediate or one of the first three underlying causes of death. There is some concern surrounding the cause of death recorded on death certificates for persons with CHF since these persons typically have many co-morbidities. Hence, the findings below may underreport persons dying with, rather than of, CHF.

In Nova Scotia, persons dying of CHF are older and more likely to die out-of-hospital with fewer emergency and specialist visits than for persons dying of cancer. Care of younger men with CHF is often more acute care-based in contrast to older women with CHF who are more likely to be long-term care residents.

4.3.1. Physician Services

During the four-year period 1998-2001, there were a total of 170,092 physician visits during the last six months of life for 2,809 adults dying of CHF. These persons saw a physician on average 60.6 times (median 42) with the distribution and the mean number of visits given in Table 14. This is in contrast to the 38.8 average number of physician visits (median 32) seen in persons dying of cancer (Table 9). Of these physicians' visits for persons dying of CHF, 69% were family physician visits (Figure 21), compared to 59% family physician visits for cancer decedents (Figure 15). Thus, proportionally, more of the medical care is provided by family physicians, rather than specialists, in end of life CHF care than in cancer. For family physician services, the majority of these visits take place within the hospital (Table 15).

Table 14: Mean and median number of physician visits in the last 6 months of life for adults dying of congestive heart failure, by visit type, Nova Scotia, 1998-2001 (N = 2,809).

Visit type	Mean (SD)	Median (Range)
All physician visits	60.6 (57.0)	42 (0-368)
Family physician visits	41.8 (42.6)	28 (0-340)
Specialty physician visits	18.8 (32.4)	6 (0-342)

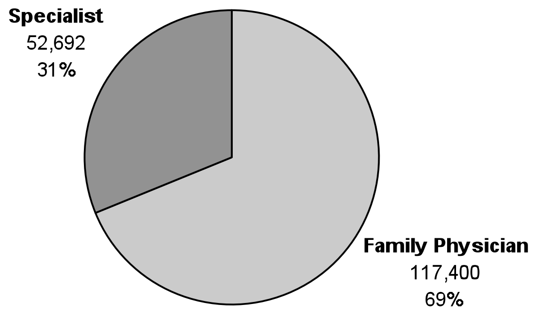

Figure 21 : Physician services utilized in the last 6 months of life by adults dying of congestive heart failure, Nova Scotia, 1998-2001 (N = 2,809).

Table 15: Family physician service locations in the last 6 months of life for adults dying of congestive heart failure, Nova Scotia, 1998-2001 (N = 2,809).

Service Location	Frequency (%)*	Mean (SD)⁺
All family physician visits	117,400 (69.0)	41.8 (42.6)
Hospital (outside emergency dept)	74,722 (43.9)	26.6 (40.7)
Office	14,839 (8.7)	5.3 (7.2)
Long term care	14,428 (8.5)	5.1 (11.2)
Home	5,953 (3.5)	2.1 (6.9)
Emergency department	7,418 (4.4)	2.6 (3.7)

* of all physician services (170,092)
⁺ per patient

For specialist physician services, the majority of visits take place in the hospital or office (Table 16). Negligible numbers of visits occurred in long-term care facilities or in the home. This is in keeping with what is known about specialist practice.

Table 16: Specialist physician service locations in the last 6 months of life for adults dying of congestive heart failure, Nova Scotia, 1998-2001 (N = 2,809).

Service Location	**Frequency (%)***	**Mean (SD)⁺**
All specialist physician visits	52,692 (31.0)	18.8 (32.4)
Hospital (includes emergency department)	43,885 (25.8)	15.6 (29.7)
Office	8,727 (5.1)	3.1 (8.9)
Long term care	58 (-)	0.02 (0.4)
Home	15 (-)	0.01 (0.1)

* of all physician services (170,092)
⁺ per patient
- Too few to meaningfully summarize

4.3.2. Hospital Services

The 2,809 persons who died of CHF from 1998-2001 had 3,625 hospital episodes, including inpatient and day surgeries, in their last six months of life. Their total inpatient length of stay was 53,860 days with a mean of 19.2 inpatient days per person dying of CHF. Twenty-two percent had no days in hospital. The range was up to 181 days for a hospital stay (Table 17).

Table 17: Hospital services utilized in the last 6 months of life by adults dying of congestive heart failure, Nova Scotia, 1998-2001 (N = 2,809).

Hospital episodes (includes inpatient & day surgeries)	3,625
Mean / patient (SD)	1.3 (1.2)
Median (Range)	1 (0-11)
Inpatient length of stay (days)	53,860
Mean LOS / patient (SD)	19.2 (26.7)
Median (Range)	9 (0-181)

4.3.3. Long-term Care Services

Long-term care services utilization was defined using a different method than was used for the analyses for persons dying of cancer (Section 4.2.5). For this CHF analysis, a person was deemed as being a long-term care resident if one or more physician visits in the last six months of life were billed as long-term care facility visits. Long-term care residents were subdivided into longer term residents if all physician visits were in a long-term care facility and recent residents if some physician visits were in the physician's office or the person's own home.

Predictably, as age increases, so does the use of long-term care facilities. Totalled across the four years (1998-2001), an increase from 59 individuals less than 75 years, to 255 aged 75-84 years, to 609 persons 85+ years was observed. Regardless of age, CHF decedents were more likely to be longer term residents than recent residents (Figure 22).

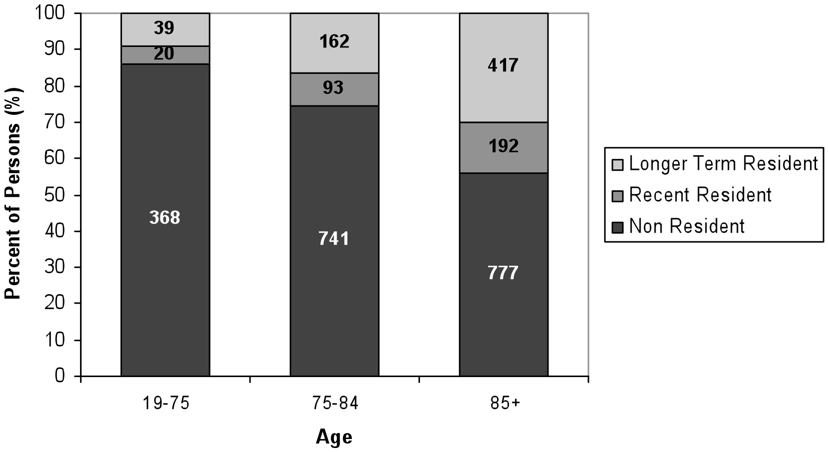

Figure 22: Nursing home residence at time of death for adults dying of congestive heart failure, by age, Nova Scotia, 1998-2001 (N = 2,809).

When long-term care facility residence is examined at time of death, by sex, for persons dying of CHF (Figure 23), females outnumber males in all categories. The most appreciable difference is in the longer term resident category where women outnumber men approximately 2:1.

Regardless of sex or age, CHF decedents were more likely to be in their own home than be a long-term care resident.

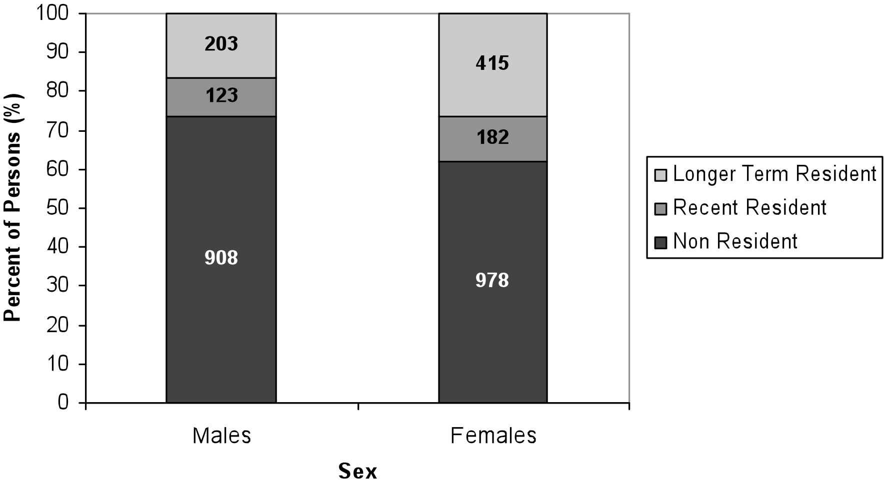

Figure 23: Nursing home residence at time of death for adults dying of congestive heart failure, by sex, Nova Scotia, 1998-2001 (N = 2,809).

4.4. COSTING

Information on the costs of health services utilization is essential to estimate financial resources being used to provide services at end of life. This costing work is critical for determining whether public resources are being used effectively, and to plan how best to move further toward attaining equity in access to quality end of life care for all persons dying in the province of Nova Scotia.

While the mandate for ICE funding does not include completion of this costing step, the utilization data from NELS ICE would be of assistance to costing studies. In Table 18, a basic plan is presented for obtaining costing data to enable dialogue for consideration and development in this important area. For this basic plan, which was designed to engage discussion and critique, most counts of services and unit costs are not included.

Table 18: Basic plan for costing publicly funded health care in the last 6 months of life for adults dying of cancer, Nova Scotia.

Health Services in Last 6 Months of Life (Year[s] of Death of Study Subjects)	Total annual counts of service	Cost per unit of service ($)	Health system cost per annum	Average cost per decedent
Physician Visits (1998-2003)	329,761			
Family Physician	230,484			
Specialist Physician				
Hospital Days (1998 – 2003)			……	
Palliative Care				
Intensive Care				
Alternate Care				
Other Service				
Home Care Enrollments (2003)	1,785			
Long Term Care Residents (2000-05)	995			
Palliative Radiation (2000-05)	3,959			
Medical Oncology Consult (2000-03)	2,054			

The list of services in Table 18 is not exhaustive but illustrative. Available years of utilization data vary by service, e.g., data for home care is only available for 2003 and the most current data available for palliative radiation is for 2005. Utilization data are more available for cancer decedents than for persons dying of other chronic diseases. Currently, data is not available for publicly funded ambulance services and for medications provided through hospitals, the seniors' pharmacare program or other means. It is unknown what services are for palliative versus non-palliative care. Some of the measures available are crude, for example, hospital days. Also, the extent to which service type should be subdivided needs to be determined. For example, is it useful to know the quantity of various types of hospital days – for palliative care, intensive care, alternate care waiting for a long-term care (LTC) bed, or other hospital ward? An electronic database of days in a LTC facility by person is not available for the province.

To calculate annual costs of health services used, the total quantity of services e.g., visits, inpatient days for the population of interest e.g., adults dying of cancer for the time period of interest e.g., 2005 would be multiplied by the cost per unit of service e.g., $ per visit, $ per inpatient day, and then summed across services.

The proposed plan to obtain costing data would include publicly funded health system costs but would not include other publicly funded assistance, for example, Compassionate Care Benefit or other assistance. Provincial home care and long-term care facilities provide care. The extent of their costs that are publicly funded is based on the financial need of individuals receiving this care. In Nova Scotia, medication costs are covered by a range of public, private, and voluntary society programs and personal resources. A cost to the public purse perspective is a very narrow view of costs since it omits those costs paid by employee-based or privately purchased insurance coverage, and by expenses that individuals directly pay, as well as unpaid services and loss to society through premature deaths. Other important questions include: Should unit costs be used that would enable comparison of programs between provinces, or actual cost estimates for Nova Scotia? Should unit costs be used for a specific year to control for changes in costs over time? Is it possible to cost the need for palliative care, versus use of services at end of life? Answers to these questions depend on the reason why a costing study is being carried out. Once an accepted plan for costing data is put in place and complete data are available, annual and per decedent cost for end of life care can be estimated.

NELS ICE team members are co-investigators in other palliative and end of life care costing resource allocation studies which could complement this plan (Asada, Kephart, & Hurley 2006; Dumont et al. 2004). For example, the Dumont et al. research will provide costs that include and go beyond health system costs for 50 persons who were registered in the palliative care programs in five Canadian cities including Halifax. The study by Asada et al. investigates whether end of life should be explicitly accounted for in allocating resources based on need.

Programs and policies to provide financial support for end of life care are evolving. Estimating the costs of resources to try to attain equity in access to quality end of life care for vulnerable populations entails consideration of issues that are larger than this brief overview. While it is acknowledged that there is a need for cost studies, work in this area is only in its early stages. In time, further progress could be made on costing care at end of life in Nova Scotia given funding, time, expertise, and staff.

4.5. SUMMARY

Health service utilization data provide information about potential inequities in access to care. A proper understanding of the current situation with respect to end of life care in Nova Scotia requires an understanding of health service utilization, but taken by themselves, the data provided here are insufficient and therefore should not be used to draw any firm conclusions. There is much more work that can be done to identify inequalities in access and then move on to provide a better understanding of inequities.

What is known…	Health service utilization data for individuals dying of cancer and congestive heart failure as well as some information by potentially vulnerable groupings (children, elderly, female/male, urban/rural and neighbourhood income).
What is unknown…	Utilization for individuals who died of other diseases.
What we NEED to know…	Health service measures offered for those dying of chronic terminal diseases as well as information on other vulnerable and invisible populations.

RECOMMENDATIONS

Recommendation 8: In partnership with end of life care providers, improve the classification of end of life and palliative care.

Recommendation 9: Provide a broader understanding of the role of the hospital for end of life care including delineating the in-patient services that are critical for symptom control and terminal care; the role of the emergency department, intensive care unit, and alternate care beds; and the relationships between the use of hospital services and alternative community care, e.g., substitution and available options.

Recommendation 10: Continue to explore the use of the SEA (single entry access) MDS (minimum data set) home and long-term care data including an examination of its potential for recording palliative symptom assessment.

Recommendation 11: Encourage the development of palliative care service databases across the province with common data fields and definitions.

Recommendation 12: Further examine the role of long-term care facilities in the provision of end of life care.

Recommendation 13: Carry out multivariate statistical analyses to test hypotheses and control for confounding and interaction among variables to provide a more rigorous understanding of resources used to provide end of life care.

To assess provision of end of life care and to discern if needs are being met, population-based indicators of health and quality care are required. The traditional health care measures of survival and reduction of mortality are not the primary goals in end of life care. Instead, the aims are to reduce morbidity and achieve desired goals, e.g., symptom control, optimal communication, and preferred location of death.

Persons at end of life wish to have their physical, emotional, spiritual and practical, including financial, needs met. They also want to have trusted and knowledgeable health care providers, coordinated care, participation in decision making, and time to spend with loved ones (Heyland et al. 2006). This list outlines measurement challenges that require new approaches in subsequent surveillance reports. NELS ICE will not be able to measure all possible indicators of quality care, but aspires to begin to build mechanisms to measure what is important and possible.

Potential indirect population-based indicators of outcomes and quality care available from existing data include: location of death, continuity of care, time spent out of hospital, number of emergency visits, transfers to hospital in the last 48 hours of life, physician home visits in the last two weeks of life, home care use in the last six months of life, use of palliative care, and number of employed family caregivers utilizing the compassionate care benefit. While some of these are indicators of care provided they may also be seen as proxies for desired outcomes. This report will provide examples of a few of these variables: location of death, family physician continuity and home visits, time frame between palliative enrollment and death, and number of emergency visits. Appendix 2 of this report provides an overview of the development of these data.

There is debate surrounding the validity of proxy indicators of quality care reported herein. Recent qualitative research indicates that these fairly easily measurable indicators may need to be replaced by those that are more important to patients, their families and other care providers (Earle et al. 2003; Stewart et al. 1999). Indicator measurement work is expected to improve over the life of the NELS ICE grant. There is substantial work to be done in developing quality care measures for those dying of conditions other than cancer.

5.1. INDICATORS

5.1.1. Location of Death

Studies indicate that most people prefer to die at home if adequate community-based care is available. Hence, location of death has been used as an indicator of quality end of life care (Burge et al. 2003b).

In Nova Scotia, only 23% of adults dying of cancer between 1998 and 2003 died outside of hospital or long-term care facility; 73% died in hospital (Table 19).

Table 19: Location of death for adults dying of cancer, Nova Scotia, 1998-2003 (N=14,426).

Location of death	**Frequency (%)**
Out of hospital	3,261 (23.0)
Hospital	10,376 (73.2)
Long term care facility (2000-03 only)	543 (3.8)
Location of death dichotomy	
Out of hospital	3,804 (26.8)
Hospital	10,376 (73.2)

Location of death, as an optimal marker for quality of care, has been questioned by those who contend that a person's wishes may change as death approaches Also, the wishes of the dying may differ from that of their family. Furthermore, acute events may intervene making care at home challenging in the last few days before death. A better measure, therefore, may be time spent in hospital in the last weeks of life rather than the actual location of care in the last hours of life. If hospitalized, location within the hospital may also be relevant. The care received can potentially be quite different if the place of care is an emergency department, a palliative care inpatient service, an alternative level of care bed, or an intensive care unit.

5.1.2. Family Physician Continuity of Care and Home Visits

Continuity of care is cited as an important aspect of quality end of life care (Burge et al. 2003c; Burge et al. 2003a). Table 20 shows that 72.5% of adults dying of cancer had high family physician continuity (>0.8) as measured by the Modified Modified Continuity Index. Only 3.5% of these patients had a low (<0.5) continuity score. Continuity of care has been shown to also be associated with other indicators of quality such as emergency department use and location of death (Burge et al. 2003c).

Table 20: Modified Modified Continuity Index score for adults dying of cancer with at least three ambulatory family physician visits, Nova Scotia, 1998-2003 (N=14,426).

MMCI Continuity Score	Frequency (%)
High (1-0.8)	8,654 (72.5)
Moderate (0.5 - <0.8)	2,861 (24.0)
Low (<0.5)	420 (3.5)
Mean (SD)	0.86 (0.18)
Median (range)	0.91 (0.02-1.0)

A direct relationship was observed between the percent of adults dying of cancer that received at least one family physician home visit during the end of life and the neighbourhood income quintile. Table 21 shows that 54.8% received a home visit in the high income neighbourhoods and 40% in the low income neighbourhoods. 5.1.3. Timing of Palliative Care Program Enrollment

Table 21: Percent of adults dying of cancer that received at least one family physician home visit during the end of life, by neighbourhood income quintile, Nova Scotia, 1992-1997 (N=9,793).

Neighbourhood Income Quintile	Percent
High Income	54.8
Upper Middle Income	47.4
Middle Income	48.5
Lower Middle Income	41.6
Low Income	40

5.1.3. Timing of Palliative Care Program Enrollment

The percentage of persons dying of chronic disease that are enrollled in palliative care can be used as a marker of quality care at end of life. It is not clear what an appropriate upper level for palliative care referral rates should be. For example, many of those not referred in Halifax and Cape Breton Counties are long-term care facility residents who may be receiving appropriate care without a palliative care program referral. Also, specialized palliative care consultation program service is not required for all persons receiving home-based end of life care.

In Figure 16, reports that about 80% of adults dying of cancer are enrolled a palliative care program in the areas where these data are available. This rate is higher than rates typically reported. Rather than simply concluding the palliative care programs in Halifax and Cape Breton are performing comparatively well, NELS ICE indicator work has moved beyond this basic measure of quality of care.

Time from palliative care program enrollment to death has been proposed as a possible useful marker of quality care at end of life. This is because people dying of cancer who are only referred to palliative care within a week or two of their death, may not receive a comprehensive range of integrated services due to time restraints.

However, using the interval between palliative care program referral and death as a potential indicator of quality care has a number of challenges. Some persons are only diagnosed with terminal disease very close to the time of death, so in these cases, late referral may be the best that can be achieved. In addition to referral too late for optimal care, it is unclear whether a referral and assessment that are too far in advance of the need for terminal care is optimal, given that a very early referral to specialized palliative care may not be for complex and difficult symptom control. Thus, referrals to specialized palliative care more than three to six months before death may not be an optimal use of resources. Rather than the timing of referral in relation to the date of death, the number of transitions between care teams as death approaches may be a more meaningful indicator of quality care.

Females had a longer time period between enrollment and death than males for each of the 6 years studied (2000-2005) (Table 22). Among women, the lowest quartile (25%) was enrolled 20 days or fewer while this was about 17 days for men. The highest quartile was enrolled 150 days (five months) for women, and 125 days (four months) for men. The mean number of days between enrollment in a palliative care program and death for adults dying of cancer by urban rural classification illustrates that urban residents showed no substantial change in this marker over time while rural residents demonstrated a general increase in the number of days between palliative care program enrollment and death over the time period (Figure 24). The relationship

Table 22: Mean number of days between enrollment in a palliative care program and death for adults dying of cancer, by year and sex, Halifax and Cape Breton counties, Nova Scotia, 2000-2005 (N=4,764).

Year	Female	Male
2000	148	96
2001	149	119
2002	134	131
2003	153	149
2004	136	124
2005	134	107

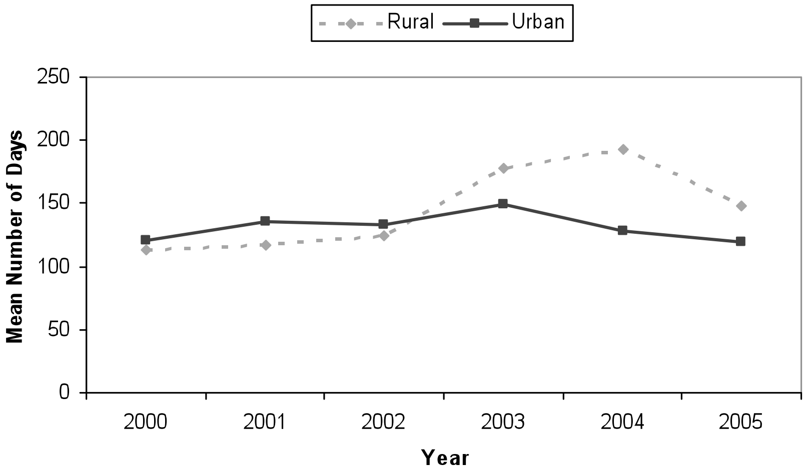

Figure 24: Trends in mean number of days between enrollment in a palliative care program and death for adults dying of cancer, by urban/rural classification, Halifax and Cape Breton counties, Nova Scotia, 2000-2005 (N=4,764).

between this variation and the expansion of the Halifax-based program into an integrated service versus other factors such as random variation inherent in small numbers of rural deaths has yet to be investigated.

These data highlight a measurement issue (Asada 2007). Should quality indicators be mean (arithmetic average) values, which may give undue weight to extreme times? Are median times with quartile ranges more useful, or is it more appropriate to discern whether a program operates within target or benchmark measures, e.g., referral to palliative care at least two weeks before death for persons diagnosed with terminal disease at least a month prior to death?

5.1.4. Emergency visits

Recurring use of the emergency department for end of life care is generally regarded as a potential marker of inadequate community-based care, and thus a flag for investigation of ways to improve end of life care.

Table 23 reports that of adults dying of cancer in Nova Scotia from 1992-1997, 44.3% reported no visits to the emergency department during the last six months of life. Approximately 26.4% had one visit while 13.2% had two, and 16.1% had three or more visits. An examination of the mean number of emergency department

Table 23: Emergency department visits in the last 6 months of life for adults dying of cancer, Nova Scotia 1992-1997 (N=9,793).

Number of ER Visits	Frequency (%)
0	4,339 (44.3)
1	2,585 (26.4)
2	1,296 (13.2)
3+	1,573 (16.2)
Median (range)	1.0 (0-29)

visits in last six months of life by family physician continuity score shows an inverse relationship between these variables (Burge et al. 2003a). Those with low continuity reported more visits to the emergency room.

From informal communications, it is noted that the emergency department serves a wide range of critical roles, from the initial diagnosis of a terminal disease, to symptom control in crisis situations, to advanced care support for long-term care facilities. Time spent in an emergency department waiting for a hospital bed, specialist consultation, and diagnostic tests may be useful to identify. Beyond the emergency department, the role of the ambulance and Emergency Health Services in end of life care also needs attention.

For these analyses, emergency department visit data was obtained from physician billing claims. It is assumed that the data for shadow billing i.e., services provided by salaried rather than fee-for-service physicians, are complete. Emergency department and ambulance services databases exist but have not yet been explored for use in NELS ICE end of life studies for validation of the physician-based emergency data, and for expansion of analyses of end of life care provision.

5.2. INTER-PROVINCIAL RESEARCH

Other Canadian provinces have also been working to identify indicators that may be useful in measuring the quality of care at end of life. One study used a retrospective breast cancer cohort to assess the feasibility, validity and reliability of using administrative databases to measure quality indicators of end of life care in Nova Scotia (NS) and Ontario (ON) (Grunfeld et al. 2006). Building on earlier conceptual work (Johnston et al. 2002), the authors concluded that using administrative data is an efficient way of monitoring quality and this can compliment other data collection methods (Grunfeld et al. 2006). For a summary of these results see Table 24. Although the results are specific to breast cancer, most of these indicators can easily be adapted to end of life care for any chronic disease.

5.3. SUMMARY

Population-based proxy or indirect measures of quality end of life care which have face validity can be obtained from linked administrative data. Included in this chapter were rates of dying out of hospital, continuity of care, home visits, palliative care enrollment, and few or no emergency department visits at end of life. These quality indicators can be reported by age, sex, geographic area of residence at death, cause of death, and other potential markers of vulnerable populations.

What is known…	Location of death, continuity of care, emergency room use and other indirect measures of quality care for cancer patients and some sub-populations
What is unknown…	How to best measure, at a population level, indicators of primary importance to the dying and their families.
What we NEED to know…	Relevant and valid indicators of quality care, and determine how to use them to ensure access to quality care for vulnerable populations of interest.

Table 24: Quality indicators in Nova Scotia and Ontario. Adapted from Grunfeld, Lethbridge, et al. 2006

Quality Indicator	**Statistic Description**	**NS**	**ON**
Interval between last chemotherapy and death	Any % receiving chemotherapy within the last 14 days	9.3%	15.7%
	Average number of days between last chemotherapy and death		
	Proportion receiving chemo in the last 6 months	71.1	60.3%
	Proportion receiving chemo in the last 14 days	26.2%	41.0%
		2.4%	6.4%
Site of death	Died in the hospital	63.4%	52.9%
Frequency of ER visits	More than one ER visit in the last month	5.6%	6.9%
	Average number of ER visits in the last month	0.41	0.44
	Average number of ER visits per available day in the last month	0.02	0.02
Hospital days near the end of life (Any inpatient days)	More than one hospital admission in the last month	11.7%	15.6%
	More than 14 days in the hospital in the last month	29.1%	23.9%
ICU days only	Average number of hospital days in the last month	9.9	9.8
	Average number of hospital admissions in the last month	0.70	0.86
	Percent with at least 1 ICU admission in the last month	*2.1%*	*4.1%*
Continuity of care	Modified Modified Continuity Index		
	i. GP only	0.79	0.73
	ii. Non-GP only	0.59	0.79
	Average number of GP visits (excluding <3 visits)	7.07	8.80
	Average number of GPs (excluding <3 visits)	2.18	2.66
	Average number of non-GP visits (excluding <3 visit)	10.28	57.29
	Average number of non-GPs (excluding <3 visits)	4.37	10.67
Time and location of care	Percentage of home and office visits that occurred in the last 2 weeks	10.5%	22.7%
Adverse events	Bedsore, infection, fall or injury	9.3%	12.6%
Enrollment in palliative care within three days prior to death	Enrolled in palliative care program within three days prior to death (for those enrolled in palliative care)	4.2%	NA
Access to palliative care	Enrolled in palliative care program	78.3%	NA
Radiotherapy for uncontrolled bone pain	Received radiation to the bones	21.9%	NA
Potent antiemetic for emetogenic chemotherapy	Prescription for Potent antiemetic in the last 6 months (65 years and older)	5.9%	10.5%
Multi disciplinary care	(a) Percentage of visits by GP	60.7%	30.3%
	(b) Percentage of visits by non-GP	39.3%	69.7%
Access to care	Rural residence	39.8%	15.1%
Interval between new chemotherapy and death	Had new chemotherapy in the last 30 days of life	2.6%	NA

RECOMMENDATIONS

Recommendation 14: While gaining insights from other countries and Canadian provinces, continue to contribute to the further development of population-based surveillance of quality care at end of life.

Recommendation 15: Use prospective study designs, as well as retrospective methods, to begin to examine the optimal sequences and combinations of end of life care provision given variations in needs and the timing of the identification of these needs to improve access to quality end of life care.

Recommendation 16: Promote the development of a sustainable province-wide end of life care surveillance system to plan how best to provide quality end of life care, evaluate programs, monitor care, carry out research, enable the provision of cost-effective equity in care at end of life.

In 2002, more than two million individuals aged 45 and older provided informal care to senior family members and friends in Canada (Keefe, Fancey, & White 2005). Among these, a vital role is played by informal care givers in delivering palliative and end of life care that enables more people to die at home. Care being provided often comes at considerable physical, emotional and financial cost to the persons involved. The financial burden and employment jeopardy of informal care providers led to calls for social and economic policies to ease the burden to informal caregivers providing.

There are national taxation and other policies that offered some compensation for family caregivers in Canada (Service Canada 2007), but no national direct compensation initiatives such as caregiver allowances or wages (Keefe et al. 2005) for the provision of end of life care by family or friends. Within Nova Scotia, new palliative care support policies and programs are emerging (Nova Scotia Department of Health 2007b). By including this chapter, recognition is given to the need for research development related to publicly funded programs that support end of life care by informal care givers in the home. Towards this goal, the new Canadian Compassionate Care Benefit was selected as a place to start.

6.1. COMPASSIONATE CARE BENEFIT

Canada introduced the Compassionate Care Benefit (CCB) in 2004 to enable family members to receive Employment Insurance (EI) to take time off work to provide supportive care to persons dying of terminal disease. The CCB is viewed internationally as an innovative means of support for palliative care. The CCB parallels the EI parental/maternity leave benefit, and is a direct response to the fact that the bereaved have been relatively disenfranchised in terms of access to funded health care services and support. However, the CCB has not been used to the degree expected.

Just over 300 Nova Scotia families submitted claims in 2004 and 2005 during a time period when an estimated 5000 (Canadian Cancer Society & National Cancer Institute of Canada 2005; Canadian Cancer Society & National Cancer Institute of Canada 2004) cancer deaths occurred, let alone deaths from other chronic diseases. Across Canada, fewer than 10,000 claims (Markovich 2005) or one family for every 25 persons dying of a chronic disease, were submitted for this new benefit in the 21 months after its inception. In fiscal year 2004/5, there were 445 claims per month being submitted; this decreased to 280 per month in 2005/6. Experience in Nova Scotia has been similar to patterns across Canada with a decrease from 15 to 11 submissions a month. Applicants were being denied claims due to eligibility and other restrictions (Williams et al. 2008) and this led to the federal government extending the definition of an eligible caregiver (Greenaway 2005) to help address the accessibility issue.

The CCB is targeted towards employed caregivers of children, parents or spouses at risk of death (Figures 25 and 26). In order to be eligible, regular weekly earnings from work must have decreased by more than 40% and the individual must have accumulated 600 insured hours in the last 52 weeks or since the start of the last claim. Persons who meet the eligibility criteria are entitled to a basic benefit rate of 55% of an individual's average insured earnings, to a maximum, taxable benefit of $413 per week. There is a limit of 6 weeks of benefits that can be shared by more than one family member (Service Canada 2007). Concurrent employment earnings are allowed up to a maximum of $50 or 25% of weekly benefits, whichever one is higher (Keefe et al. 2005).

The CCB, coupled with federal and provincial compassionate care leave protections, can help to provide "much-needed income support and job protection to individuals who care for seriously ill or dying family"(Osborne and Margo 2005). However, the issue of low uptake remains. Some studies have been and are being carried out on the CCB, but as yet most have not been released.

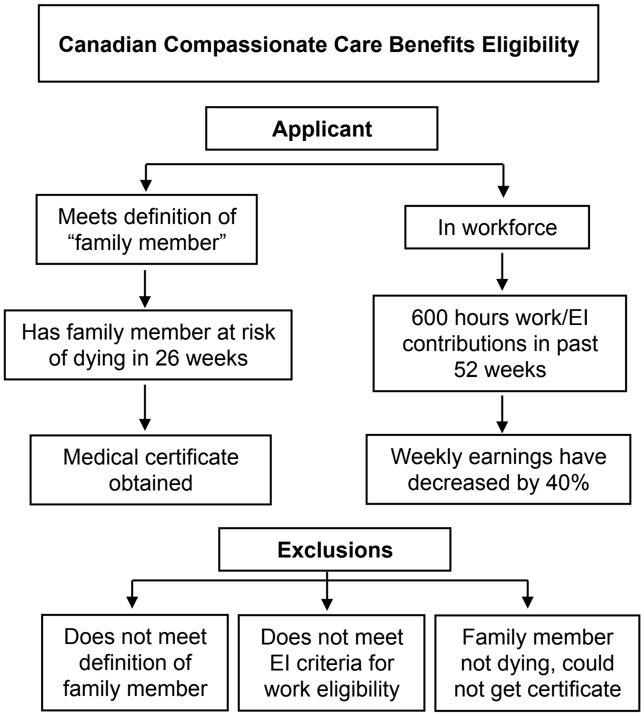

Figure 25: Human Resources and Social Development Canada Employment Insurance Compassionate Care Benefits eligibility criteria. Provided by Julie Lachance, Health Canada

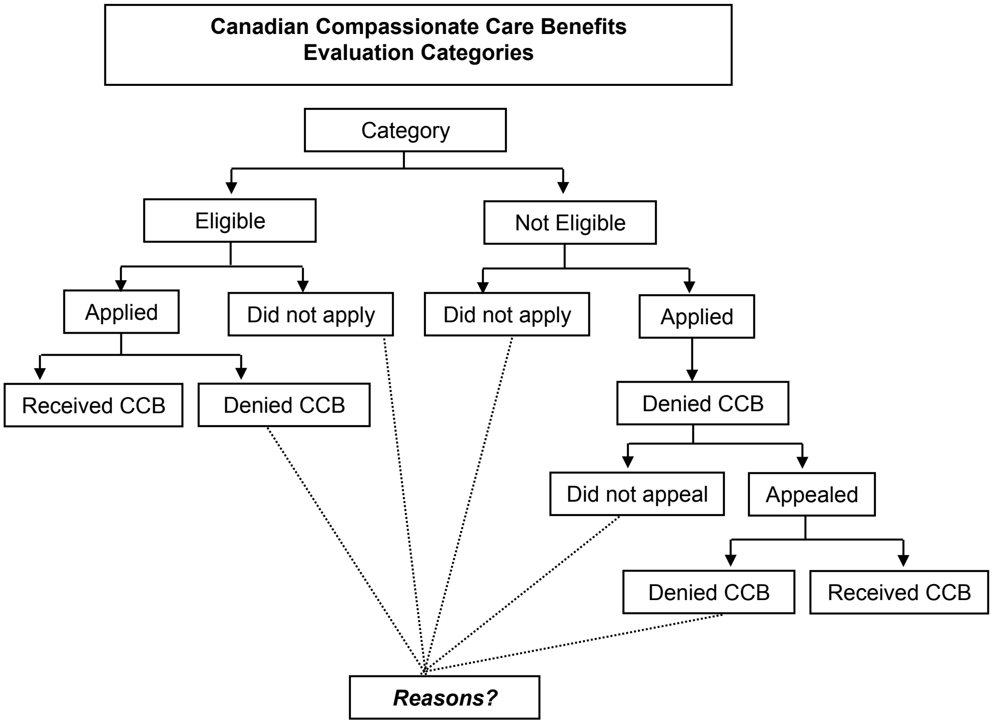

Figure 26: Human Resources and Social Development Canada Employment Insurance Compassionate Care Benefits evaluation categories. Provided by Julie Lachance, Health Canada

ICE researchers propose to complement other CCB studies through a focus on systems intervention points and the differential impact on vulnerable populations. A continuous improvement (Berwick 1989) cycle involving formal palliative care home visitation staff and human resource departments of employees caring for family members with terminal conditions is proposed for consideration to develop processes to improve understanding and extend home-based support for persons dying of terminal disease.

6.2. SUMMARY

Some federal and provincial support is in place for caregivers to help ease their financial burdens while caring for a loved one who is at the end of life. These services can help in maintaining emotional, physical and financial well-being of family care providers. However, the extent of support is limited and access can be seen as complex at a time when family coping is already strained. Recommendations 14, 16, and 17 in the previous and next chapters also apply to this chapter.

What is known…	Some national and provincial programs are in place to support those at end of life and their caregivers.
What is unknown…	Why uptake on some of these programs appears low.
What we NEED to know…	How to more effectively support family-based caring for persons at end of life.

To meet the expected demand for palliative care, health care professionals and consumers need user-friendly tools and educational resources to predict and plan for appropriate care (Dunbrack 2006). There is widespread societal, patient, family, and provider denial that death could be expected. As a result, there can be requests for more treatment to cure even when all available evidence indicates that this is futile.

When needs are greater than or differ from those that can be addressed by publicly funded services, individuals will need to seek help from within their communities. Engaging communities in varied ways can build support for meeting the emerging end of life care demands, as well as inform the development of new research. The NELS ICE knowledge translation plan is presented in Table 25. This Surveillance Report is one means of knowledge exchange between the NELS ICE research team and a range of persons and agencies interested in and affected by end of life care provision.

7.1. END OF LIFE TERMINOLOGY

Understanding is contextual, based on individual experiences and education. The lack of standardized definitions can also be problematic. Less experienced care providers report more confusion with terminology than their counterparts who have more experience (Dunbrack 2006). Members of interdisciplinary health care teams need to communicate effectively with one another, as well as with the person diagnosed with a life-threatening disease process and their family members. A common understanding and use of terminology is needed.

The World Health Organization (World Health Organization 2007) defines palliative care as:

> "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

A palliative care definition similar to that of the WHO is used by the Canadian Hospice Palliative Care Association (Canadian Hospice Palliative Care Association 2003b). Senator Sharon Carstairs, who has been the leader of the Secretariat on Palliative and End of Life Care, defines end of life care as all forms of care provided for the dying, including hospice palliative care (Carstairs 2005). While these are useful definitions to begin discussions on needs for education and community awareness, they are only the tip of the iceberg when it comes to language and meaning for effective communication.

7.2. EDUCATION OF HEALTH CARE WORKERS

Within Nova Scotia, several universities and the provincial community college educate health care professionals at both the pre- and post-licensure levels. Continuing professional education is also available through these institutions as well as professional associations. For example, the College of Registered Nurses of Nova Scotia (CRNNS) sponsored eight telehealth continuing nursing education programs on palliative care during the first quarter of 2006 (College of Registered Nurses of Nova Scotia 2006) and the Ian Anderson Continuing Education Program in End of Life Care from the University of Toronto (Faculty of Medicine University of Toronto 2006) conducts continuing professional education targeting end of life care. As well, Cancer Care Nova Scotia has Oncology Education for Health Professions and Palliative Care Front-Line Education Programs for community-based, primary care health professionals (Cancer Care Nova Scotia 2007). The oncology program is delivered onsite as well as online. Continuing professional education availability and delivery differs somewhat across Nova Scotia. For more information on how palliative and end of life care is integrated in some of these programs see Table 26.

7.3. PUBLIC AWARENESS

Individuals with internet access are able to access a number of public information and support sites such as the Hospice Society of Greater Halifax, Cancer Care Nova Scotia, Caregivers Nova Scotia, Nova Scotia Hospice Palliative Care Association, Capital Health Palliative Care Links, IWK Pediatric Palliative Care and the Canadian Virtual Hospice. Those who lack or prefer not to access computer resources or the Internet may request information by telephone or in person. Some printed materials lack the breadth and depth of the online versions, and often refer readers to the internet site. Online information is in English with some in French. Information in languages other than English or French is limited. Individuals without Internet access are often restricted to accessing information during the day from Monday to Friday.

To raise awareness, in conjunction with the 2007 May 7th to 13th National Hospice Palliative Care Week, the Canadian Hospice Palliative Care Association (CHPCA) distributed by Canada Post a small four-page, bilingual report. Readers were referred to websites for education, resources, event details, and donating. Not infrequently, the media is used as a means to review issues associated with care at end of life.

In addition to the availability of media, printed, and Internet information, a more comprehensive public awareness plan would include community engagement in active discussion and action plans. How this should be done is beyond the scope of this report, but NELS ICE recognizes its importance.

Table 25: NELS-ICE knowledge translation plan.
Source: First two columns are adapted from Davis et al (2005) with input from our own expertise and other literature. Table is included in NELS ICE proposal which CIHR funded (Johnston et al, 2005).

Features	Effective Knowledge Translation	NELS ICE Application
Settings for initiatives	Practice settings	1) Homecare, nursing home and other units providing community based end of life care; 2) Policy setting agencies and departments; 3) Research and professional trainee
Tools	To overcome barriers to change in terms overcoming health disparities	Surveillance reports, research pilot projects, international collaborators, Canadian networks
Targets for leadership in change efforts	Clinicians, systems managers, policy makers, populations at risk for inequity in provision of quality end of life care	Palliative, oncology, intensive and primary care clinicians; government, health care institutions, palliative and chronic disease agencies, vulnerable populations including advocates for African Canadians, women, children, and the elderly
Content	Evidence based information; systematic reviews; language that is clear, understandable and respectful of target groups	Synthesis of existing knowledge on quality end of life care, research project proposals, pilot project implementation, insights from listening and reflection
Guiding Model(s)	Holistic, clinician-learner, educational delivery, vulnerable populations and diversity	Interdisciplinarity, learning organizations, mentoring, continuous quality improvement, equity
Relevant disciplines	Medicine, varied research methodologies, education	Palliative and end of life clinical care, quality care processes, health services research, ethical analysis, database development, policy analysis, health and social systems management

Table 26: Inclusion of palliative care education at Nova Scotia universities and community colleges.
Prepared by Greta Rasmussen, 2007.

Institution	Profession	Undergraduate	Graduate
Dalhousie University	Medicine	•Four week medicine subspecialty clinical rotation in palliative medicine.	▪Palliative Care in first 2 yrs of Family Medicine post -grad curriculum. ▪Videoconferences, refresher courses, and community hospital programs as per site needs assessment. Online distance learning in collaboration with Memorial University plus web-accessible palliative care management materials.
	Nursing	•Palliative care elective; senior-level course includes end of life and brain death. ▪Nursing students may elect mandatory community placement study at a site offering end of life care and/or public education	•Elective courses on Death and Dying/Palliative Care and Oncology Nursing for those studying a Master of Nursing
	Pharmacy	Senior seminar deals with cancer and addresses some end of life care issues. ▪Pharmacy students may opt for compulsory Community Experience Program at a site offering end of life care and/or public education. Required hospital placement.	
	Social Work	Palliative Care education integrated in course on Aging.	•Palliative Care education integrated in course on Aging plus an elective on HIV/AIDS and Social Work Practice for those studying a Master of Social Work
	All health care professions	Students from 22 independent health care profession programs participate in 2-hr+ inter-professional learning module on Palliative Care which involves group work and a large panel discussion	
Cape Breton University	Nursing	*Information unavailable at this time*	
St. Francis Xavier	Nursing		•RN Certificate in Continuing Care via distance delivery
Nova Scotia Community College	Licensed Practical Nursing	•Oncology Nursing/Palliative Care is a required course	
	Continuing Care Worker	•Continuing Care is a required course	

7.3.1. Cancer Care Nova Scotia

Cancer Care Nova Scotia (CCNS) works in conjunction with the cancer care programs at the nine district health authorities to provide cancer care education and support to patients, families, volunteers, and professional caregivers. Their material is available in print and online.

In their 2000 and 2003 Public Opinion Surveys, CCNS reported that for approximately 80% of the people who directly or indirectly experience cancer, access to information about specific cancer types and treatment is critically important. Yet, approximately 80% of those individuals were less than completely satisfied in accessing this information (Cancer Care Nova Scotia 2000; Cancer Care Nova Scotia 2003). As a result, CCNS initiated the Cancer Patient Navigator program. Patient Navigators work in five of the nine health districts in Nova Scotia to provide cancer patients and their families with information about their cancer, in addition to coordinating visits for cancer treatment and assisting with transfer back into the home community after treatment (Capital Health & Cancer Care Nova Scotia 2005). Much of the navigator work may be associated with supportive care for persons with advanced disease.

7.3.2. Vulnerable Populations

Cancer Care Nova Scotia appears to be a leader in providing support for vulnerable populations at end of life. In CCNS's 2001 qualitative study on African Nova Scotians' Experience (Benton and Loppie 2001), participants indicated that their family or attending physicians experienced great difficulty and appeared detached when discussing cancer diagnoses. Furthermore, it was felt that these professionals could benefit from education on how to deal with the human aspect of diagnosis. Participants wanted to know as much as possible about treatment and community, cultural, spiritual, and health care resources. Participants had concerns about whether they may be experiencing lower levels of care due to issues of race and non-fluency in English. Basic patient needs such as ensuring the patient was comfortable and able to eat Western food were compromised. Participants also advised they were not made aware of information ranging from respite and support to transportation for treatment.

The recommendations that arose from these studies include: the need for more culturally specific materials, research based on the experiences of minority groups, anti-racism education for volunteers, and an acknowledgement by the main stream health care system of supportive services available in the cultural communities. The next chapter provides an example of new NELS ICE research focused on the African Canadian community. Some initial work has begun to focus on the experiences of the Mi'kmaq people and South East Asian immigrants.

7.4. SUMMARY

There appears to be a lack of general awareness of end of life care issues within the wider community. However, the emergence of new advocacy and information initiation are encouraging. Attention is being paid to educating health professionals and as a result, this sector has grown. At the pre-licensure level, educational institutions have taken steps to include palliative care in their health care coursework. At the continuing education level, professional associations such as those in nursing and medicine offer discipline-specific training. Some inter-professional continuing education is available. There is no one place or online site to obtain information. Some cancer specific education is available but equivalent end of life education and awareness beyond cancer is unknown.

What is known…	Some academic institutions and other organizations are taking steps to provide end of life care education and advocacy.
What is unknown…	The level of education and awareness of the general public with regards to end of life care.
What we NEED to know…	How best to target education and awareness initiatives.

RECOMMENDATIONS

Recommendation 17: Assist providers of professional and public education to help ensure this research is accessible for translation into evidence-based practice.

Chapter 2 provided an overview of potential vulnerable populations and their distribution. This Highlight chapter features the African Canadians in Nova Scotia by providing a more in-depth understanding of what is known and the research that is currently being undertaken. In this chapter, the terms African Canadian and Black are used interchangeably. The term African Nova Scotian has a more specific meaning in that it refers to the subgroup of indigenous Black people who settled in Nova Scotia prior to 1815 and their descendents.

Research began with Nova Scotia's African Canadian community because it is the largest visible minority group within the province, and some early end of life care research work has begun in this community. It is hoped that future reports will further elucidate aspects of culturally competent end of life care for a range of vulnerable populations.

NELS ICE believes that when discussing potential vulnerable and invisible populations, concerns should not be combined into broad categories to be addressed using cookie cutter methods. Each population is unique and their concerns surrounding health care and end of life care vary. It is necessary to take time to identify and address issues at the level of relatively homogeneous groups while noting variations within and across groups.

8.1. END OF LIFE ISSUES IN NOVA SCOTIA'S AFRICAN CANADIAN POPULATION

African Canadians comprise approximately 2% of Nova Scotia's population and they represent 52% of the province's visible minorities (Statistics Canada 2003). People of African descent were some of Nova Scotia's earliest settlers, with the exception of Aboriginal Peoples. There were three main waves of immigration in the period 1780-1815 that brought the Black Loyalists, Trelawney Maroons and Refugee Blacks to Nova Scotia (Henry 1973). In the period from 1815 to the present there have been several smaller migrations and in more recent times, there has been an increase in immigration from African and Caribbean countries. While there may be a shared cultural identity among African Canadians, there remains significant diversity within this community in terms of age, education, income, spiritual beliefs and practices, ability status, employment status, and country of origin, among others.

While there is a limited but growing body of literature documenting the health status of African Canadians, there is a substantial body of literature originating in the United States documenting the poor health status of African Americans and other cultural, racial and ethnic minority populations. Possible explanations for this difference in health status between Black people and non-Black people include racism, socio-economic deprivation, social exclusion, marginalization, the location of health services, lack of transportation, under-representation of Black people in the health care system, cultural insensitivity, and genetics (Enang 2002; Nazroo 2003).

While these findings can not be generalized to the Canadian setting, the literature on the health status of African Americans documents a strong relationship between racism and poverty and racism and poor health status (Marchand, Wikler, & Landesman 1998; Ross et al. 2000). In addition, there is research that demonstrates a strong relationship between poor health status and low socioeconomic status in minority populations (Adler and Newman 2002; Enang 2002; Marchand et al. 1998). Thomas (2001) defines racism as a "…pathogen with biological consequences" (p.1046). Racism has been a persistent feature of Canadian society that has been institutionalized in the form of legislation and public policy since the arrival of European settlers in the 1600s (Canadian Council on Social Development 2000; Driedger and Halli 2000). Institutionalized racism is present in the health care system (Maddalena et al. 2007).

One of the health issues facing the Black community in Nova Scotia is access to culturally appropriate end of life and palliative services. In 2005, the CIHR New and Emerging Team, Palliative Care in a Cross Cultural Context, funded a pilot study to begin examining cancer care experiences and the use of complementary and alternative medicine at end of life in Nova Scotia's Black communities (Maddalena et al. 2007). This research was conducted in partnership with the Health Association of African Canadians (HAAC), a Halifax-based organization that exists to promote the health and well-being of African Canadians living in Nova Scotia through community mobilization, development, and leadership in research.

Concurrently, NELS ICE quantitative researchers were exploring the use of postal code derived ecological measures to search in linked health administration databases for possible disparities in end of life care utilization by communities that have higher than average proportions of identifiable minority residents and indicators of deprivation. Individuals are not identified; rather, census derived profiles of enumeration areas are used for exploratory surveillance of cultural community patterns of care. While the emerging analyses are far from definitive, data is beginning to be generated that fosters dialogue among quantitative and qualitative researchers leading to new hypotheses and investigations. For example, preliminary data indicate that age adjusted rates of persons dying at home with cancer are higher than the Nova Scotian average for Black Nova Scotians. Literature indicates that higher rates of home death may be a marker of better quality care. However, a recent focus group study of Halifax Caucasians with terminal cancer which was led by Eva Grunfeld, a NELS ICE team member, challenges this premise when options for comprehensive community-based end of life care are inadequate. With ICE funding, another NELS ICE team member, Victor Maddalena, will be working with HAAC to explore end of life care issues in more depth for African Canadians living in one region of Nova Scotia.

Prior to this research being initiated, there was very little research examining palliative and end of life care in Nova Scotia's Black community. Cultural beliefs can influence many aspects of people's lives including their family decision-making structure, body image, and attitudes towards health, illness, pain, suffering and death, all of which have implications for end of life and palliative care. There are also cultural differences regarding the beliefs and practices of people from African and Caribbean cultures regarding palliative and end of life care (Spence, Merriman, & Binagwaho 2004).

The results of the pilot HAAC associated studies suggest that while differences exist among people of African descent in terms of cultural beliefs regarding death and dying, and gender roles in caregiving, there is a general expectation that family members will assume the primary caregiving role at end of life, and that this care will be in the home setting. While family-centered care is a well accepted feature of caring for the terminally ill in Black communities, there are challenges associated with this model of care including the multiple demands experienced by caregivers and the lack of culturally competent support systems to facilitate caregiving in the home setting and issues related to accessing medical care services. Rural-urban differences exist in experiences related to accessing health care services and to end of life care. Family interaction with the health system, communication between health professionals and families, knowledge of services available to support end of life care and the importance of spirituality were other themes identified.

Based on this pilot work, the researchers believe there is a need to conduct further research and develop policies and practices to support culturally competent end of life and palliative care in the Black community. Fostering understanding and accommodating the influence of culture when dealing with individuals and their families during terminal illness can facilitate the delivery of culturally competent patient care.

There is a need to develop new knowledge and new ways of engaging the Black community, researchers and health organizations in identifying, understanding and attending to the health needs of African Canadians. There is a need to develop information systems that document population demographics and health status in the Black community. In terms of future research specifically in the areas of palliative and end of life there are several areas worthy of further exploration including understanding the role of spirituality in terminal illness, exploring family knowledge of the health and social service systems to support end of life care, cultural understandings of pain and suffering and rural-urban differences in end of life experiences, among others. NELS ICE wishes to improve the basis for making policy decisions and designing interventions identified as being needed.

8.2. SUMMARY

This chapter was included to raise awareness on research to improve end of life care for people of African descent living in Nova Scotia. This chapter provides an example of research NELS ICE would like to encourage for other vulnerable groups.

What is known…	The history and emerging profile of African Canadians living in Nova Scotia identifying them as a potentially vulnerable population in terms of publicly funded end of life care provision.
What is unknown…	The care needs for identifiable cultural groups including African Nova Scotians.
What we NEED to know…	How best to provide end of life care for all. In particular, we need to also explore the needs and effective options provided to other subgroups who face marginalization including other ethnic/cultural groups, the deaf and hard of hearing, the disabled, and the homeless.

The Network for End of Life Studies (NELS) enhances interdisciplinary research capacity through collaborations that:

- identify disparities and inequities in quality end of life care;
- explicate end of life care vulnerabilities; and,
- develop and test applications to overcome inadequacies in publicly funded quality care for persons approaching end of life with chronic disease.

Through the Canadian Institutes of Health Research funded Interdisciplinary Capacity Enhancement (ICE) strategic grant, efforts are being made to identify and reduce health disparities and promote equity in access to quality end of life care for vulnerable populations.

NELS ICE research is focused in Nova Scotia and, in particular, the Capital Health district which includes the city of Halifax. This surveillance report is a synthesis of research progress to date and plans for upcoming years.

NELS ICE team members will continue to work with others to extend this program of research, help translate research into practice and build a sustainable and useful surveillance system. This work is important since it is known that what can be measured tends to be what is managed. Creativity, interdisciplinary reflection, and dialogue with national and international colleagues grounded in an understanding of local practice will be hallmarks of NELS surveillance and research.

NELS ICE researchers aim to make a difference in the lives of others. Through the uptake of ideas from research, access to quality care for persons dying of chronic diseases can be improved. In particular, NELS ICE hopes to improve the situation for vulnerable populations having less than optimal end of life experiences as a result of factors beyond their control. Thus, throughout this report and listed together below, are the recommendations that have been developed during the preparation of this first surveillance report. The recommendations are focussed on what research and research support is needed to provide the necessary evidence for program and policy initiatives.

Recommendations that relate to issues deemed beyond the ability or the mandate of the NELS ICE research team to address directly have not been included. For example, recommendations for health systems change to increase the integration of end of life care provision or to increase health system funding are excluded. However, advocates for improved hospice, end of life, and palliative care may use this report and the research of the NELS ICE team to build the evidence needed to improve access to quality care for all.

Recommendation 1
In dialogue with others, continue to refine and develop comprehensive conceptual frameworks that help elucidate dimensions of vulnerability, disparities, and inequities in access to and receipt of quality end of life care.

Recommendation 2
Produce further reports that openly share and critique ideas and examples from research that challenge and extend the way we think about access to quality end of life care.

Recommendation 3
Work with others so that worthwhile aspects of end of life care surveillance, quality indicator reporting, knowledge exchange, and improved access to quality end of life care for vulnerable populations become sustainable.

Recommendation 4
Design and carry out population-based studies to better understand the needs of children and youth and the elderly as well as factors associated with sex and gender so that we can better discern where access to quality care may be sub-optimal and interventions can be designed to help improve care at end of life.

Recommendation 5
Improve our ability to identify factors associated with race, ethnicity, language, and culture that may adversely influence end of life care provision or, conversely, learn from these groups about ways and means to potentially improve care for all.

Recommendation 6
Gain a better understanding of the costs associated with end of life care in rural and urban areas with particular attention to persons living in communities where household incomes may compromise access to quality care.

Recommendation 7
Expand the clinical breadth of the research team so that we can gain a better understanding of end of life care issues for persons dying of chronic diseases other than cancer and including co-morbidities.

Recommendation 8
In partnership with end of life care providers, improve the classification of end of life care.

Recommendation 9
Provide a broader understanding of the role of the hospital for end of life care including delineating the in-patient services that are critical for symptom control and terminal care; the role of the emergency department, intensive care unit, and alternate care needs; and the relationships between the use of hospital services and alternative community care, e.g., substitution and available options.

Recommendation 10
Continue to explore the use of the SEA (single entry access) MDS (minimum data set) home and long-term care data including an examination of its potential for recording palliative symptom assessment.

Recommendation 11
Encourage the development of palliative care service databases across the province with common data fields and definitions.

Recommendation 12
Further examine the role of long-term care facilities in the provision of end of life care.

Recommendation 13
Carry out multivariate statistical analyses to test hypotheses and control for confounding and interaction among variables to provide a more rigorous understanding of resources used to provide end of life care.

Recommendation 14
While gaining insights from other countries and Canadian provinces, continue to contribute to the further development of population-based surveillance of quality care at end of life.

Recommendation 15
Use prospective study designs, as well as retrospective methods, to begin to examine the optimal sequences and combinations of end of life care provision given variations in needs and the timing of the identification of these needs to improve access to quality end of life care.

Recommendation 16
Promote the development of a sustainable province-wide end of life care surveillance system to plan how best to provide quality end of life care, evaluate programs, monitor care, and carry out research to enable the provision of cost-effective equity in care at end of life.

Recommendation 17
Assist providers of professional and public education to help ensure this research is accessible for translation into evidence-based practice.

In addition to the organizations and the team members cited in the acknowledgments at the beginning of this report, the NELS ICE research team is grateful for the contributions of the following individuals.

Name	Role and Agency	Contribution
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Sandra Cook	Manager, Patient Navigation Project, Cancer Care Nova Scotia	Patient Navigator information
Jafna Cox	Professor, Division of Cardiology, Dalhousie University	Congestive heart failure references and insights
Natalie Dawson	Research Secretary, Department of Family Medicine, Dalhousie University	Editing final report
Ron Dewar	Epidemiologist, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia	Projections for dying of cancer, CHF and COPD
David Emmett	NELS ICE Research Coordinator, May 2008 onward	Administrative Support
Jun Gao	Statistical Research Associate, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia	Cancer data for Chapters 4 and 5 for years 2000-2005
Mary Gillis	Administrative Assistant, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia	Meeting arrangements and NELS ICE staff support
Saleema Karim	Lecturer, School of Health Administration, Dalhousie University	Drafting the costing section
Karen Kieley	Research and Statistical Officer, Vital Statistics, Service Nova Scotia and Municipal Relations, Government of Nova Scotia	Grouped death counts for Chapter 3
Ruth Lavergne	MSc Student, Department of Community Health and Epidemiology, Dalhousie University	Rural-urban measures; Statistics Canada citation checking

Beverley Lawson	Research Associate, Department of Family Medicine	Family medicine, hospital and other data for cancer and CHF decedents in Chapters 4 and 5
Maureen MacIntyre	Director, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia	NELS ICE project and staff support; understanding of cancer data
Shauna McVorran	NELS ICE Knowledge Broker Trainee, April to August 2007	Prepared first drafts of this report with input from range of people and sources
Meaghan O'Brien	MHSA and Medical Student, Dalhousie University	Definitions and data background; drafting vital statistics tables
Greta Rasmussen	NELS ICE Co-ordinator, April to September 2007	Drafting Chapter 7; pre-release contact list; and advising on report
Judy Simpson	Palliative and Supportive Care Coordinator, Cancer Care Nova Scotia	Understanding of palliative care programs and education
Andrea Smith	MSc Student, Department of Community Health and Epidemiology, Dalhousie University	Proofreading early version of report
Christine Smith	Communications Coordinator, Cancer Care Nova Scotia	Preparation and leadership for press release of report
Robin Urquhart	Research Associate, Cancer Outcomes Research, Cancer Care Nova Scotia	Knowledge translation consultation
Rosalee Walker	Registry Assistant, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia	Citation support
Gordon Walsh	Epidemiologist, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia	Nova Scotia maps
Kim Widger	PhD candidate, University of Toronto	Pediatric palliative care references and insights
Alison Zwaagstra	Health Information Analyst, NELS ICE project starting January 2008	Proofreading and checking data in final report

The descriptive data reported in Chapter 2 were obtained from the 2001 Canadian Census maintained by Statistics Canada (Statistics Canada 2008). Information on the burden of death in Nova Scotia in Chapter 3 was obtained as group data counts from the Vital Statistics Division of Service Nova Scotia and Municipal Relations and classified according to the International Classification of Diseases (ninth and tenth revision) codes (Table 27).

The methods used for the data presented in Chapters 4 and 5 are provided in "Detailed Methods of Data Preparation for Research on Access to End of Life Care for Adults Dying of Cancer in Nova Scotia" by Meaghan O'Brien and Jun Gao (O'Brien and Gao 2005) and NELS published papers (Burge et al. 2002; Burge et al. 2003a; Burge et al. 2003c; Burge et al. 2003b). This section provides a brief synopsis of this methodology.

The end of life dataset was created through the linkage of individual-level data from population-based administrative data. The first phase of the linkage occurs within the Surveillance and Epidemiology Unit and includes data from the Nova Scotia Cancer Centre Oncology Patient Information System (OPIS), Nova Scotia Vital Statistics, the Capital District Health Authority palliative service serving Halifax County and the Cape Breton District Health Authority palliative care program serving Cape Breton County. Using probabilistic record-linkage software, LinkageWiz, and patients' names, dates of birth, OPIS chart numbers and health card numbers, the various data sets were linked. Ethics approval was obtained from the research ethics committees of Capital Health and Cape Breton District Health Authorities.

Place of death was obtained from death certificate information in OPIS. Also obtained from OPIS were sex, date of birth, date of death, cancer cause of death, postal code and county of residence, province of death, date of cancer diagnosis, and radiation and medical oncology consultation information. Palliative Care Program (PCP) databases were used to determine which subjects were enrolled in a PCP and the length of time from PCP enrollment to death.

These linked data were then sent to the Nova Scotia Department of Health where, after health card number encryption and removal of patient identifiers, deterministic linkages using encrypted health card numbers were made to the provincial hospital admissions and physician billing claims data through the Population Health Research Unit (PHRU). Provincial homecare data from the single entry access (SEA)scape minimum data set (MDS) were added by the Department of Health for 2003. Ethics approval was also obtained from the research ethics committees of Capital Health and Cape Breton District Health Authorities for this second linkage phase.

Table 27: Selected chronic diseases and their corresponding International Classification of Diseases codes.

Disease	**ICD-9[1] (Prior to year 2000)**	**ICD-10[2] (Year 2000 onward)**
Malignant neoplasms (cancer)	140-208	C00-C97
Diabetes mellitus	250	E10-E14
Chronic ischemic heart disease	412-414	I20, I25
Congestive heart failure	428	I50
Cerebrovascular disease (stroke)	430-434, 436-438	I60-I69
Chronic obstructive pulmonary disease (excluding asthma)	490-492, 496	J40-J44
Renal failure	584-586, 588-589	N17-N19

[1] ICD-9 refers to the Ninth Revision of the International Classification of Diseases

[2] ICD-10 refers to the Tenth Revision of the International Classification of Diseases

Aboriginal Identity: A Statistics Canada term that is used to refer to those persons who reported identifying with at least one Aboriginal group as well as those who reported being a Treaty or Registered Indian and those who were members of an Indian Band or First Nation.

African Canadian: This term refers to people of African decent who were born in or immigrated to Canada.

African Nova Scotian: This term refers specifically to indigenous Black people who settled in Nova Scotia prior to 1815.

Age: The specific age at which a significant event (e.g., death) occurs.

Compassionate Care Benefit: Canadian Employment Insurance benefit that is paid to persons who apply and are granted leave to be away from work temporarily in order to provide care or support to a family member who has been certified by a physician as having less than six months to live.

Culture: This term generally refers to dynamic, ever evolving and changing patterns of human activity that are created through individuals' interactions with the world. It is often symbolic, and identified through language, dress, music and behaviors. In general, the term culture denotes the whole product of an individual, group or society and is usually integrated into all aspects of an individual's life (Nova Scotia Department of Health 2005).

Cultural Competence: A set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals that enables the system or professionals to work effectively in cross cultural situations (Cross et al. 1989; Isaacs and Benjamin 1991).

Culturally Sensitive: This term refers to an individual that reduces resistance and defensiveness during interactions and acknowledges any bias that may influence their behaviour (Nova Scotia Department of Health 2005).

Data: Within this report, the term data is primarily used to refer to quantitative data (e.g., numeric or count data) although it can also be used to refer to qualitative information (e.g., case narratives, interviews).

District Health Authority (DHA): Organizational structure that governs, plans, manages, delivers, monitors, evaluates, and funds the health services for people of a defined geographic area. There are nine DHAs in Nova Scotia. Funding is provided by the provincial government.

End of Life: The months prior to death during which time the provision of quality, supportive care would be beneficial in achieving a good death for persons at high risk of dying of chronic diseases. This time period is typically defined by the regulatory environment rather than by empirical scientific data.

End of Life Care: All forms of care provided for the dying including hospice palliative care (Carstairs 2005) as well as curative treatments and care related to co-morbidites. In this report, hospital, physician, homecare, long-term care and oncology care that are publicly funded in whole or in part are included.

Ethnicity: Character, background or affiliation with a group of people who share a common ancestry or history (Nova Scotia Department of Health 2005).

Health: A state of complete physical, mental, social and spiritual well being and not merely the absence of disease or infirmity (World Health Organization 1946).

Health Inequality: Generic term used to designate differences, variations, and disparities in the health of individuals and groups (Kawachi, Subramanian, & Almeida-Filho 2002).

Health Inequity: Avoidable and unfair health inequalities (Whitehead 1992). A moral concept often associated with injustice and unfairness (Kawachi et al. 2002).

Homecare: The array of government funded (in whole or in part) services that are provided in the home and community setting, including nursing and personal care worker services.

Integrated Palliative Care: A palliative care approach in which all aspects of care are coordinated and teams of providers work closely together to provide health services and ensure a seamless flow of care as the patient moves through the system.

Marginalized Groups: Those societal groups, who, overtly or covertly, are perceived as lacking desirable traits or deviating from the group norms and therefore tend to be excluded by wider society. This can include racial and ethnic minority groups, the poor, the elderly, the sick, the disabled, the obese, teenage mothers and homosexuals amongst others.

Mean (Average): The mean of a list of numbers is the sum of all the members of the list divided by the number of items in the list.

Median: The value found in the middle of an ordered distribution (i.e., half the values are above the median and half of the values are below the median).

Median Household Income: The median household income is used to describe the socio-economic status of families in a geographic area. It divides households into two equal segments with the first half of households earning less than the median household income and the other half earning more. The median income is considered by many statisticians to be a better indicator than the average household income as it is not dramatically affected by unusually high or low values.

Medical Oncology: The treatment of cancers with chemotherapy, biological products or immunotherapy.

Modified Modified Continuity Index (MMCI): An index to measure the degree to which primary care services are provided by the same physician over time (Magill and Senf 1987).

Palliative Care: An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other physical, psychosocial and spiritual problems (World Health Organization 2007).

Palliative Radiation: Radiation therapy that is used to control the symptoms associated with many localized tumours that cannot be treated by other methods. These symptoms include pain, bleeding, and decreased function. This form of therapy can reduce pain and improve the patients' quality of life.

Quality Care: Health services for individuals and populations that increases the likelihood of desired health outcomes and is consistent with current professional knowledge (Donaldson and Field 1998).

Race: A social category used to classify humankind according to common ancestry or descent and reliant upon differentiation by general physical characteristics such as color of skin and eyes, hair type, stature and facial features (Nova Scotia Department of Health 2005).

Range: The difference between the highest and lowest values in a data set.

Standard Deviation: The most common measure of statistical dispersion, measuring how widely spread the values are in a data set. If the data points are close to the mean, then the standard deviation is small. Conversely, if many data points are far from the mean, then the standard deviation is large. If all the data values are equal, then the standard deviation is zero.

Surveillance: Ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and to improve health (US Centre for Disease Control 2001).

Vulnerable Populations: Those at risk at any particular point in time for unequal opportunity to achieve maximum possible health and quality of life because of differences in intrinsic and extrinsic resources that are associated with good health (Danis et al. 2002).

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