SOCIOECONOMIC PREDICTORS OF SHORT DIAGNOSIS TO DEATH FOLLOWING COLORECTAL CANCER DIAGNOSIS: A POPULATION-BASED STUDY USING RECURSIVE PARTITIONING

by

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The undersigned hereby certify that they have read and recommend to the Faculty of Graduate Studies for acceptance a thesis entitled "SOCIOECONOMIC PREDICTORS OF SHORT DIAGNOSIS TO DEATH FOLLOWING COLORECTAL CANCER DIAGNOSIS: A POPULATION-BASED STUDY USING RECURSIVE PARTITIONING" by Sheri Roach in partial fulfilment of the requirements for the degree of Master of Nursing.

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DEDICATION

This work is dedicated, with love and thanks, to the family and friends who provided support, collaboration, commiseration, and encouragement through the past four years. In particular, two people share credit for any and all of my accomplishments: Bill, who tolerated the exchange of a gainfully employed, participative partner for a quazi-sane student (again) with more grace and goodwill than one could hope for, and Nate, who joined us for the last two and a half years, and allowed me to definitively answer the question “how do people do this with kids?” I love you both immeasurably.

"I'm glad I did it, partly because it was worth it,
but mostly because I shall never have to do it again."

~ Mark Twain

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ABSTRACT

Timely access to end-of-life care is a growing problem. One under-referred group is adults who die shortly after cancer diagnosis. This group's challenges include a lack of definition for short diagnosis-to-death (SDTD), and inability of health care providers to identify risks for SDTD. Research indicates socioeconomic factors may influence access to end-of-life care, though how is unclear.

This study used recursive partitioning methods to define SDTD for decedent adults with colorectal cancer and identify socioeconomic predictors of SDTD. SDTD was defined as less than 18.5 days. Socioeconomic predictors included long-term care residence and community-level characteristics such as education, immigration, marital status, Aboriginal status, and income.

Results showed existing SDTD timeframes may be too long to adequately understand the population's needs, and indictors of risk may be unique for this population. Additional research could establish consistency for defining SDTD and clarify the utility of socioeconomic predictors for mitigating barriers to care.

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CHAPTER 1

Introduction and Background

Timely access to high quality end-of-life care is a growing problem for Canadians. Though research indicates that 90% of people who die in Canada could benefit from palliative care, only 30% have access to palliative care programs (PCPs; Carstairs, 2010). Currently, Canada has no national strategy for end-of-life care. Within individual provinces, palliative care is inconsistent with respect to availability of services, location of delivery, funding, and provider education (Carstairs, 2010; NELS ICE, 2008b, Quality End-of-Life Care Coalition of Canada, 2008). In Nova Scotia, palliative care programs have developed in an inconsistent and fragmented way across districts and care settings (Provincial Palliative Care Project, 2004). The disparity between need for care and provision of care exists even among populations that have traditionally had greater access to PCPs, such as people with cancer.

Despite recommendations that palliative care begin upon diagnosis of a life-threatening condition (Carstairs, 2010), research suggests that one in five adults dying of cancer in Nova Scotia's two largest health districts (Halifax and Cape Breton County) are not enrolled in a PCP (NELS ICE, 2008a). Additionally, there is evidence that certain groups are less likely to access palliative care. In Nova Scotia, one such group is people who die shortly after receiving a cancer diagnosis (Gao et al., 2011). It is reasonable to assume that despite their rapid demise, these individuals and their families would benefit from the holistic focus on symptom management, wellbeing, and coping with loss and bereavement that are the hallmarks of palliative care (Canadian Hospice Palliative Care Association, 2010b). Barriers to PCP access for this group include the inability of health care providers to consistently and accurately predict impending death at the time of

diagnosis and, more fundamentally, lack of a clear understanding of what constitutes a "short" diagnosis-to-death (SDTD) time frame.

While the interplay between multiple factors such as lifestyle, biological characteristics, and health service usage is undoubtedly important, researchers in population-based cancer care have voiced a need to understand how socioeconomic factors in particular impact cancer mortality and access to care (Walshe et al., 2009). Such knowledge, in combination with existing prognostic tools, might assist health care providers in recognizing individuals who are at higher risk of SDTD and ultimately, in providing those individuals with timely and appropriate care options. Additionally, socioeconomic indicators could provide insight for administrators and policy makers regarding efficacious use of available resources for end-of-life care.

The proposed study will employ a statistical process known as *recursive partitioning* as a means to identify socioeconomic predictors that are associated with SDTD following receipt of a colorectal cancer (CRC) diagnosis. Existing databases will be used. The purpose of this research is to determine which socioeconomic characteristics are potential predictors of SDTD, and consequently, reduced access to palliative care. This purpose will be addressed through two objectives: first, to define SDTD following diagnosis with CRC in a way that is meaningful and relevant for Nova Scotia and second, to identify socioeconomic predictors of SDTD. It is anticipated that these outcomes could be used to improve equity of access to palliative care within the province, identify opportunities for efficacious resource allocation that could improve Nova Scotians' death experiences, and contribute to earlier diagnosis by attending to the indicators earlier in individuals' illness trajectories.

Background

Colorectal cancer. CRC exists worldwide, with approximately 1 million incident cases per year (World Gastroenterology Organisation, 2007) and 610,000 deaths annually (WHO, 2011). In both Canada and Nova Scotia, CRC is an important health issue. It is the second leading cause of cancer death for both men and women (NELS ICE, 2008) and the fourth most common cancer diagnosis overall (Canadian Cancer Society's [CCS] Steering Committee on Cancer Statistics, 2011). CRC has a 63% five-year relative survival (CCS's Steering Committee on Cancer Statistics, 2011), and more than 35% of people diagnosed with CRC die of metastatic disease (CCS, 2006), often with substantial and unfulfilled palliative care needs. Though Canada's provincial cancer registries have not historically collected data on cancer staging at time of diagnosis, figures from the United States demonstrate a stark contrast between the relative five-year survival of people diagnosed in the early stages of CRC when the cancer is confined to its primary site (90.1%) and in late stage CRC when the cancer has metastasized to other sites (11.7%; National Cancer Institute, 2011). However, that time between diagnosis and death is far from uniform at any stage, and does not increase systematically with increasing stages, complicating health care providers' abilities to assess the need for palliative care (CCS's Steering Committee, 2010).

Palliative care. In Nova Scotia, palliative care is defined as: "a combination of active and compassionate therapies that address the physical, psychological, social, spiritual and practical needs of individuals who are living with a life threatening illness and their families," (Provincial Hospice Palliative Care Project, 2005, p.1). The broad aims of palliative care are to relieve suffering, improve quality of living and dying, and support the bereaved (Provincial Hospice Palliative Care Project, 2005). Cancer Care

Nova Scotia (CCNS, ND) states that palliative care should be introduced early in conjunction with other services, and is appropriate for any duration of care whether it be days, months, or even years. The small body of research examining the impact of palliative care on the lived end-of-life experience of the client and their family suggests that PCPs can improve the client's physical and psychological symptoms (Manfredi, Morrison, Morris et al., 2000; Morrison & Meier, 2004), and improve family members' satisfaction with care (Gelfman, Meier, & Morrison, 2008; Teno et al., 2004). Participation in a palliative care program is a well-documented and widely accepted indicator of high quality end-of-life care (Earle et al., 2003; Gelfman, Meier, & Morrison, 2008; Grunfeld et al., 2008).

In Canada, there is growing awareness of the need to focus on palliative care as indicated by: the national establishment of specialized certification for registered nurses in hospice and palliative care nursing (Canadian Hospice Palliative Care Association Nursing Standards Committee, 2009); integration of palliative care into the curricula of Canadian medical schools (Educating Future Physicians in Palliative and End-of-life Care, 2008); the denotation of palliative care as a priority within Canada's federally funded cancer control strategy (Canadian Partnership Against Cancer, ND); identification of palliative care as a strategic national research priority (CIHR, 2010); and the initiation of legal analysis on whether palliative care could be considered an enforceable human right under the Canadian Charter of Rights and Freedoms (Carstairs, 2010). Yet despite the increasing acknowledgement of the need for consistent, high quality end-of-life health care, Canada lacks a national palliative care strategy, health care providers lack a consistent and collective understanding and means of providing palliative care, and the general public continues to misconstrue the purpose of palliative care. These factors

contribute to the glacial pace of implementing palliative care as standard treatment for terminal illness in Canada (Carstairs, 2010).

In Nova Scotia, the availability, funding, setting, and staffing of palliative care services vary widely across health districts and health care settings. Despite a swell of interest in creating and implementing a comprehensive, accessible, and integrated provincial approach to palliative care services in the early 2000s (CCNS, 2011a; Provincial Hospice Palliative Care Project, 2005), Nova Scotia has no provincial strategy or guidelines.

Description of the Problem

Recent evidence suggests that palliative care is far from universal (Bacon, 2008; Canadian Hospice Palliative Care Association, 2010c; Canadian Institute for Health Information, 2007; Marshall, Howell, Brazil, Howard, & Taniguchi, 2008). Though palliative care is theoretically considered an essential element of high-quality cancer care (Carstairs, 2010), and individuals with cancer have greater access to palliative care than those with other chronic diseases (Canadian Institute for Health Information, 2007), CCNS (2011b) reports that only about 70% of Nova Scotians who die from cancer access PCPs.

Research on end-of-life care indicates that socioeconomic factors may have an important influence on access to PCPs, though the nature of that influence in not fully understood (Lewis, DiGiacomo, Currow, & Davidson, 2011; Walshe, Todd, Caress, & Chew-Graham, 2009). Additionally, certain groups appear to be chronically under-referred to PCPs, including people who die shortly after receiving a cancer diagnosis (Johnston, Gibbons, Burge, Dewar, Cummings, & Levy, 1998; Gao et al. 2011, Gray & Forster, 1997, Moller et al.,2010; Morris et al., 2011).

The existing problem around palliative care access for people who die a short time after a CRC diagnosis is twofold: first, though research points to the gap in access, there is a lack of consistency and evidence for what is considered a SDTD time frame; and second, current prognostic tools and clinical indicators do not appear to sufficiently allow health care providers to identify individuals who require expedient referral to PCPs because they are at risk of dying shortly after diagnosis. For individuals who fall into this group, this means their health care needs, including pain and symptom management, psychological distress, and spiritual distress, may not be adequately addressed (Registered Nurses' Association of Ontario [RNAO], 2011), From a health systems perspective, this means the potential for misallocation of human and other health care resources, as well as financial costs associated with unnecessary hospital admissions (Brumley, Enguidanos, & Cherin, 2003; Brumley, et al., 2007), use of critical care beds in hospital (Gade et al., 2008; Gomez-Batiste, et al, 2006; Penrod et al., 2006), and inpatient hospital days (Gomez-Batiste, et al, 2006).

Research identifying socioeconomic indicators that might help to predict risk of SDTD following a CRC diagnosis could minimize barriers to access by assisting health care providers to introduce palliative care in a timelier manner. Additionally, these indicators could enhance the evidence base used by health administrators to make decisions about resource allocation and plan services in a way that is more conducive to providing appropriate care for this population.

Purpose and Objectives

The purpose of this study is to determine which socioeconomic characteristics may hold value as potential predictors of SDTD and consequently, lack of access to PCPs. From a patient-care perspective, the results of this study may contribute evidence

that will assist health care providers in making more timely referrals to PCPs, thus improving quality of care for individuals who die shortly after diagnosis and their families. From an administrative perspective, it may contribute to evidence used in planning and implementing a comprehensive, province-wide palliative care strategy and allow for increasingly efficacious resource allocation.

This study fulfills its purpose through two main objectives: (a) to develop a definition for a short diagnosis-to-death time frame for adults in Nova Scotia who are diagnosed with CRC; and (b) to identify evidence-based socioeconomic predictors of SDTD for adults with CRC that can be used to determine which clients may require expedited referrals to PCPs.

Context

The larger study. The proposed study is a component of a larger Nova Scotia cancer study (currently in progress) examining potential pre-diagnosis predictors related to palliative care for individuals with CRC. The proposed study will draw from the same population and data set as the larger study. The larger study will examine the predictive effects of numerous individual and population-based variables (see Appendix A for full list) on five outcomes that influence quality palliative care with the ultimate goal of identifying factors that contribute to poor quality palliative care (personal communication, G. Johnston, November 10, 2011). The outcomes under examination include: (a) enrolment in a PCP prior to death; (b) time between PCP enrolment and death; (c) location of death (hospital or home); (d) number of visits to an emergency department in the six months prior to death; and (e) time from diagnosis to death using predetermined lengths of time ranging from two weeks to 24 months. While socioeconomic factors will be included as part of the larger study, they will not be the

primary focus of analysis, and it is anticipated that their predictive effects may be overshadowed by other elements such as clinical factors and health services use patterns. This thesis was designed to focus primarily on SES predictors.

Socioeconomic focus. Currently, a focus on biomedical and behavioural risk factors dominates health sciences research as well as Canadian health policy and organization of health services (Raphael, 2009). This can be seen, for example, in the strong focus on factors such as genetic predisposition (biomedical) and alcohol or tobacco consumption (behavioural) when describing the risk for developing CRC. However, there is also a strong and longstanding argument that the social and economic conditions that shape the health of individuals and communities are equally, if not more influential when examining patterns of health and health service use (Raphael, 2009). As early as the mid-1800s, Engels (1845) argued that living conditions and day-to-day stress were equal to health behaviours in determining population health. More recently, numerous studies have demonstrated that social and economic health determinants are stronger predictors of health status than behavioural risk factors. For example, studies have shown that income (Diez-Roux, Link, & Northridge, 2000; Lanz, House, Lepkowski, Williams, Mero, & Chen, 1998), and geographic place of residence (Roux, Merkin, & Arnett, 2001) can influence health outcomes. Lanz et al., (1998) demonstrated that even if high-risk behaviours (tobacco and alcohol consumption, sedentary lifestyle, and increased body weight) were reduced in low-income groups, differences in mortality would persist between socioeconomically advantaged and disadvantaged groups in the United States. More recently, Galea, Tracy, Hoggatt, DiMaggio, and Karpati (2011) conducted a systematic meta-analysis of articles published between 1980 and 2007, and calculated that the number of deaths attributable to low education in the United States in 2000 (245,000

deaths) was comparable to that for myocardial infarction, the leading cause of death in the country that year (192,898 deaths). Similarly, they found the number of deaths attributed to racial segregation (176,000 deaths) was comparable to deaths from the third leading cause of death, cerebrovascular disease (167,661 deaths), and the number of deaths attributed to low social support (162,000 deaths) was comparable to deaths from lung cancer (155,521 deaths; Galea et al., 2011). Though their populations and methods differ, other studies have also found that socioeconomic factors such as lack of education (Woolf, Johnson, Phillips, & Philipsen, 2007) and poverty (Hanh, Eaker, Barker, Teutsch, Sosniak, & Krieger, 1995; Muennig, Franks, Jia, Lubetkin, & Gold, 2005) are as influential on mortality as pathophysiological and behavioural causes. This clearly demonstrates the need to give these factors due consideration when assessing health outcomes, as well as access to health services such as PCPs. Despite the fact that these studies focus on mortality rather than access to palliative care, they clearly show that the socioeconomic conditions shape the health of individuals and populations. Socioeconomic variables are strong, consistent predictors of health outcomes, and should be considered important indicators of access to health services such as PCPs (McGibbon, 2009). Based on this argument, socioeconomic variables will be the focus of this present study.

Theoretical Framework

Introduction to the Andersen framework. Andersen's behavioural model of health services use will be used as a framework for this study. Created in the 1960s, this model was the result of Andersen's efforts to operationalize the concept of health care access. Andersen observed that the goals of health policy and program reform were frequently directed at improving access or ensuring equal access to the health care

system, however definitions and measures of access were ill-defined or absent from these initiatives (Aday & Andersen, 1974). Optimally, the model offers a means to define and measure access to health care. Andersen's original model conceptualized access in the context of four contributing elements: characteristics of the health delivery system, characteristics of the population at risk, utilization of health services, and consumer satisfaction (Aday & Andersen, 1974). While these elements do not stand alone in the most recent iteration of the model (Appendix B), it is useful to understand them because they formed the original pillars of thought on which the model was constructed.

Characteristics of the health care delivery system. The first contributing element, characteristics of the health care delivery system, encompasses two elements: resources (e.g. health care providers, supplies) and organization, which is described as "the manner in which medical personnel and facilities are coordinated and controlled in the process of providing medical services" (Andersen, Smedby, & Anderson, 1970, p. 7). Organization of the health system can be broken into entry and structure. Entry is the process by which clients gain access to and move through the health care system, and can be assessed using indicators such as distance from services, travel time, and wait times (Andersen et al., 1970). Structure concerns what happens to a client once he or she is in the system, for example which health professionals provide care and the treatments and programs provided (Aday & Andersen, 1974).

Characteristics of the population at risk. The second contributing element, characterization of the population at risk, are the predisposing factors, enabling factors, and needs that influence a population's access to health care (Aday & Andersen, 1974). Predisposing factors are those that exist prior to the onset of need for health care and influence whether and how, an individual will access health services (Andersen, 1995).

These include demographic characteristics, socioeconomic factors, and beliefs about health, and may be measured using such variables as age, race, religion, and minority status. Enabling factors describe an individual's capacity to access and use social and economic resources in order to cope with health problems and access health care resources (Aday & Andersen, 1974). These include such measures as income, education, employment, and rural or urban residence. The final component, need, refers to the reason that an individual is seeking care (Aday & Andersen, 1974). Need may be defined from two different points of view: the individual's perception of their own need for care, or the health care provider's evaluation of the individual's need for care (Andersen, 1995). These two perspectives may or may not be congruent. Two assumptions are implicit in Andersen's characterization of at-risk populations: first, certain groups of people have more or less access to medical care than other groups, and second, access can be improved by utilizing knowledge about populations at risk to direct appropriate changes in health policy and health services (Aday & Andersen, 1974).

All three of the factors describing the population at risk – predisposition to use, enabling factors, and need for health services – may be described using both individual and contextual measures. Individual measures, such as age and sex, can be linked to a single person. Contextual determinants are aggregate measures that describe a community of residence such as mean levels of income and education as determined by census data (Andersen, 2008).

Utilization of health services. The third contributing element to access, utilization of health care services, refers to the type of care received, the setting in which care was received, the purpose of the care received (preventative, curative, or palliative), and the time frame over which care was received (Aday & Andersen, 1974). Utilization

is not only concerned with determining who receives care, but equally with determining who does not receive care. Utilization measures such as contact (whether or not a person accesses the health care system), volume (the number of contacts in a given time interval), and continuity (the coordination between health care services) are often used to validate the effects of various characteristics of the health care system on at risk populations (Aday & Andersen, 1974). Inherent in this is the assumption that utilization may be used as a proxy for access.

Consumer satisfaction. The final contributing element to access, consumer satisfaction, measures client satisfaction with the quantity and quality of care received (Aday & Andersen, 1974). Consumer satisfaction is usually related to a single episode or series of linked episodes of care, and is often centred around elements such as convenience, courtesy of health providers, and receipt of health information and education (Aday & Andersen, 1974).

Primary determinants of health services use. Andersen's conceptual model of health services use has evolved over time. In particular, the concepts around characterizing populations at risk have become increasingly prominent. This is clearly seen in the model's current iteration (Appendix B), in which Andersen (2008) has refocused the original four contributing elements into three primary determinants of health service use: contextual characteristics, individual characteristics, and health behaviours. The inclusion of separate categories for contextual and individual characteristics represents an evolving recognition of the importance of including aggregate measures that describe community characteristics in comparison to the more traditional focus on individual characteristics (Andersen, 2008). Additionally, the inclusion of predisposing factors as a stand-alone concept within each category is

underpinned by the belief that social and economic factors have become essential to understanding health care access (Andersen, 2008). While rooted in the overall theoretical tenets of the Andersen framework, which purport that access to health care is multi-facetted and complex, and its measurement requires consideration of multiple factors, the proposed study will capitalize on the increased theoretical focus on socioeconomic characteristics in an effort to explore and illuminate some of the socioeconomic factors that influence access to palliative care for dying individuals with CRC.

Use of the Theoretical Framework in Study Design

Andersen's conceptual model was used both in the selection of the analytical method for the proposed study and in identifying variables for predicting a SDTD following CRC diagnosis.

Analysis. Andersen (2008) suggests his model would best be utilized with an innovative statistical analytical process. Though he does not identify particular statistical methods, his framework, which facilitates consideration of multiple variables simultaneously, would be well served by the application of a statistical approach that is designed to incorporate multiple variables. Since the data for the proposed study is drawn from a series of large, linked administrative databases, algorithms extending from data mining technologies were examined for their potential use.

In health care, as in other information-rich fields, the challenges related to information are shifting from a focus on data generation and storage to a focus on how to best interpret and analyze large volumes of multidimensional data (Berger & Berger, 2004). Data mining uses advances in machine learning and artificial intelligence to extend traditional statistical methods in order to examine large data sets in different ways

than was previously feasible (Fayyad, Piatetsky-Sharpiro, & Smyth, 2002). Recursive partitioning is a means of predictive modeling that examines the effects of any number of predictor variables (e.g. multiple socioeconomic variables) on a single outcome variable (e.g. time from diagnosis to death). Recursive partitioning will be further described in the methods chapter (Chapter 3) of this thesis.

Selection of variables. Andersen's conceptual model was also instrumental, in conjunction with a review of existing literature, in identifying appropriate predictive variables for inclusion in the proposed study. In keeping with Andersen's evolving emphasis on contextual characteristics, Canadian census data was referenced heavily to establish relevant predisposing and enabling factors within contextual characteristics. Variables were also drawn from several databases to establish predisposing and enabling individual level predictors, need, and health behaviours. Table C1 (Appendix C) provides a summary of the variables that were considered for testing potential predictors of SDTD based on the Andersen model and review of literature.

Strengths and Limitations of the Theoretical Framework

Strengths. There are a number of elements of Andersen's model of health services use that facilitated the conceptualization of the proposed study. First, the model was intended to generate information that could be used by multiple end users, including those providing care and those making administrative decisions (Andersen, 1995). Since the objectives of this study include creating information that can be used by both health practitioners and administrators, Andersen's model provided a good fit. Second, the model was designed to assess the use of formal health services (Andersen, 1995) such as PCPs, or to explain health services access around a specific health outcome (Andersen, 2008) such as time from CRC diagnosis to death. Third, Andersen (1995) intended that

the model be used not only to explain, but to predict health services use. This was key in the decision to use the Andersen framework, as the purpose of the proposed study is to identify predictors of SDTD, and the guidance of a model with predictive intent was valuable in selecting variables to include in analysis. Fourth, the importance that the model places on assessing contextual, population-based predisposing characteristics and enabling resources (Andersen & Davidson, 2007) is congruent with the proposed study's focus on socioeconomic factors, and offers a framework for selecting relevant variables to include in the study from the vast pool of data available. Finally, the model was designed to accommodate the inclusion of different types of information from various sources (Andersen, 1995), which is ideal for a study that proposes to utilize data from a series of large, linked administrative health databases as well as Canadian census data, as is the case with the proposed study.

Limitations. There are also some limitations in utilizing Andersen's framework for the purposes of the proposed study. First, the concept of need is difficult to define. Though it is one of the key elements in describing both individual and population-based characteristics, Andersen's conceptualization of need has been described by critics as amorphous and contentious due to the frequent incongruence of client and caregiver perspectives (Andersen, 1995). Need in the proposed study will be based on diagnostic assessment of cancer stage at diagnosis, which is demonstrative of the caregiver perspective of need. Because the study is focusing on pre-diagnosis predictors, there is no available variable that adequately represents client perception of need for end-of-life care.

The second limitation is the potential incongruence of Andersen's original utilization goals with those of the current health care system. When the model was

developed in the 1960s, increased utilization of health care services was a major policy goal, and fiscal constraints did not wield the same omnipresent influence that they do today (Andersen, 1995). Simply stated, one of the basic assumptions during the design of the model was that increased health services use was the central goal of analyzing access. Andersen (1995) has addressed these concerns by suggesting that researchers who utilize the model select outcomes and design analysis that focus on equal and equitable access that meets demonstrated need within the system.

A third limitation of the model for research in the current health care climate is its lack of means for addressing system capacities to accommodate changes that may be indicated as a result of research, especially increases in service provision. This is essential to consider for the purposes of knowledge translation and implementation of findings. Simply because gaps or shortcomings in the system may be identified, there is no guarantee that resources to address these gaps will be readily available. For example, the current capacity of existing PCPs in Nova Scotia may not be able to accommodate an increase in referrals. Despite the ethical challenge inherent in identifying a need for care that the system could potentially be unable to accommodate, there is an equally strong ethical dilemma in diagnosing clients with a terminal illness for which there is no curative treatment and failing to provide adequate health care that meets their end-of-life needs. For the purposes of the proposed research study, this shortcoming will be accommodated by addressing system capacity in the discussion section in the context of the analysis of findings. Initial exploration of the literature suggests that clients who are not receiving palliative care may be receiving other care that is less appropriate to their condition, and that reorganization within the system could allow resources to be reassigned in a way that

meets the needs of all clients more efficaciously (Dumont, Jacobs, Fassbender, Anderson, Turcotte, & Harel, 2009).

CHAPTER 2

Review of Literature

The following sections present a review of additional literature pertinent to achieving the purpose of the proposed study: to determine which socioeconomic characteristics may hold value as potential predictors of SDTD, and consequently, lack of access to PCPs. These sections will provide insight into the current state of knowledge around the influence of socioeconomic characteristics on access to palliative care, as well as existing knowledge around SDTD.

Socioeconomic Indicators for CRC Outcomes

Gaps in research around end-of-life care. Review of the literature identified only a modest number of studies examining the influence of socioeconomic inequalities on CRC outcomes, particularly related to end-of-life care and access to PCPs (Palmer & Schneider, 2005; Byers, 2010). Palmer and Schneider (2005) reviewed American research articles to examine which domains of social inequity had been investigated related to CRC care, and found the most widely researched domains were race, income, sex, age, immigrant status, insurance status, and geographic location. The authors identified points along the CRC health care continuum such as prevention, screening, diagnosis, and treatment, but did not include end-of-life or palliative care as one of those points. It was unclear in the review whether this omission was a reflection of the literature or the authors' views of what constituted a point of care along the CRC continuum. Despite the omission of palliative care, it was relevant that the major trends identified in the review included later CRC stage at presentation and decreased survival for people who were black, had lower income levels, lacked adequate health insurance, or lived in rural areas (Palmer & Schneider, 2005). The authors also found that while

women with CRC were at greater risk for death overall, there were conflicting results about the influence of sex on later stage at diagnosis (Palmer & Schneider, 2005). Palmer & Schneider (2005) also found that the vast majority of research on inequality in CRC care focused on screening, and identified a need to focus on other points along the cancer care continuum.

Byers (2010) examined trends in cancer mortality related to disparity and found that living in a neighbourhood with high levels of poverty and/or low levels of educational attainment was associated with later stage of CRC at diagnosis and lower levels of treatment. He also found that demonstrated improvements in cancer outcomes, such as the steady decrease in cancer mortality since 1990, were less pronounced for African Americans and those with lower levels of education, income, and employment (Byers, 2010). This review indicated an increasing gap in cancer treatment and outcomes driven by socioeconomic disparity (Byers, 2010). As with Palmer and Schneider's review (2005), Byers (2010) did not address access to palliative care at end-of-life in his review, punctuating the gap in research knowledge around this essential element of CRC care.

Deprivation and CRC mortality. Moller et al. (2011) found that more disadvantaged socioeconomic groups, as defined using an income-based deprivation index, experienced higher excess death rates from CRC than less disadvantaged groups, and that the effect was strongest in the first month after diagnosis and decreased over time. The authors suggested this was evidence of a CRC survival gradient based on socioeconomic status (Moller et al., 2011). Other studies using similar methods have found similar patterns of excess death in socioeconomically disadvantaged groups with other cancer diagnoses (i.e. higher excess death rates immediately following diagnosis

that tapered over time; Holmburg et al., 2010; Moller et al., 2010; Morris et al., 2011). It may be notable, however, that the same core group of researchers conducted all four studies. The postulated socioeconomic survival gradient resulting from these studies suggests two things: first, that there is a need to identify indicators that would help to predict which clients are most vulnerable to death immediately after diagnosis; and second, that socioeconomic characteristics may play a major role in helping to identify these clients in order to ensure they receive appropriate care.

Kelsall et al. (2008) also found a correlation between socioeconomic inequalities and CRC survival using a different deprivation index than Moller et al. (2011). The Australian index used in the study combined low income, low educational attainment, unemployment, unskilled occupation, and dwellings without motor vehicles to create an aggregate measure of socioeconomic status (Population Health, Planning and Performance Directorate, 2008). Kelsall et al. (2008) found the hazard ratio for dying of CRC was 0.80 (95% CI, 0.57-1.12) for the least disadvantaged group compared to the most disadvantaged group (1.00). The association remained after adjustments for numerous factors including age, sex, tumour stage, tumour characteristics, waist circumference, adjuvant chemotherapy and radiation, hospital caseload, and lifestyle factors. Findings of a relationship between socioeconomic disadvantage and poorer survival from CRC were consistent with several previous studies (Brenner, Mielck, Klein, & Ziegler, 1991; Munroe & Bentley, 2003; Wrigley et al., 2003).

However, there are also studies that refute these findings. Lejune et al. (2010) found that disparities in CRC survival, as measured by a third different deprivation index, only persisted after adjustment for age and stage for clients who received late treatment or no treatment at all. The deprivation index used by Lejune et al. originated in the United

Kingdom (UK), and was comprised of unemployment, not owning a car, not owning a home, and household overcrowding (Smith, Whitley, Dorling, & Gunnell, 2001), No disparities in survival were observed among clients who received treatment within one month of diagnosis (Lejune et al., 2010). However, Lejune et al. (2010) noted that the more deprived patient groups were the most likely to receive late treatment or no treatment. Shack (2009) also found that differences in stage at diagnosis at least partially attenuate the socioeconomic survival gradient.

Nur et al. (2008) found evidence of a survival gradient, but no significant deprivation gap in CRC survival at one and five years after diagnosis. The authors concluded that the gradient was likely due to health system factors such as delay in diagnosis and unequal access to optimal treatment (Nur et al., 2008). This study differed methodologically from those previously discussed. While the majority of research in this area consisted of population-based retrospective studies, Nur et al. (2008) performed a secondary analysis on a cohort from a randomized trial.

Lack of consistency for socioeconomic variables in existing research. There was very little consistency in the socioeconomic variables assessed across the studies reviewed. Four studies used deprivation indices (Kelsall et al., 2009; Lejeune et al., 2010; Moller et al., 2011; Nur et al., 2008), which are aggregate measures that include multiple socioeconomic factors. Even though three of the four were studies from the UK (Lejeune et al., 2010; Moller et al., 2011; Nur et al., 2008), all used different indices that included a different complement of variables, and offered little in the way of explanation about the authors' choices of indices. Smith et al. (2001) state that different deprivation indices are designed for different purposes, and are therefore likely to result in the identification of varying patterns of mortality. The lack of discussion around the choice

of deprivation index was a clear exemplar of a gap across all the literature reviewed: rationale for the use of selected variables or aggregates was not consistently provided. Walshe et al. (2009) suggest this may be because the vast majority of such studies are not theoretically driven. Whether it is a choice of the researchers or a limitation of space and submission criteria of various publications is unclear, but the lack of theoretical grounding makes data interpretation more difficult, obscures knowledge for use by end users such as health care providers and administrators, and may restrict the abilities of researchers to offer suggestions for future research directions (Walshe et al., 2009).

Other socioeconomic indicators: Literacy and location. Two additional socioeconomic variables – language/literacy barriers and geographic location– were addressed in the literature and bear mentioning for the purposes of the proposed study**.**

***Language and literacy*.** Though no literature was found about the relationship between language or literacy and CRC, there are studies that attribute language and literacy barriers to late-stage diagnosis and poorer survival in breast cancer (Longman, Saint-Germain, & Modiano, 1992; Ramirez, Suarez, Laufman, Barroso, & Chalea, 2000) and prostate cancer (Bennett et al., 1998). The literacy aspect seems congruent with the previous discussion related to the influence of education on cancer outcomes, but language barriers are not discussed in the research around cancer mortality. However, barriers to health services access faced by people who do not speak the language of majority are well documented in Canadian literature (Redwood-Campbell, Fowler, Laryea, Howard, & Kaczorowski 2011; Wu, Penning, & Schimmele, 2005). Minority status and ethnicity, including Aboriginal identity, are closely tied to language in research literature, and have also been shown to influence access to cancer care (Austin, Ahmad, McNally, & Stewart, 2002; Johnson, Mues, Mayne, & Kiblawi, 2008; Redwood-

Campbell et al., 2011). Though none of these studies focus specifically on CRC or access to palliative care, it would be reasonable to consider the potential effects of language barriers if socioeconomic variables such as immigrant status, Aboriginal identity, or a primary language other than English were shown to have predictive value in the analysis resulting from the proposed study.

Geographic location of residence. Existing research demonstrates the influence of geographic location on access to palliative care. In Nova Scotia, indicators of poor quality end-of-life care for individuals with end stage CRC such as visits to the emergency department in the last month of life and dying in hospital appear to be most significantly influenced by where the individual resides (Maddison, Asada, Burge, Johnston, & Urquhart, 2011). Maddison et al. (2011) found that urban residents dying of CRC were 3.31 (95% CI: 2.2-5.1) times more likely to visit an emergency department at least once during their last 30 days of life, but had lower odds of dying in hospital (0.48, 95% CI: 0.3-0.7). Gao et al. (2011) found that 72.8% of Nova Scotians with end stage cancer who lived less than 30 kilometers from the nearest PCP were registered in a PCP, as opposed to 48.3% of those who lived 30 or more kilometers away. Similarly, Lavergne, Johnston, Gao, Dummer and Rheaume (2010) found that the use of palliative radiotherapy by people dying of cancer in Nova Scotia declined with increased travel time to cancer treatment sites. This was consistent with a review of Canadian literature conducted by Maddison, Asada, & Urquhart (2010) that found geography and age were the two most influential factors for accessing end-of-life cancer care in Canada. Ahmed, Bestal, Ahmdzai, Payn, Clark, & Noble (2004) suggest this may be due in part to the dependence on primary care provider initiative in determining the need for PCP referral. They contrast this to curative care, which tends to follow a treatment trajectory

established by cancer care programs rather than depending on the discretion of individual practitioners (Ahmend et al., 2004).

SDTD Time Frame Following CRC Diagnosis

There is very little research that describes what constitutes SDTD following CRC or any cancer diagnosis. In Nova Scotia, two studies have suggested a U-curve relationship in which people with either a very short or very long time between cancer diagnosis and death have an elevated risk of low PCP enrolment (Gao et al., 2011; Johnston et al., 1998). However, the time frames suggested by these studies are difficult to compare due to differing settings, populations, and methodologies. Johnston et al. (1998) used multiple regression to examine all adults who died of cancer in the province between 1988 and 1994, and found that a time frame of less than six months between diagnosis and death was associated with a greater risk of late referral (referral within 14 days of death) and under referral to PCPs. Gao et al. (2011) used classification and regression tree analysis to examine all adults who died of cancer in Halifax and Cape Breton Counties between 2000 and 2005, and found that for people who did not live in nursing homes, 12 days was the point at which the largest difference occurred. In that study, only 36% to 54% of people who died within 12 days of receiving their diagnosis were registered in a PCP (Gao et al., 2011). A unique result from the Gao et al. (2011) study is that time from diagnosis to death was ranked as having greater influence on referral to palliative care than age at death, sex, and distance to a the nearest PCP.

Other studies suggest that the 12 day time frame is closer to a relevant definition of SDTD than six months. A study by Gray and Forster (1997) showed that people who died within 100 days of diagnosis were significantly less likely to receive specialist palliative care, and that those who died within 50 days were at even higher risk.

Additionally, in the previously discussed studies by Holmburg et al. (2010), Moller et al. (2010, 2011), and Morris et al. (2011), the findings that excess death from CRC occurred most frequently in the first month following diagnosis suggest that SDTD may be more aptly defined at or under 30 days. With the exception of Gao et al. (2011), all studies reviewed utilized lengths of time between diagnosis and death that were selected by the researchers with little or no discussion about the selection process. Though this omission may have been a function of content or space constraints dictated by individual publishers rather than oversight or intentional exclusion on the part of the authors, it nonetheless complicated efforts to determine a reasonable definition of SDTD.

The study by Gao et al. (2011), which employed a continuous variable for time between diagnosis and death along with a methodology designed to split the data at the point of greatest variance, produced a shorter SDTD time frame than had been suggested in any previous study. Utilizing a similar approach for the express purpose of defining SDTD in a way that is relevant in Nova Scotia could offer a data-driven value that assists health practitioners and administrators in providing more timely and appropriate care to individuals upon diagnosis of CRC.

The need for improved SDTD indicators. Beyond the need to identify a time frame for SDTD, this literature review demonstrated that the majority of health care practitioners struggled to determine the point along the cancer care trajectory when they should introduce or offer palliative care to individual clients (CCS's Steering Committee, 2010). At the root of the issue is the lack of consensus on a how to define end-of-life and at what point the approach of clinicians should change from a strictly curative approach to a combined or strictly palliative approach (Lorenz et al., 2008). In the absence of ability to anticipate death with a great deal of accuracy, and with the knowledge that "waiting for

near-certainty" (Lorenz et al., 2008, p. 150) would fail to identify most dying people in time, the effort to identifying predictors of SDTD that could guide clinicians by identifying subpopulations at greater risk of SDTD time frames seems like an appropriate step towards addressing this issue.

In light of the fact that the literature reviewed relied almost exclusively on categorical socioeconomic variables, there may also be an opportunity to identify data-driven predictors using continuous variables as indicators. While some variables, such as sex, are inherently categorical, the predominant use of logistic regression in previous studies may have resulted in the creation of groupings for variables such as levels of income or education that could be analyzed categorically. Multiple logistic regression, by nature, favours analysis of fewer variables over more variables, categories containing relatively equal numbers of individuals, and categorical variables over continuous variables (Kranzler, 2007). Using an alternate method of analysis with differing strengths and constraints than multiple logistic regression offers the opportunity to make use of continuous variables and allow data driven predictors to surface. The proposed study will capitalize on the selected methodology and employ continuous community-level variables such as median income and proportions of the population that are immigrants or Aboriginals. In order to assess the potential of each variable, no deprivation indices will be used.

Conclusion

The purpose of the proposed study – identifying socioeconomic characteristics that may be predictors of SDTD and consequently, increase probability of lack of access to palliative care – necessitates two objectives: (a) defining SDTD for the population of the study, and (b) evaluating the predictive value of various socioeconomic variables.

Existing research lacked clarity or a uniform approach to SDTD, demonstrating the need to create a definition of SDTD for the population in the proposed study.

While there is no doubt that socioeconomic variables play a prominent role in CRC outcomes and access to health services, palliative care was absent from the vast majority of studies and discussions. However, both the theoretical framework used to ground the proposed study and the literature reviewed supported investigation into the predictive value of socioeconomic variables on access to PCPs for individuals who die shortly following diagnosis.

Use of an analytical method that is novel to health care research may facilitate exploration of SDTD and identify socioeconomic predictors of SDTD in a way that would not be possible with logistic regression. This methodology will be more fully explained in the following research methodology chapter.

CHAPTER 3

Research Methodology

The analytical method chosen for the proposed study, Classification and Regression Tree (CART) analysis, has rarely been used in nursing research. However, as the challenges facing health researchers begin to shift from acquiring information to managing and finding meaning in the vast amounts of existing data, analytical tools such as CART offer the opportunity to process large amounts of data and extract patterns that might not otherwise come to light. The following sections describe the planned population, setting, and methods to conduct the proposed study, and will demonstrate why this novel method provides an ideal fit for the study's purpose: determining which socioeconomic variables could be used as predictors of SDTD, and consequently, lack of access to PCPs.

Sources of Data

The Access to Colorectal Cancer Services in Nova Scotia (ACCESS) database was developed to provide a five year population-based cohort that could be used as a resource for studies examining equitable access to CRC services along all points of the care continuum, including end-of-life care (Porter et al., 2012). Through the Nova Scotia Cancer Registry (NSCR), the ACCESS team identified all individuals diagnosed with CRC in the five year period between January 1, 2001 and December 31, 2005 (n=3501). Each case was staged through a comprehensive chart review and anonymously linked to several administrative health databases, including: the Oncology Patient Information System (OPIS), hospital discharge abstracts, physicians' billings, Vital Statistics, Pharmacare data, local palliative care and radiology department data from the major teaching hospitals in Nova Scotia, and the Mental Health Outpatient Information System

(see Appendix D for database descriptions). Statistic Canada 2001 census data was also linked to the ACCESS database. Using the Postal Code Conversion File Plus (Census Canada, 2007), each individual's postal code at the time of diagnosis was linked to a small geographic unit called a census dissemination area (DA), and therefore also linked to the socioeconomic census information in that DA (Porter et al., 2012).

Census data was also used to determine rural/urban residence based on the Statistics Canada statistical classification area (SACtype). SACtype classifies census subdivisions into three categories: census metropolitan areas (CMAs), which have an urban population of 100,000 or more and includes neighbouring municipalities where 50% or more of the labour force commutes to the urban core; census agglomerations (CAs), which have a population of 10,000 to 99,999 and includes neighbouring municipalities where 50% or more of the labour force commutes to the urban core; and CMA/CA influenced zones (MIZs), which are outside of a CMA or CA (McNiven, Puderer, & Janes, 2000). Further subdivisions of MIZs are strong MIZ (30% to 49% of workforce commutes to a CMA or CA); moderate MIZ (5% to 29% of workforce commutes to a CMA or CA), weak MIZ (0 to 5% of workforce commutes to a CMA or CA); and no MIZ (none of the workforce commutes to a CMA or CA or there are less than40 people in the workforce; McNiven et al., 2000). In the ACCESS database, and for the purposes of this study, the designation urban applies to CMAs, CAs, and strong MIZs, and the designation rural applies to moderate, weak and no MIZ categories.

Approval of data access. Ethical approval for creation of the ACCESS database, which extends to use for this present research study, was obtained from the Capital Health Research Ethics Board. The database was developed and is maintained in accordance with the Tri-Council's guidelines for database linkage. All personal

identifiers including name, health care number, address) as well as physician identifiers were removed prior to release of information to researchers for use (Porter et al., 2012).

Population

The population for the study was composed of adults (20 years and older) within the ACCESS cohort who died between January 1, 2001 and December 31, 2008 (n = 1,733). Date of death was determined from Vital Statistics records.

Study Variables

There are two sets of variables required to meet the objectives of the proposed study. The study variables are described, according to each objective, below.

Objective A: Defining SDTD in Nova Scotia.

Outcome variable. The first objective of the proposed study was developing a definition for SDTD for adults diagnosed with CRC in Nova Scotia. The outcome variable for this objective was registration of each individual in a PCP (yes/no). This variable was drawn from the palliative care databases of the province's two largest PCPs, Halifax and Sydney, which are located in Capital District Health Authority (CDHA) and Cape Breton District Health Authority (CDHA) respectively. These two district health authorities (DHAs) include about half of the provincial population. While it would be ideal to include all districts' palliative care databases, review of other databases at the time of formation of the ACCESS database found most of them to be incomplete and inconsistent in the recording of data related to palliative care programs and participation (R. Urquhart, personal communication, September 2011).

Predictor variable. The predictor variable for objective A was time from diagnosis to death (days). Date of diagnosis was determined through an extensive chart review by the ACCESS team (Porter et al., 2012). The use of a continuous predictor

variable was intended to illuminate data-driven patterns of time between diagnosis and death that would predict PCP enrolment. This would identify a SDTD that is relevant for the Nova Scotia population, in contrast to the arbitrary SDTD time frames that appear in previous studies (Gray & Forster, 1997; Holmburg et al., 2010; Johnston et al., 1998; Moller et al., 2010; Moller et al., 2011; Morris et al., 2011). The SDTD value determined from the population would then be used in the analysis for objective B.

Objective B: Identifying predictors of SDTD in Nova Scotia.

Outcome variable. The second objective was to identify socioeconomic predictors of SDTD for adults with CRC that could help determine which individuals would require expedited referrals to PCPs. The outcome of interest for this objective was anticipated to be time from diagnosis to death (days).

Predictor variables. The socioeconomic variables proposed for the second objective were selected based on the theoretical framework for the study, Andersen's model for health services use, and the literature reviewed. These included both individual-level and community- level variables. Individual-level variables were those that could be directly linked to an individual who was diagnosed with CRC. These were drawn from various sources in the ACCESS database (see Appendix C) and included: age, sex, DHA of residence, residence in a long-term care facility, and geographic location of residence (rural/urban). Community-level variables were those that could not be linked directly to an individual, but rather to the DA in which they resided. These were drawn from 2001 census data and included median income for each decedent's DA of residence as well as the proportion of a decedent's DA of residence that had not graduated from high school; was unemployed; was separated, widowed or divorced; were single parent households; lived alone; were immigrants; had Aboriginal ancestry; was

Black; and identified French as their mother tongue. Appendix C presents a summary of these variables, including definitions, data sources, and references from the literature review that support their inclusion in the study.

Analysis

The proposed study utilized CART methods in the R statistical software environment to model the effects of predictor variables on the outcomes of interest. CART is a means of predictive modeling that was developed from an inductive paradigm (Carbonell, 1989). CART models organize data in a way that facilitates recognition of general principles based on the known experiences of individuals; the basic assumption is that the past can serve as a good predictor of the future (Berger & Berger, 2004). CART methods employ a splitting process called binary recursive partitioning to repeatedly divide a population into increasingly smaller groups based on the effect that predictor variables have on a single response variable (Breiman et al., 1984). This process creates a decision tree which can be simply presented as a diagram (see Figure 1). Such trees are useful in clinical environments because they can generate decisions rules to be used by clinicians in numerous health care scenarios (e.g., wound care, treatment of a stroke) and are thus intuitively comprehensible to clinicians.

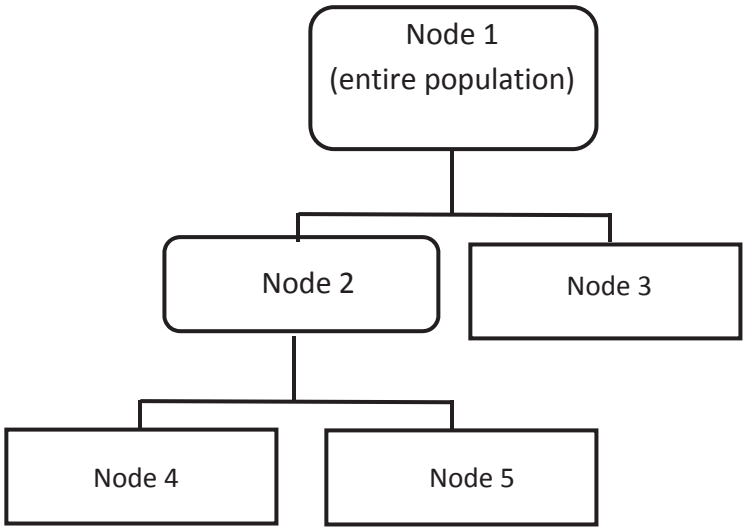

Figure 1. Sample of a classification and regression tree

Each group that forms in the tree is called a node. In Figure 1, nodes are represented by rectangles. The tree begins with the entire population in a single group called the root or parent node (Node 1), which is split into two groups called child nodes (Nodes 2 and 3). Node 2 represents the top of the tree's left branch and Node 3 is the top of the tree's right branch. Node 2 subsequently becomes the parent node for two more child nodes (Nodes 4 and 5). Each of Nodes 3, 4, and 5 could potentially become parent nodes for further binary splits, and so on.

CART methodology can be used whether the outcome of interest is categorical or continuous. If the outcome variable is dichotomous, such as whether or not members of a population were registered in a PCP (objective A), the resulting diagram is called a classification tree (Cheung, Moody, & Cockram, 2002). Trees that are used to predict

continuous variables, such as number of days between cancer diagnosis and death (objective B), are called regression trees (Cheung, Moody, & Cockram, 2002).

In both classification and regressions trees, each split occurs according to a formula that reviews all the potential splits based on the predictor variable(s) and chooses the split by which the resulting two child nodes have the greatest possible reduction of within-node variance (for continuous outcomes) or impurity (for categorical outcomes; Zhang & Singer, 2010). In the classification tree for objective A, this characteristic, which is described as "goodness of split" is mathematically represented by

$$\Delta I\,(s, \tau) = i(\tau) - \mathrm{IP}\{\tau_L\} i(\tau_L) - \mathrm{IP}\{\tau_R\} i(\tau_R)\,,$$

where τ is the parent node of τ_L (left child node) and τ_R (right child node), $i(\tau)$ is the impurity of the parent node, and $\mathrm{IP}\{\tau_L\}$ and $\mathrm{IP}\{\tau_R\}$ are the probabilities that a case falls into τ_L and τ_R respectively (Zhang & Singer, 2010). The program calculates the goodness of split for every possible split point in every predictor variable, and chooses the split that achieves the greatest goodness of fit. Essentially, this means that Nodes 2 and 3 are as different from one another as possible based on the selected split point and each child node contains cases that are as similar to one another as possible. So, for example, in objective A of the proposed study, the splitting point would be the number of days from diagnosis until death that creates two child nodes with the maximum possible difference in PCP registration (the outcome variable). If the split point was 12 days, as found by Gao et al. (2011), and the subsequent split on the right branch was at 34 days, the first three levels of the resulting classification tree might visually resemble Figure 2.

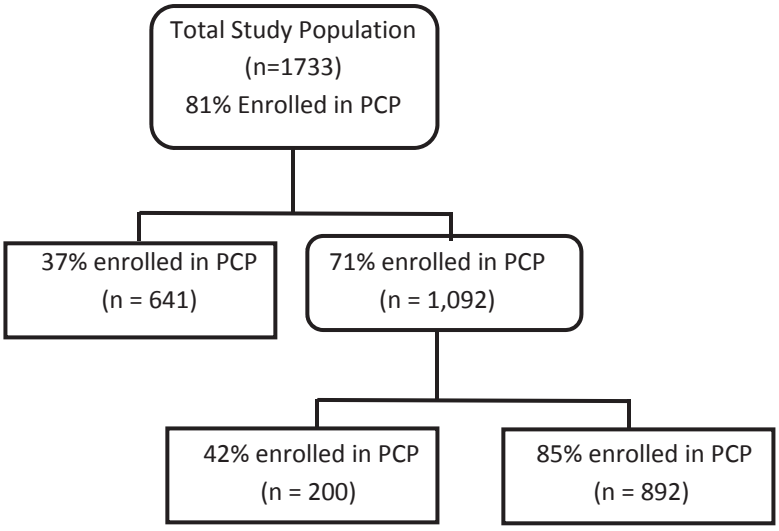

Figure 2: Hypothetical classification tree for objective B

The regression tree diagram for objective B would have a similar basic structure but operate under slightly different statistical principles, since the outcome variable is continuous. Statistically, a continuous outcome variable necessitates the assumption that the underlying relationship between the outcome (Y) and the set of *p* predictor (*x)* variables can be described by

$$Y = f(x_1,\ldots,x_p) + \varepsilon$$

where f is an unknown function and ε is a measurement of error (Zhang & Singer, 2010). The split function that must be maximized is

$$\phi(s, \tau) = i(\tau) - i(\tau_L) - i(\tau_R)$$

where s is an allowable split and

$$i(\tau) = \Sigma_{\text{subject } i \in \tau} (Y_i - \ddot{Y}(\tau))^2,$$

where $\ddot{Y}$ is the average of Y_i's within node τ (Zhang & Singer, 2010).

Not all predictor variables are represented in a CART diagram because some variables do not have a strong influence on the impurity of the nodes. Additionally, the same variable may come up more than once in the resulting tree, as is the case with the "age at death" variable in the example in Appendix E used with permission from Gao et al. (2011). The example demonstrates a more complex example of a CART diagram with numerous predictor variables. Trees such as this with multiple layers can be conceptualized as describing interactions between predictor variables (Merkle & Shaffer, 2010).

Setting parameters. The process of splitting parent nodes into successively more homogenous child nodes continues until one of three events occurs: further heterogeneity between terminal nodes and homogeneity within terminal nodes cannot be improved by further splits, there is only one element in each terminal node, or each terminal node satisfies an established preset condition that halts the process (Zhang & Singer, 2010). In order to ensure privacy of individuals within the database and avoid over-fitting the model to the data set such that the model becomes useless outside the study population, parameters are set to halt the splitting process. In the present research study, two such stopping criteria were used: minimum split and minimum bucket. The minimum split parameter is a guideline programmed to ensure that nodes that are smaller than a set size do not undergo further splitting. In this study, the minimum split size was 20 cases (minsplit < 20), thus any terminal node containing 19 or less cases did not undergo further splitting. The minimum bucket parameter ensures that the software will not perform a split that will result in a child node that is smaller than a specified size, regardless of the number of cases in the parent node. This prevents a scenario in which a node that is larger than the minimum split size ($\geq$20) is divided into two groups, one of which has

only one or very few members. In this study, the minimum bucket size was the rounded result of the minimum split divided by three (minimum bucket = rounded [minimum split/3]), or seven. Thus, there would never be fewer than seven cases in a terminal node.

Iterative analysis. Data mining is an interactive, iterative process, and often requires more flexibility in its design than traditional quantitative analysis. Initial stages such as understanding of the problem, understanding of data, and data preparation are frequently revisited and retooled throughout the research process including during later stages such as analysis and evaluation (Berger & Berger, 2004; Shearer, 2000). It was understood that during the analysis process, the value of including some variables might be reassessed and trees could be produced and were not conceived during the initial planning stages. This chapter focuses on the proposed research, and alterations to the proposed research plan are addressed with the discussion of results (Chapter 5).

Pruning. Since the objective of recursive partitioning is to distil homogenous subgroups from the original population for the purposes of predicting an outcome, the quality of a CART diagram resides in the quality of its terminal nodes (Zhang & Singer, 2010). Initial trees produced by CART programs may be so large as to be unwieldy, and additionally, may be saturated, thus running the risk of over fitting the model to the study population (Zhang & Singer, 2010). Determination of the quality of the terminal nodes allows the initial tree to be pruned to an optimal subtree that reduces these two problems. The quality of tree *T* is mathematically defined by:

$$R(T) = \sum_{\tau \in T}{}^{1} IP\{\tau\} r(\tau),$$

where T^l is the set of terminal nodes of T and r(τ) is a measure of the quality of node τ that is similar to the sum of squared residuals in linear regression (Zhang & Singer, 2010).

Optimal pruning was accomplished in this study using cross validation. In cross validation, the data is randomly divided into a determined number (K) of equal and exclusive partitions, K trees are generated on (K-1) / K of the data, and the average performance of these trees is used to assess the performance of the model. This is referred to as a K-fold cross validation. For example, to generate a 10-fold cross validated estimate of the performance of the CART model in the proposed study, the population (N = 1733) would be divided into K=10 groups, seven groups with 173 members and three groups with174 members. The tree-growing algorithm would then be applied 10 times to 90% of the data, each time with a different 10% removed, creating 10 different trees, each of which would contain 90% of the data. The performance of the model would be the average of the 10 trees. The resulting testing set tree will likely be too large and will over-fit the data. The tree can be pruned by evaluating the error at each set of two child nodes with a common parent by evaluating the error on the testing set to see whether the sum of squares would decrease if the two child nodes were removed (Zhang & Singer, 2010). If so, they would be pruned. This method is superior to arbitrary pruning and helps to ensure the tree remains grounded in evidence (Zhang & Singer, 2010).

Strengths and challenges of CART methodology. CART methodology has a number of strengths that make it an ideal fit for this study. First, unlike linear regression, CART is non-linear and can accommodate large numbers of variables (Berger & Berger,

2004), which would be conducive to examining SES variables. Second, the models produced by CART are highly transparent, so outcomes are easily explained and visualized (Berger & Berger, 2004). Second, as previously mentioned, for the purposes of knowledge translation, graphic portrayal of the results of a regression tree analysis offers an interpretation that is familiar and highly accessible to health care providers regardless of their background in mathematics or statistics (Teng, Lin, & Ho, 2006). Finally, like other machine-learning multivariate methods, CART is blind and unbiased in its selection of optimal splitting points (Baca-Garcia et al., 2006).

There are also challenges to consider when using CART analysis. One of these is that unlike logistic regression, CART does not calculate effect size, and therefore is not useful for consideration of independent effects of various variables on the outcome variable (Teng et al., 2006). While this is not a disadvantage in itself, it affects the comparability of results with studies that use more common traditional statistical methods such as logistic regression Another potential challenge with CART is that the nature of recursive partitioning may result in isolation of extremes within a sample that may pose a risk to the privacy of individuals by rendering them identifiable (Goodwin et al., 2003). Setting minimum split and minimum bucket parameters that prevent the isolation of single cases as previously discussed will remedy this problem. A final weakness of the CART methodology exists because of its ability to accommodate a large number of variables. Researchers may be tempted to include so many that the resulting process becomes an exercise in data dredging rather than an examination for meaningful patterns and information (Berger & Berger, 2004; Goodwin et al, 2003). The use of a theoretical model such as the Andersen model of health services use can assist in curbing the impulse to take a kitchen sink approach to analysis.

CHAPTER 4

Results

The following chapter will outline the results of the statistical analysis. As expected, the analysis was iterative and required revisiting the data set and the literature on a number of occasions as a measure to ensure that the two study objectives were addressed correctly and as accurately as possible. The following chapter will provide a summary of the key characteristics of the study sample and the final results of the analysis according to the two study objectives, which were to develop a definition of SDTD for adults in Nova Scotia diagnosed with CRC; and to identify evidence-based socioeconomic predictors of SDTD for this group.

Study Sample

The sample used for this analysis was drawn from the ACCESS database, which included all individuals in Nova Scotia who were diagnosed with CRC between January 1, 2001 and December 31, 2005 (n = 3,501). Excluded from the ACCESS database were individuals younger than 20 years old (n = 7), those diagnosed by death certificate or autopsy (n = 40), those with non-invasive or collaborative stage 0 CRC diagnoses (n = 262), and those diagnosed with lymphoma (n = 4) or cancer of the appendix (n = 18). Individuals with more than one diagnosis of CRC over the five year period were only included for their first diagnosis (or for the higher stage diagnosis in the case of synchronously diagnosed cases) (n = 117), meaning each person in the cohort was counted only once.

This thesis is based on a subset of the ACCESS database. The subset included all individuals from the ACCESS cohort who lived in CDHA or CBDHA[1] and stopped receiving care (i.e. died or left the study) between January 1, 2001 and March 31, 2008 (n = 894). Of these 894 individuals, 887 (99.2%) died and 7 (0.8%) lost their provincial medical services insurance (MSI) eligibility. Common reasons for loss of MSI eligibility include moving out of the province or switching to another health insurance program. Time from CRC diagnosis to death for individuals in the study ranged from 0 - 2,431 days.

Table 1 compares the study cohort to all ACCESS decedents. These individual-level data showed the study cohort was comprised of 604 individuals from CDHA and 290 individuals from CBDHA. There were n = 408 female and n = 486 males in the study. Individuals ranged in age from 27 - 98 years with a mean age of 72.6 years. Urban residents made up 89.8% (n = 803) of the cohort, while 10.2% (n = 91) were rural residents. Individuals who lived in long-term care facilities made up 11.9% (n = 99) of the cohort. The study cohort was more urban and younger than the overall provincial population.

Along with individual-level data, Table 1 shows community-level census data were also used to describe the study cohort. See Appendix F for a full list of community-level descriptors used in the analysis.

[1] This is a departure from the proposed plan of using a province-wide cohort (n=1,733) for objective B. Please refer to the discussion section (chapter 5) for explanation of the decision process associated with this change.

Table 1

Individual-Level Characteristics of Adults diagnosed with CRC who Died from 2001-2008 in CDHA and CBDHA compared to Nova Scotia

Variable	CDHA and CBDHA (n=894) n (%)	Nova Scotia (N=1733) n (%)
Sex		
Female	408 (45.6 %)	797 (46.0 %)
Male	486 (54.4 %)	936 (54.0 %)
Age (years)		
Range	27.0-98.0	21.0-101.0
Mean	72.6	73.2
Median	75.0	75.0
Cancer Stage at Diagnosis[a]		
I	73 (8.2 %)	152 (8.8 %)
II	213 (23.8 %)	391 (22.6 %)
III	197 (22.0 %)	408 (23.5 %)
IV	340 (38.0 %)	651 (37.6 %)
Unknown	71 (7.9 %)	131 (7.6 %)
Cause of Death		
CRC	602 (67.3 %)	1,201 (69.3 %)
Other cancer	80 (8.9 %)	143 (8.3 %)
Non-cancer cause	212 (23.7 %)	389 (22.4 %)
DHA of Residence		
CDHA	604 (67.6 %)	604 (34.9 %)
CBDHA	290 (32.4 %)	290 (16.7 %)
Other[b]		839 (48.4 %)
Rural Residence		
No	803 (89.8%)	1,045 (60.3%)
Yes	91 (10.2%)	679 (39.2%)
Unknown		9 (0.5%)
Long-term Care Resident		
No	795 (88.9%)	1,553 (89.6%)
Yes	99 (11.1%)	180 (10.4%)

Note. CDHA = Capital District Health Authority. CBDHA = Cape Breton District Health Authority. DHA = district health authority.
[a] Percentages are rounded, therefore may not add up to 100%. [b] Other includes: Annapolis Valley DHA, South Shore DHA, South West DHA, Colchester-East Hants DHA, Cumberland DHA, Pictou County DHA, and Guysborough Antigonish Strait DHA.

Table 2

Community-Level Characteristics of Adults Diagnosed with CRC who Died from 2001-2008 in CDHA and CBDHA compared to Nova Scotia

Variable	CDHA and CBDHA (n = 894)				Nova Scotia (N = 1,733)			
	Range		Mean	Median	Range		Mean	Median
	Min	Max			Min	Max		
Household income	$0	$138,930	$40,918	$38,357	$0	$138,930	$38,768	$36,590
Unemployment	0.0%	91.9%	47.9%	46.7%	0.0%	91.9%	48.5%	48.7%
Did not graduate	0.0%	75.7%	30.7%	30.4%	0.0%	75.7%	33.8%	35.2
SWD	5.2%	66.2%	19.2%	17.7%	5.2%	66.2%	19.3%	18.0%
Immigrants	0.0%	34.0%	5.4%	3.5%	0.0%	34.0%	4.6%	3.1%
Aboriginal origins	0.0%	99.4%	2.7%	1.9%	0.0%	99.4%	3.2%	2.2%

Note. CDHA = Capital District Health Authority. CBDHA = Cape Breton District Health Authority. All variables measured in percentage are proportions within the Census Canada dissemination area (DA) where each individual in the cohort resides. Unemployment = proportion of DA population over 15 years old without paid work. Did not graduate = proportion of the DA population over 15 years old that have not graduated high school. SWD = proportion of DA population who are separated, widowed, or divorced. Immigrants = proportion of DA who immigrated to Canada prior to 1986. Aboriginal origins = proportion of the DA who have Aboriginal ancestry.

Results by Objective

Objective A: Defining SDTD for the Study Cohort. Objective A was to identify a SDTD time that was relevant for Nova Scotians diagnosed with CRC. At the time this study was proposed, CDHA and CBDHA were the only two districts for which PCP registry data was available. Linkage to the PCP data in these districts showed that 560 (62.64%) of the 894 individuals with CRC who died in these two districts were registered in a PCP.

Recursive partitioning of the outcome variable *registration in PCP* (yes/no) by the continuous predictor variable *time from diagnosis to death* (days) produced the following classification tree (Figure 3).

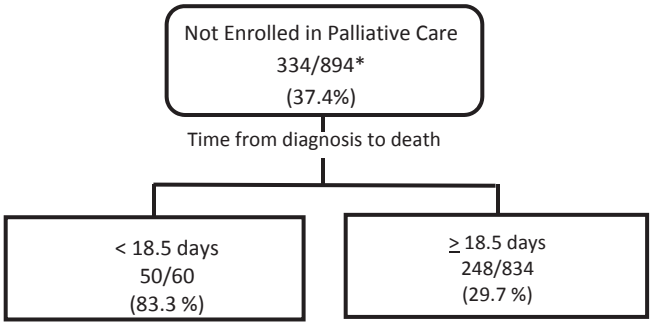

Figure 3. Classification tree showing registration in a palliative care program (PCP) as a function of time from diagnosis to death for study cohort.
*334 (37.4%) of the total study cohort (n = 894) were not registered in a palliative care program. All fractions in this figure represent the number of individuals not enrolled in a PCP (numerator) over the total number of individuals in the node (denominator).

Figure 3 shows that the only split in the classification tree occurred at 18.5 days from diagnosis to death, indicating that this is the split point at which the time from diagnosis to death caused the greatest heterogeneity in whether or not individuals were enrolled in a PCP between the two terminal nodes as well as the greatest homogeneity in PCP enrolment within the terminal nodes. CART analysis halts the splitting process when the predictor variable (time from diagnosis to death) can no longer split the outcome variable (enrolment in a PCP) in a way that decreases the heterogeneity of the terminal nodes. Figure 3 shows that no other lengths of time met the goodness of split criteria to predict whether or not individuals in the study cohort were enrolled in a PCP; 18.5 days was the definition of SDTD based on risk for not accessing palliative care in the study cohort.

The left terminal node shows that 83.3% of the 60 adults diagnosed with CRC who died in less than 18.5 days were not registered in a PCP. Comparatively, 29.7% of the 834 adults who died in 18.5 days or more were not registered in a PCP. Table 3 and Table 4 provide an overview of the key individual and community-level characteristics

respectively of the groups in each of the two terminal nodes in Figure 3. Table 3 shows that individuals in the SDTD group are more likely to be female (55.0% compared to 45.0% for the group who died in 18.5 days or more [non-SDTD group]), older (median age was 78.0 compared to 75.0 for the non-SDTD group), rural (13.3% compared to 10% for the non-SDTD group), and live in CBDHA (41.7% compared to 31.8% for the non-SDTD group). There are a greater proportion of individuals with unknown stage of cancer at diagnosis in the SDTD group (21.7) than the non-SDTD group (7.0%), and a greater proportion of the SDTD group (48.3%) died of non-cancer causes than the non-SDTD group (21.9%). Table 4 shows that individuals in the SDTD group live in DAs that had a lower median income ($36.668 compared to $38,445 for the non-SDTD group), higher unemployment (median was 49.7% compared to 46.7% for the non-SDTD group), higher proportions of residents who did not graduate from high school (median of 34.9% compared to 30.1% for the non-SDTD group), fewer immigrants (median proportion of 2.5% compared to 5.3% for the non-SDTD group), and fewer Aboriginals (median proportion 0.0% compared to 1.9% for the non-SDTD group).

Table 3

Individual-Level Characteristics of Adults from CDHA and CBDHA who Died Less than 18.5 Days vs. 18.5 Days or More Following Diagnosis

Variable	Diagnosis-to death < 18.5 days (n = 60) n (%)	Diagnosis-to-death ≥ 18.5 days (n = 834) n (%)
Age (years)		
Range	55.0-92.0	21.0-101.0
Mean	77.1	73.2
Median	78.0	75.0
Sex		
Female	33 (55.0 %)	375 (45.0 %)
Male	27 (45.0 %)	459 (55.0 %)
Cancer Stage at Diagnosis[a]		
I	4 (6.7 %)	69 (8.3 %)
II	14 (23.3 %)	199 (23.9 %)
III	12 (20.0 %)	185 (22.2 %)
IV	17 (28.0 %)	323 (38.7 %)
Unknown	13 (21.7 %)	58 (7.0 %)
Cause of Death		
CRC	29 (48.3 %)	573 (68.7 %)
Other cancer	2 (3.3 %)	78 (9.4 %)
Non-cancer cause	29 (48.3 %)	183 (21.9 %)
DHA of Residence		
CDHA	35 (58.3 %)	569 (68.2 %)
CBDHA	25 (41.7 %)	265 (31.8 %)
Rural Residence		
No	52 (86.7 %)	751 (90.0 %)
Yes	8 (13.3 %)	83 (10.0 %)
Long-term Care Resident		
No	50 (83.3 %)	745 (89.3 %)
Yes	10 (16.7 %)	89 (10.7 %)

Note. DHA = district health authority. CDHA = Capital District Health Authority. CBDHA = Cape Breton District Health Authority. CRC = colorectal cancer.

[a] Percentages are rounded, therefore may not add up to 100%.

Table 4

Community-Level Characteristics of Adults from CDHA and CBDHA who Died Less than 18.5 Days vs. 18.5 Days or More Following Diagnosis

Variable	Diagnosis-to-death < 18.5 days (n = 60)				Diagnosis-to-death ≥ 18.5 days (n = 834)			
	Range		Mean	Median	Range		Mean	Median
	Min	Max			Min	Max		
Household income	$0	$74,690	$37,419	$36,668	$0	$138,930	$41,170	$38,445
Unemployment	18.0%	91.1%	50.0%	49.7%	0.0%	91.9%	47.7%	46.7%
Did not graduate	4.4%	60.5%	33.9%	34.9%	0.0%	75.7%	30.5%	30.1%
SWD	8.9%	66.2%	20.4%	17.8%	5.2%	66.2%	19.1%	17.7%
Immigrants	0.0%	19.1%	4.4%	2.5%	0.0%	34.0%	5.5%	5.3%
Aboriginal origins	0.0%	9.5%	2.2%	0.0%	0.0%	99.4%	2.8%	1.9%

Note. All variables measured in percentage are proportions within the Census Canada dissemination area (DA) where each individual resides. Unemployment = proportion of DA population over 15 years old without paid work. Did not graduate = proportion of the DA population over 15 years old that have not graduated high school. Marital status = proportion of DA population who are separated, widowed, or divorced. Immigrants = proportion of DA who immigrated to Canada prior to 1986. Aboriginal origins = proportion of the DA who have Aboriginal ancestry.

Objective B: Socioeconomic predictors of SDTD. Objective B was to investigate socioeconomic variables as predictors of SDTD for adults diagnosed with CRC. The outcome variable for this objective, *death in less than 18.5 days* (yes / no), was based on the result of objective A. Recursive partitioning of this outcome variable by the socioeconomic predictor variables (see Appendix G for full list of study variables) resulted in the following classification tree (Figure 4).

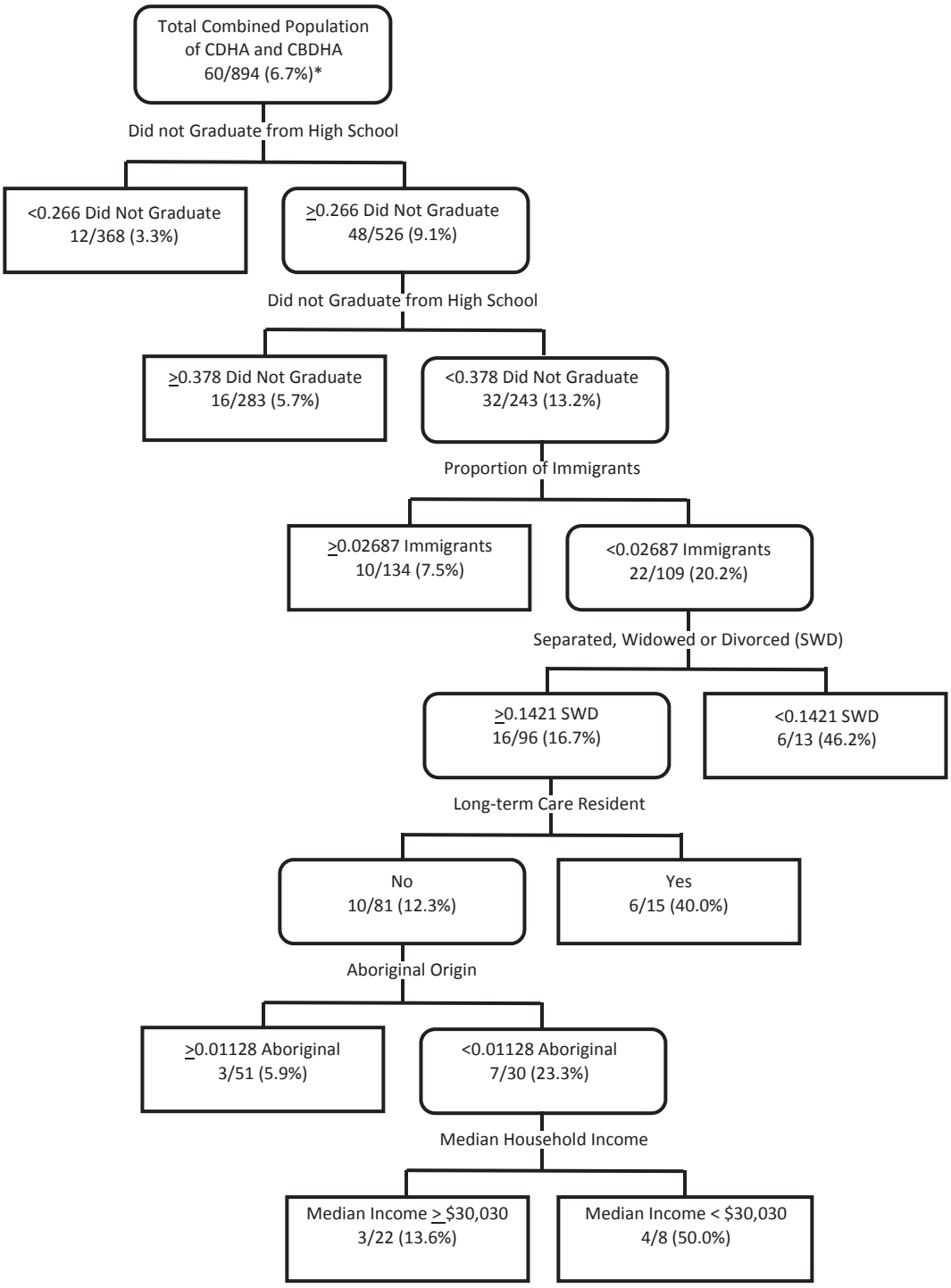

Figure 4. Classification tree showing socioeconomic predictors of diagnosis to death time of < 18.5 days for adults who died following colorectal cancer diagnosis in Capital District Health Authority (CDHA) and Cape Breton District Health Authority (CBDHA). [a]60 individuals out of the total number in the node (n=894) died in <18.5 days; each fraction is the number who died in <18.5 days (numerator) out of the total number in the node (denominator). The percentage is indicated in parentheses following each fraction.

Figure 4 shows the key socioeconomic predictors for dying in 18.5 days or less following a CRC diagnosis were: proportion of the community that graduated from high school; proportion of immigrants in the community; proportion of separated, widowed and divorced individuals in the community; residence in a long-term care facility; proportion of Aboriginal people in the community; and median household income for the community.

The first and second partition in the tree shown in Figure 4 was by proportion of people in the decedent's DA who did not graduate from high school. Individuals who were grouped in the left node (n = 368) lived in DAs where less than 26.62% of the DA population had not graduated from high school. Twelve individuals in this node (3.3%) died less than 18.5 days after being diagnosed with CRC. This node did not undergo any further splits and was therefore a terminal node. The individuals who were grouped in the right node (n = 526) lived in DAs where 26.6% or more of the population did not graduate from high school. In this node, 48 individuals (9.13%) died less than 18.5 days following diagnosis. In summation, this split showed that individuals living in DAs with high school completion rates higher than 26.6% were less likely to have a SDTD time frame.

The right node was again partitioned based on high school graduation. This split, however, showed that for the group that lived in DAs where high school completion was higher than 26.6%, individuals who also lived in DAs where fewer than 37.8% did not graduate from high school were more likely to have a SDTD time frame. High school graduation was the only predictor that appeared twice in the tree. Subsequent splits, in sequence, showed higher risk of a SDTD time frame for individuals who: lived in DAs

where less than 2.7% of the population were immigrants; lived in DAs where less than 14.2% of the residents were separated, widowed, or divorced; were long-term care residents; lived in DAs where fewer than 1.1% of the population had Aboriginal origins; and lived in a DA where the median income was less than $30,030. The two nodes resulting from the split based on income were the final terminal nodes.

Cross validation. The full regression tree from objective B (Figure 4) was pruned to the sub-tree shown in Figure 5 using 10-fold cross validation. This sub-tree was selected based on a mathematical balance between complexity (i.e. the size of the tree) and error (i.e. predictive accuracy). Error in a classification tree is generally highest when the tree has too few nodes (e.g. is pruned down to the root node) or too many nodes (i.e. the full tree). In a case such as this where there is no means of externally evaluating the predictive ability of the model, cross validation can be used to ensure the model is not over fit to the data.

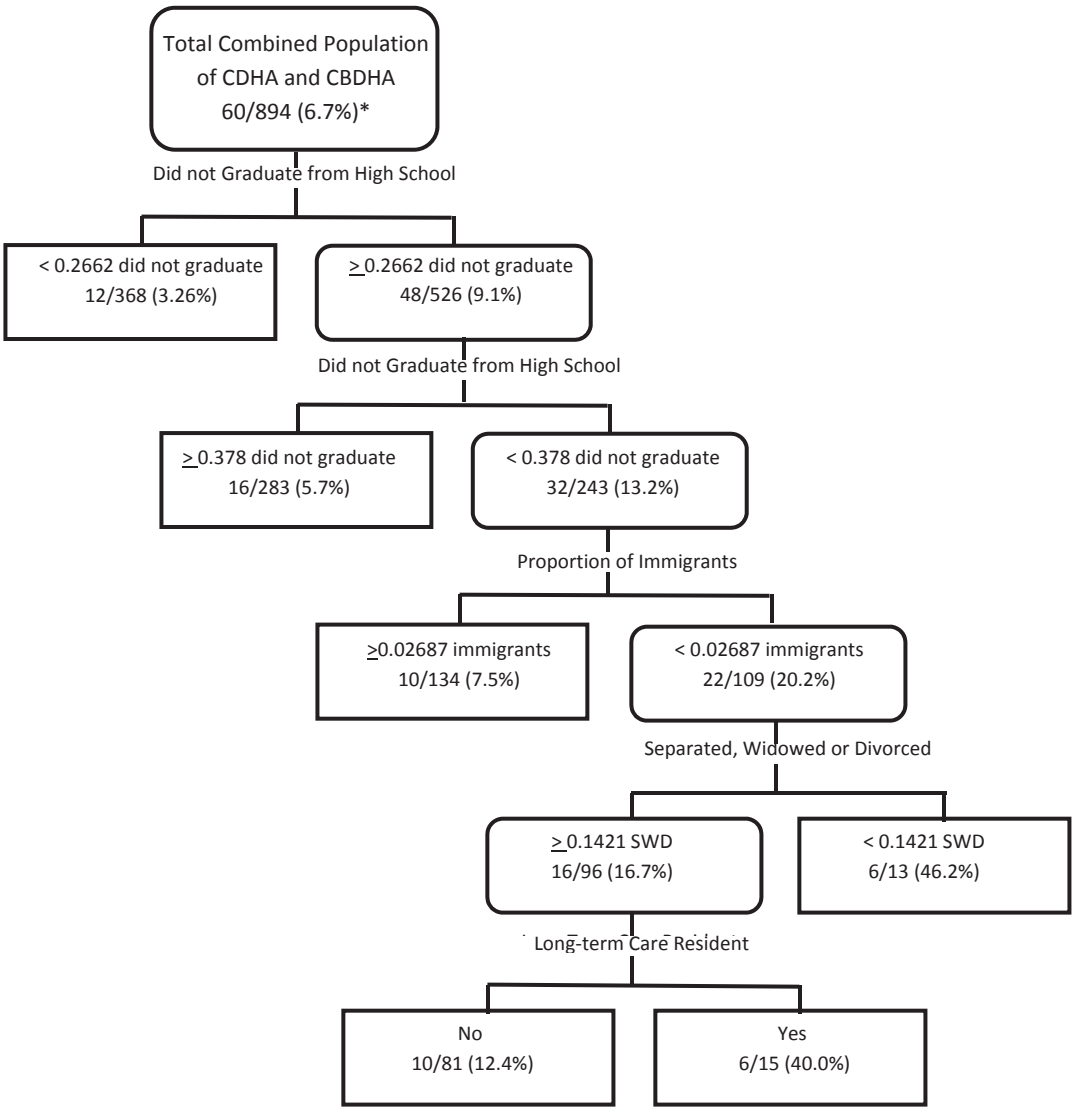

Figure 5. Cross validated classification tree showing socioeconomic predictors of diagnosis to death time of < 18.5 days for adults who died following colorectal cancer diagnosis in Capital District Health Authority (CDHA) and Cape Breton District Health Authority (CBDHA).
[a]60 individuals out of the total number in the node (n=894) died in <18.5 days; each fraction is the number who died in <18.5 days (numerator) out of the total number in the node (denominator) as determined using the proportion calculated by the program. The percentage is indicated in parentheses following each fraction.

Summary. The literature review in Chapter 2 indicated that socioeconomic variables were predictive of access to care, but were not well understood in palliative care studies. The literature also showed that SDTD was predictive of decreased access to

PCPs, however, a consistent, evidence-based empirical definition of SDTD was lacking. Therefore, CART methodology was used in this study to: (a) arrive at a definition of SDTD for Nova Scotians decedents diagnosed with CRC and (b) identify socioeconomic predictors of SDTD. The SDTD cut point identified was 18.5 days. In general, the SDTD group was older, more rural, more likely to live in a long-term care facility, and more likely to die from a non-cancer cause than the non-SDTD groups. Additionally, there were higher proportions of women, unknown CRC stage, and CBDHA residents in the SDTD group. The socioeconomic predictors of SDTD were: living in a community where more than 26.6% but less than 37.8% did not graduate from high school; living in a community where fewer than 2.7% of the population were immigrants; living in a community where fewer than 14.2% of the population were separated, widowed, or divorced; living in a long-term care facility; living in a community where fewer than 2.7% of the population had Aboriginal origins, and living in a community with a median household income lower than $30,030. Application of 10-fold cross validation to this classification tree resulted in a pruned sub tree that retained the following predictors: graduation from high school, proportion of immigrants in the community, marital status, and residence in a long-term care facility.

CHAPTER 5

Discussion

The objectives of the study were to develop a definition of SDTD following a CRC diagnosis for the population of CDHA and CBDHA and, to identify socioeconomic predictors that could help determine which individuals were at highest risk for SDTD at the time of CRC diagnosis. These objectives were intended to increase understanding about the socioeconomic factors that might prevent access to appropriate palliative care at the end-of-life for people with CRC who are dying and their families. The purpose of this research was to determine which socioeconomic characteristics held value as potential predictors of SDTD, and consequently, lack of access to PCPs. This would build on previous research, which demonstrated that socioeconomic factors impact outcomes along the CRC disease continuum (Palmer & Schneider, 2005; Byers, 2010; Moller et al., 2011), and that individuals with cancer who had a SDTD time frame were less likely than those with a longer diagnosis to death time frame to be enrolled in PCPs (Gray & Forster, 1997; Johnston et al., 1998). Increased understanding of what constitutes SDTD and potential predictors of SDTD could increase the ability of health care providers and health administrators to meet the end-of-life needs of individuals who are diagnosed with CRC and their families.

Andersen's behavioural model of health services use provided the theoretical framework for the study. This model supports the notion that contextual and individual characteristics are key contributors in determining access to health care (Andersen, 2008). The model, in conjunction with the literature review, was instrumental in the selection of individual and population-based variables. This chapter will discuss the results of this

study in relation to existing literature, study limitations, and implications for people requiring end-of-life care and nursing knowledge as well as future recommendations.

Objective A: SDTD for the Study Cohort

Objective A was to develop a definition of SDTD for adults diagnosed with CRC in CDHA and CBDHA. Previous research had associated time frames of less than 50 days (Gray & Forster, 1997) and one month (Holmburg et al., 2010; Moller et al., 2010, 2011; Morris et al., 2011) with increased CRC mortality. However, research literature held no clear definition of SDTD. Based on the knowledge that SDTD increased the risk that an individual diagnosed with cancer would not access palliative care (Hunt & McCaul, 1996; Johnston, 1998), CART methodology was used to find the point at which length of time between diagnosis and death (i.e. the indicator variable) had the greatest impact on whether or not adults diagnosed with CRC in Nova Scotia were registered in a PCP (i.e. the outcome variable). The resulting classification tree (Figure 3) showed a single split that occurred at 18.5 days between diagnosis and death, providing a clear definition of SDTD for the population. The lack of further splitting indicated there was no other point on the diagnosis-to-death continuum that would further split the terminal nodes such that the resulting child nodes would have meaningfully different diagnosis-to-death time frames (Breiman et al., 1984). For this population, the greatest time-related predictor that an individual would not be enrolled in a PCP was dying less than 18.5 days after diagnosis.

Differences between the SDTD and non-SDTD groups.

Cancer stage at diagnosis. The terminal nodes in Figure 3 showed two vastly different pictures of PCP access, with 70.3% of individuals who died in 18.5 days or more enrolling in PCPs compared to only 16.7% of those who died in less than 18.5 days.

Tables 3 and 4 provided a comparison of the two terminal nodes from Figure 3, and demonstrated some unexpected outcomes. For instance, it was anticipated that there would be a smaller proportion of individuals diagnosed at earlier stages of CRC in the group that died less than 18.5 days after diagnosis (the SDTD group), given the tendency for increasingly poor prognoses through progressively later stages of diagnosis (American Cancer Society, 2008). However, Table 3 showed less than two percent difference in stage I diagnoses between the SDTD group (6.7%) and the group that died 18.5 days or more following diagnosis (the non-SDTD group; 8.3%). Stage II (23.3% for the SDTD group and, 23.9% for the non-SDTD group), and stage III (20.0% for the SDTD group and, 22.2% for the non-SDTD group) also had similar proportions to one another as well as to the greater population of adults diagnosed with CRC in Nova Scotia (22.6% for stage II, and 23.5% for stage III; Table 1). The greatest differences in stage at diagnosis between the two groups were in the proportions of stage IV diagnoses (28% and 38.7% respectively) and unknowns (21.7% and 7.0% respectively). The large proportion of unknowns in the SDTD group was likely due to health care providers having insufficient time to identify the stage of the cancer before death, or perceived lack of benefit from a full diagnostic workup due to comorbidities. Given the existing consistency between the SDTD and non-SDTD groups, as well as between the study cohort and the provincial population, one might expect that the majority of the unknowns in the SDTD group would be classified as stage IV, however this cannot be stated with certainty. An important implication of the similarity in staging between the groups is that SDTD is not limited to the late stages of CRC. This information could be useful for health care providers since stage at diagnosis is considered to be one of the strongest prognostic

indicators for five-year relative survival (American Cancer Society, 2008), but does not appear to carry the same importance for very short term survival.

Age at diagnosis. Along with stage, age is considered another strong prognostic indicator for survival in CRC (CCS's Steering Committee on Cancer Statistics, 2011). Overall CRC incidence and mortality increases steeply after age 50, and five-year survival ratios drop in the oldest age group (75-99 years; CCS's Steering Committee on Cancer Statistics, 2011). However, as with stage, the difference in median ages between the SDTD group and the non-SDTD group was not as pronounced as might be expected: 78.0 and 75.0 years respectively. This suggested that when it comes to SDTD time frames, some indicators that are generally viewed as the strongest predictors of poorer outcomes for cancer – stage and age – may not be as influential as might be expected. While lack of research related to SDTD means there is nothing with which to directly compare these results, the results of objective A suggested that these two indicators might be less important in the context of SDTD than for cancer overall, and this observation might contribute to health care provider difficulty with providing an accurate prognosis for those who die shortly following CRC diagnosis.

Biological sex. Another difference between the SDTD group and the non-SDTD group was the proportion of women to men in the groups. For the non-SDTD group, the proportion of women to men was 45.0% and 55.0% respectively. This was consistent with the proportion of women and men in the study cohort (45.6% women, 54.4% men) as well as for the population of people who died of CRC in Nova Scotia overall (46.0% women, 54.0% men; Table 1). It was also in line with the most recent Canadian CRC statistics, which showed a slightly lower incidence of CRC in women than men in 2011 (9,700 and 12,500 respectively) and relatively equal decreases in mortality (-1.8% and -

1.5% respectively; CCS's Steering Committee on Cancer Statistics, 2011). However, in the SDTD group, the proportion of women to men was reversed: 55.0% women and 45.0% men. While no direct conclusions can be drawn, this reversal suggests that women may be at greater risk of SDTD than men. Despite this difference, sex did not surface as a predictor of SDTD in the results of objective B. Furthermore, there appears to be no other study that notes or addresses this occurrence. More research would be needed to understand whether this sex difference represents inequity in CRC access or was simply a characteristic of this population.

Rural residence. Another difference between the SDTD and non-SDTD groups was the proportion of rural residents (13.3% and 10.0% respectively). This difference bears discussion because the proportion of rural residents in the SDTD group was smaller than expected. Additionally, as with age and sex, rural residence did not appear as a predictor in the results of objective B (Figure 4). A greater difference between the two groups in Table 3 and inclusion of rural residence in objective B was expected because existing research points to increased barriers to palliative care access for people who live in rural communities. For instance, Maddison, Asada, & Urquhart (2010) found that geography was one of the most influential factors for accessing end-of-life cancer care in Canada. Similarly, Gao et al. (2011) found that registration in PCPs was lower for Nova Scotians who lived more than 30km away from the nearest PCP location, and Lavergne et al. (2010) found that use of palliative radiotherapy in Nova Scotia decreased as travel time to cancer sites increased. The surprising results of this study were likely due in part to the demographic characteristics of the study population. As Table 1 showed, the population of decedent adults diagnosed with CRC in CDHA and CBDHA contained a much lower proportion of rural residents (10.2%) than the population of decedent adults

diagnosed with CRC in all of Nova Scotia (39.2%). As data collection for PCPs improves across the province, it would be interesting to see how the proportions and predictors might change with their inclusion.

Cause of Death. A final difference demonstrated in Table 3 was the cause of death. In the SDTD group, cause of death was split equally between CRC (48.3%) and non-cancer causes (48.3%), with a small percentage (2.2%) who died from a cancer other than CRC. In the non-SDTD group, a much higher proportion (68.7%) died from CRC, while 9.4% died from other cancers, and 21.9% died from non-cancer causes. While this study did not examine comorbidities as potential predictors, the CCS's Steering Committee on Cancer Statistics (2011) suggests comorbidities could be a contributing factor to higher mortality for older adults with CRC because they may preclude aggressive treatment at any stage. Previous research examining links between comorbidities and CRC outcomes did not demonstrate that an existing connection (Hines et al., 2009; Robbins, Pavluck, Fedewa, Chen, & Ward, 2009). While it seems clinically intuitive that people who are ill with other diseases might die in a shorter time following CRC diagnosis than those who are not, further investigation is needed to determine what relationship may exist in these clinical scenarios.

STDT and PCP access. There are very few other studies that discuss SDTD related to PCP access. Hunt & McCaul (1996) and Johnston et al. (1998) associated dying within six months of a cancer diagnosis with a greater risk of late referral and under referral to PCPs, and suggested that further research was warranted. Neither study investigated time periods shorter than six months. Gao et al. (2011) examined a similar sample and time period as the present study – adults diagnosed with any cancer in the same two health districts of Nova Scotia from 2001-2005 – and found that one predictor

of decreased PCP registration was dying within 12 days of diagnosis. Though Gao et al. (2011) also used CART methodology, time between diagnosis and death was used as a predictor variable in their study rather than the outcome variable as in objective B of this study. The split that demarcated 12 days as a predictor in the study by Gao et al. (2011) was dependent on the previous splits that occurred in their classification tree (i.e. they were individuals who did not receive palliative radiotherapy and did not reside in nursing homes; see CART diagram, Appendix E). However, despite these differences, the results of both studies provided evidence that when assessing SDTD as a barrier to PCP access, it may be necessary to look at shorter time frames than were previously examined.

There does not appear to be another instance of an evidence-based estimate of SDTD in cancer research literature. The obvious question that the outcome of objective A presents is: why 18.5 days? One possible explanation is that the SDTD population may not have the stage or age characteristics that clinicians expect. This line of reasoning, discussed previously, is based on the results of this study, which showed that adults in Nova Scotia who were within 18.5 days of death did not present with a different stage or age profile than the greater population of Nova Scotians diagnosed with CRC.

Another possible contributing factor is cancer's characteristic disease trajectory. Unlike many other chronic diseases, cancer's trajectory is typified by a long period of consistently high functioning followed by a short, steep decline ending in death (Lynn, 2001). Functional performance (e.g. ability to ambulate) is considered a key indicator of prognosis in end-of-life care (Lau, 2009; Periera, 2008), and if an individual is high-functioning, proximity to end-of-life may be even more difficult than usual to predict. Clinically, the decline phase at end-of-life in most cancers, including CRC, typically manifests in symptoms such as progressive weakness, sleeping much of the time,

decreased food and fluid intake, difficulty swallowing, and delirium not related to reversible causes (Georges, Onwuteaka-Philipsen, van der Heide, van der Wal, & van der Maas, 2005; Tilden, Tolle, Drach & Perrin, 2004). However, these symptoms frequently do not appear until the final one to two weeks of life (Teunissen, de Graffe, Voest and de Haes, 2007). The rapid change in functional status that is characteristic of cancer and late clinical signs that are present at end-of-life for many chronic illnesses may offer insight into the difficulty health care providers face in establishing the urgency of need for palliative care at the time of CRC diagnosis. The frequent inaccuracy of health care providers in estimating survival time (Lau et al, 2007) suggests that current prognostic tools and clinical judgement could be supported with additional information or strengthened as new knowledge about the diseases (including diagnostics and treatments) emerge. The results of objective A seemed to suggest that socioeconomic indicators might provide a means to support and refine estimation of diagnosis-to-death time frame at the time of diagnosis. The utility of socioeconomic indicators for clinical purposes will be further addressed in the discussion of results for objective B.

The gap between practice and best practice for palliative care. There is broad disaccord between best-practice recommendations that palliative care be initiated upon diagnosis with a life-limiting condition such as cancer and actual practice of Canadian health care providers (Canadian Hospice Palliative Care Association, 2010b; Carstairs, 2010). Even when practitioners perceive the need for a PCP, there remains a lack of consensus about the best timing for referral. Delays in diagnosing cancer, delays in referring individuals to PCPs once diagnosed, and delays on the part of the individual with CRC in consenting to the referral all contribute to the increased risk for dying prior to receipt of palliative care (Allard, Donne, & Potvin, 1995; BMJ Best Practice, 2011;

Registered Nurses' Association of Ontario, 2011). This is further complicated by the typical end-of-life trajectory for cancer, which sees a long period of high functioning followed by a short period of decline prior to death (Lynn, 2001) that may be difficult for health care professionals to gauge. While best practice guidelines exist for the provision of palliative care (BMJ Best Practice, 2011; Canadian Hospice Palliative Care Association Nursing Standards Committee, 2009; National Consensus Project for Quality Palliative Care, 2009; Registered Nurses' Association of Ontario, 2011), these guidelines tend to focus on care of individuals once the need for palliation has been established. Little guidance is available for health care providers on the process and timing of referral. Additionally, the tools that exist to assess proximity to end-of-life, while helpful, may have cultural and linguistic limitations, or may focus exclusively on symptom existence and severity at the expense of the more holistic approach espoused by PCPs (Registered Nurses' Association of Ontario, 2011).

One thing that all clinical guidelines for palliative care make abundantly clear is that regardless of the length of time between onset of palliative care and death, individuals and their families derive benefit from the palliative care approach (BMJ Best Practice, 2011; Canadian Hospice Palliative Care Association Nursing Standards Committee, 2009; Registered Nurses' Association of Ontario, 2011). This benefit may take the form of pain and symptom management (Daines, 2004; Miyashita, Morita, Sato, Hirai, Shima, & Uchitomi, 2008), sense of control and reduced burden to others for those who are dying (Singer, Martin, & Kelner, 1999), or continuity of care and caregiver support (Bernal, Marco, Parkins, Buderer, & Thum, 2007; Tilden, Tolle, Drach, & Perrin, 2004). It is essential for health care providers to understand the potential benefits of

palliative care so they do not overlook this approach to care when they believe that the individual they are caring for may have a SDTD time frame.

Summary of objective A. Analysis of the outcomes from objective A clearly showed that for decedent adults diagnosed with CRC who live in CDHA and CBDHA, SDTD was defined as dying less than 18.5 days after diagnosis. The key differences between the SDTD and non-SDTD groups were the proportion of unknown CRC stage at diagnosis, the proportion of women to men, and cause of death. Characteristics that were surprising for their similarity between the two groups were the equivalency of stages I, II, and III at diagnosis, median age, and rural residence. Based on the results of objective A and the established benefits of PCPs for individuals diagnosed with CRC who are close to death, the decision was made to move forward with objective B using the established definition of SDTD for this population – death in less than 18.5 days (yes / no) – as the outcome variable for assessing the predictive capacity of socioeconomic indicators. After extensive discussion with an expert in recursive partitioning methods, it was also decided that given the specificity of the SDTD definition to the combined populations of CDHA and CBDHA, it would add an undesirable level of complexity and uncertainty to apply this to the greater population of all adult Nova Scotians with CRC who died in the time period of the study (M. Abdolell, personal communication, March 12, 2012). Thus, the research plan was adjusted and objective B was carried out using the same study cohort as objective A.

Objective B: Socioeconomic Predictors of SDTD

Objective B was designed to determine which socioeconomic variables might serve as potential predictors of SDTD at the time when an adult is diagnosed with CRC. Previous research has predominantly focused on finding correlations between a few

variables through multiple logistic regression. CART methodology, which demonstrates predictive relationships rather than correlations, offered a new way to look a large volume of data concurrently. While the methodological differences make it difficult to directly compare the results of this study and previous studies examining CRC, SDTD, and access to care, the results will be discussed in the context of their alignment with existing findings in the literature.

Changes to the planned analysis. An iterative process of analysis and returning to the literature resulted in the regression tree (Figure 4) for objective B. The use of the combined population of CDHA and CBDHA, rather than the provincial population, was previously discussed. Additionally, the preliminary tree that diagrammed the effects of all the variables selected using the Andersen model on time from diagnosis to death (Appendix H) was dominated by the effects of stage, age, and service use variables on longer diagnosis to death time frames than were of interest for this study. For example, only three of the eight splits were based on socioeconomic characteristics (proportion of immigrants, proportion of first-generation immigrants, and residence in a long-term care facility), and the shortest diagnosis-to-death time frame that appeared in any of these splits was 389.4 days. The shortest diagnosis-to-death time for any split was 327.8 days. It was likely that the proportion of the population that died in less than 18.5 days was small enough that it did not surface in the recursive partitioning process. The previously described selection of death in less than 18.5 days as the outcome variable instead of continuous time from diagnosis to death resolved this problem and allowed relevant predictors of SDTD to surface.

During the analysis process, it was also determined that the selection of predictor variables would be narrowed to include only the socioeconomic variables that had been

selected using the Andersen model and the literature review. This was in part because the larger ACCESS study, due to its own preliminary results, was focusing on the effects of an array of indicators on diagnosis to death time frames that were shorter than initially anticipated (e.g. two weeks, four weeks, etc.). The indicators in the larger study included those from this study as well as additional service use indicators and comorbidities (see Appendix A for a full list). Given the similarities, it was decided that a strict focus on socioeconomic factors would minimize overlap between the two. Additionally, upon reflection and further reading, it was determined that concentration on socioeconomic variables was more in line with the background and literature review for this study, as well as the purpose and objectives. The research plan remained true to the Andersen model's with an emphasis on individual and population-based contextual factors as key indicators of health services access. Andersen (2008) espoused the idea that utilization and access are rooted in social and economic determinants, and that understanding pre-existing socioeconomic determinants is essential to evaluating barriers to access.

Classification tree results. The outcome of the analysis for objective B was the classification tree in Figure 4. The series of partitions in the tree demonstrated that socioeconomic variables were able to function as predictors of SDTD. A null tree (i.e. a root node with no partitions) would have indicated that the socioeconomic variables in the study did not influence whether or not individuals in the study had SDTD time frames. The classification tree that resulted from objective B showed seven partitions based on six of the socioeconomic variables used in the study, with one predictor surfacing twice. It is essential to remember when reviewing the results that the nature of CART methodology is that each partition is dependent on the preceding partitions. While each level of the tree will be discussed individually, each socioeconomic indicator's predictive value is tied

to the partitions that occurred above it in the model. These are discussed in the order they appear in the model as follows.

Graduation from high school. The proportion of the adult population without a high school diploma appeared as both the first and second indicators in the regression tree. Curiously, the two partitions that occurred appeared contradictory. The first partition showed that individuals who lived in communities where more than 26.6% of the population had not graduated from high school were at higher risk for SDTD than those who live in communities where fewer than 26.6% had not graduated from high school. This appeared consistent with existing literature that linked lower levels of education with higher CRC mortality (Jemal, Siegel, Ward, Hao, Xu, & Thun, 2009; Kelsall et al., 2008) and decreased access to health services at other points along the care continuum (Klabunde, Cronin, Breen, Waldron, Amb, & Nadel, 2011). However, the second split showed that within the higher risk group, individuals who lived in communities where less than 37.8% of the population had not graduated from high school were at higher risk for SDTD than those who live in communities where more than 37.8% had not graduated from high school. No literature linking lower educational attainment to improved CRC outcomes or health care access could be found. There was, however, a study describing greater exposure to modifiable risk factors for developing CRC (e.g. red meat intake, BMI, alcohol consumption), in communities with higher levels of education and income (Kim, Masyn, Kawachi, Laden, & Colditz, 2010). The study did not examine the effects of education and income on mortality or access to care, and did not examine the two influences separately. More research is needed to determine if the effect carries through to end-of-life outcomes. Kim et al. (2010) also suggested that differences in the effects of neighborhood socioeconomic environments on CRC vary depending on

whether the cancer is in the colon or rectum. Discerning between these two locations was beyond the scope of this study.

It is unclear what underlying factors might contribute to the increased risk of SDTD for individuals who live in communities where more than 26.6% but less than 37.8% of the population had not graduated from high school. This outcome clearly demonstrated both a strength and weakness in the CART method: The strength is that unbiased selection of partition points based solely on goodness of split can result in the emergence of new and unexpected patterns that spur further inquiry. The weakness is that as a purely predictive method, CART analysis does not allow for analysis of relationships and associations between variables. In order to understand this result, a more complete picture of the communities where individuals live would be needed, along with further research using a suitable method for investigating relationships, such as linear and/or logistic regression.

Immigrant populations. The third partition in Figure 4 was based on the total proportion of immigrants who live in the DA where an individual resides. Given the two previous partitions, this split showed that individuals who live in DAs where 2.7% or more of the residents are immigrants, are at lower risk for SDTD than individuals who live in DAs where less than 2.7% of the residents are immigrants. The issue of immigration related to colorectal outcomes and health services access is complex. While research from the United States has demonstrated decreased access at various points along the CRC care continuum for immigrant populations (Smith Nielsen et al., 2010), immigration patterns are vastly different between many areas of the United States and Canada. Unlike the United States, indicators to health care access such as having a family physician and reports of unmet healthcare needs were generally equivalent in

immigrant and non-immigrant Canadian populations (Singh Setia, Quesnel-Vallee, Abrahamowicz, Tousigant, & Lynch, 2011).

Immigrants make up 5% of the Nova Scotian population, with just over half (51.5%) hailing from Asia and the Middle East (Citizenship and Immigration Canada, 2010). The majority of Nova Scotian immigrants (69.7%) arrive during their prime working years, between the ages of 25 and 44 years old, and 51.5% of the province's immigrants have obtained university degrees prior to arrival (Citizenship and Immigration Canada, 2010). The immigrant population in Nova Scotia is generally more highly educated than the populations described in most studies linking immigrants to decreased health care access, and this may help explain the lower risk for SDTD in communities with higher proportions of immigrants. Other factors may include the relatively low levels of immigration in Nova Scotia compared to many other parts of Canada (Citizenship and Immigration Canada, 2010), as well as cultural differences in beliefs related to end-of-life care. Research into the influence of cultural beliefs on access to palliative care might shed further light on this area. It is also worth noting that the vast majority of immigrants in Nova Scotia live in CDHA, one of the two districts that make up the study population. Thus, different results might occur if a similar regression tree were constructed using provincial data rather than only CDHA and CBDHA.

Separated, widowed, and divorced. The next partition occurred according to marital status. The results showed that, given the three previous splits, individuals who live in DAs where less than 14.2% of residents were separated, widowed, or divorced were at greater risk for SDTD than individuals who live in DAs where 14.2% or more of residents were separated, widowed or divorced. While little is known about the relationship between CRC and marital status, being married has been shown to have a

positive effect on survival in some other cancers such as breast and lung (Clegg et al., 2008), and no effect on survival in bladder cancer (Nelles, Joseph, & Konety, 2008). Two previous studies focused specifically on CRC. One suggested that married individuals had a significantly lower risk of death from colon cancer (for men, HR: 0.86, CI: 0.82–0.90; for women, HR: 0.87, CI: 0.83–0.91) compared with single individuals (Wang, Wilson, Stewart, & Hollenbeak, 2011). The other found that median survival time was 7.7 months for individuals with CRC who were living alone and 11.7 months for people who cohabitated ($p < 0.0001$; Cavalli-Björkman, et al., 2009). A literature review by Walshe et al. (2009) found that in general, unmarried individuals were less likely to access palliative care resources. The risk of SDTD in this study appeared to run contrary to these findings. As with stage and age, it may be that marital status has a different or muted effect on SDTD time frames for CRC than for longer diagnosis to death time frames. Additionally, marital status is based on community rather than individual characteristics in this study, and this is not the case in other studies that examine the relationships between marital status and cancer outcomes. marital status. More investigation into individual and family interactions is needed to understand how marital status mediates CRC outcomes and access to palliative care.

Long-term care residence. The fifth split was based on whether or not individuals lived in a long-term care facility. This marked the only appearance of an individual-level predictor (as opposed to community-level predictors) in the results of objective B. This partition showed that, given the four previous partitions, individuals who lived in long-term care facilities were at higher risk for SDTD (40.0% died in less than 18.5 days) than individuals who do not live in these facilities (12.4% died in less than 18.5 days).

In Nova Scotia, individuals are referred to long-term care base on a comprehensive assessment that shows they "require the availability of personal care on a continuing 24 hours basis, with medical and professional nursing supervision and provision for meeting psycho-social needs" (Nova Scotia Department of Health and Wellness Continuing Care Branch, 2011, p. 5). Residency in American long-term care facilities has been associated with late or unstaged cancer diagnoses and high mortality within three months of diagnosis (Bradley, Clement, & Lin, 2007). This was consistent with research in Nova Scotia that showed long-term care residents were more likely than others to have their cancer diagnosed solely through their death certificates (O'Brien, Johnston, Gao, & Dewar, 2007). Individuals who live in nursing homes generally have multiple health issues with symptoms that may mimic or mask cancer symptoms (Duncan, Bott, Thompson, & Gajewski, 2009). Additionally, functional limitations of long-term care residents can affect ability to tolerate or recover from treatment, and have been associated with overall mortality (AHR: 1.33; 95% CI: 1.10–1.62; Koroukian, Xu, Bakaki, Diaz-Insula, Phillips Towe, & Owusu, 2009). There is an identified need for further research into nursing home policies and services related to palliative care, comorbidities, and individual and family preferences around end-of-life care (O'Brien et al., 2007).

Aboriginal origin. The sixth partition occurred on proportion of the population in the individual's DA of residence that had Aboriginal origins. Given the five previous partitions, individuals who lived in DAs where less than 1.1% of the population was of Aboriginal origin were at greater risk for SDTD than those living in DAs where 1.1% or more of the population was of Aboriginal origin. This was unexpected given current evidence related to CRC in Aboriginal populations. In the United States, American

Indians and Alaskan Natives represent one of only two racial groups that have not seen CRC mortality rates decrease over time (Gellad & Provenzale, 2010). In Canada, CRC outcomes and access in the Aboriginal population is not clearly understood, though research has shown high exposure to modifiable risk factors in on-reserve populations (Marrett & Chaudhry, 2003).

In Nova Scotia, the apparent protective effect of Aboriginal populations on SDTD from CRC may be related to the overall youth of the province's Aboriginal population. In 2006, the median age for Aboriginals in Nova Scotia was 29.5 years, compared to 41.8 years for the non-Aboriginal population (Nova Scotia Finance, Economics and Statistics, 2008). A higher proportion of Aboriginals in a DA suggests a lower median age, and though CRC affects all ages, 95% of new cases and deaths occur after the age of 50 (CCS's Steering Committee on Cancer Statistics, 2011). It is also important to note that individuals with Aboriginal status would not be included in this study because their health care is covered federally, and therefore they would not have MSI numbers or appear in any of the provincial health care databases. More research into CRC in Aboriginal populations is needed across Canada in order to understand the implications of this predictor.

Median household income. The final split occurred according to median household income. Given all six previous splits, individuals who lived in DAs with a median income of less than $30,030 were more likely to die less than 18.5 days after CRC diagnosis than those whose DA of residence had a median income of $30,030 or more. This was in line with the majority of research that associated income and CRC mortality or health care access. Treatment, survival, and mortality all showed less favourable results for populations with lower incomes than for populations with higher incomes

(Aarts, Lemmens, Louwman, Kunst, & Coeberg, 2010; Palmer & Schneider, 2005). Additionally, socioeconomically disadvantaged groups, as defined by income-based deprivation indexes, experienced higher excess death rates in the first month following diagnosis than groups that had high socioeconomic status (Moller, et al, 2011; Moller et al., 2010). Though access to end-of-life care was not addressed directly, previous research linked lower incomes with decreased access to screening and radiation therapy (Aarts et al., 2010; Byers, 2010). Income was one of the most heavily researched socioeconomic indicators related to CRC, but its position at the terminal end of the classification tree, along with the fact that it was pruned from the tree following cross validation, suggested that income alone is not as influential as income in combination with other socioeconomic indicators. Further research to establish the relationship between income and other indicators, as well as to determine the effect of income on access to palliative care, is warranted.

Unexpected absence of rural residence. As discussed in objective A, the absence of rural residence from the classification tree was unexpected, but may be attributed to the low proportion of rural residents in CDHA and CBDHA compared to the provincial population. This holds implications for the applicability of the model to the province as a whole, as well as to other populations that do not share the population characteristics of CDHA and CBDHA. This will be further addressed in the following discussion about the cross-validated model.

The absence of rural residence may also have occurred as a result of the definitions of *urban* and *rural* used in this study. As previously described, the study defined individuals who lived rurally as those who lived in areas with moderate, weak, or no urban influence (i.e. areas with populations of less than 10,000 people where 29% or

less of the workforce commuted to an urban centre). Maddison et al. (2011) found that Canadian research examining access to cancer care services, including end of life care, defined geographic residence in three ways: distance to the nearest cancer centre, rural vs. urban residence, and geographic region of residence. In all cases, geographic location was found to influence access to care. It is possible that in this study, a different definition of rural residence, for example one based solely on geographic location, may have resulted in a higher proportion of individuals classified as rural residents and/or inclusion of rural residence in the classification tree for objective B.

Ecological fallacy. Ecological fallacy, which occurs when one assumes the statistics that describe a group also apply directly to individuals within that group (Piantadosi, Byar, & Green, 1988), was a consideration throughout the analysis of objective B results. While methods that incorporate both individual and community-level characteristics may mediate the effects of ecological fallacy, distinguishing the individual from the characteristics of the community remains essential (Pearce, 2000). This study included both individual and community-level socioeconomic indicators, and thus it was necessary throughout the discussion to distinguish between the two, and ensure DA-level characteristics were not projected onto individuals in the study. This was particularly salient given the disproportionate number of DA-level variables compared to individual-level variables that appeared as predictors in the classification tree for objective B.

Cross validation. The database used for this analysis was the only one of its kind. As such, there was no comparable population that could serve as an external validation set for the model that resulted from objective B. In the absence of external validation, cost-complexity pruning using the technique of cross validation was used to select a sub-tree from the initial full-sized tree that was simpler (i.e. smaller) than the full

tree but still provided good predictive capacity. Cost-complexity pruning balances complexity (size) and the accuracy of the model. Using 10-fold cross validation, the bottom four nodes were pruned to reach the optimal sub-tree (Figure 5).

Despite arrival at an optimal sub-tree, it is not anticipated that this model could be used independently as a tool to predict SDTD time frames at the time of CRC diagnosis outside of the study population. Though the results showed socioeconomic indicators had predictive value, they likely cannot serve this purpose independently of clinical factors, and as previously discussed, were intended to support or enhance rather than replace current prognostic tools and clinical judgement.

Utility of Results

Utility for clinicians. The purpose of this study was to determine which socioeconomic characteristics might act as potential predictors of SDTD, and consequently, decreased access to PCPs. In the past, recursive partitioning has been utilized to create decision trees that guided clinical decisions made by health care providers. Examples included treating chest pain in emergency departments (Goldman, Cook, Johnson, Brand, Rouan, & Lee, 1996), anticipating coma outcomes (Levy, Caronna, Singer, Lapinski, Frydman, & Plum, 1985), and predicting survival in individuals with advanced cancer (Chow et al., 2008). Though a thorough health history could determine many of the predictors that appeared in the model for an individual diagnosed with CRC, the outcomes of the model were based primarily on community-level measures, and direct translation of risk based on community-level characteristics to similar individual-level characteristics cannot be assumed. Currently, information such as educational attainment, immigrant status, marital status, Aboriginal or other racial

background, income, or even long-term care residency are not collected in Nova Scotia health records.

Community-level data drawn from the census was the best option for capturing socioeconomic status indicators for this study. However, this research was a preliminary attempt to identify patterns and socioeconomic predictors that may benefit from further investigation. While health care providers who understand that socioeconomic indicators play a role in predicting SDTD and access to palliative care may be more likely to understand and ascribe to the holism consistent with the palliative philosophy of care, it may be difficult to apply such knowledge in practice. Lack of timely, convenient access to community-level socioeconomic data challenges the utility of the results in their current form for use by clinicians as prognostic SDTD indicators. The advent of electronic health records could allow increased linkage of individual data from health records with population-based data such as census data to enhance evidence-based prognostic ability upon CRC diagnosis, but further understanding of the interaction and influence of socioeconomic indicators, as well as clear evidence that these indicators enhanced existing prognostic ability would be essential.

Utility for health administrators. While the challenges associated with the exploratory level of the study and inability to validate the model externally necessitate further research, this method and the research results hold more promise for health policy and planning than for health care providers. The ability to identify populations at risk for SDTD allows for targeted assessment of the needs of those populations. Community health assessment tools may provide further insight into these communities and enhance understanding of needs and means of adjusting or enhancing existing health services. This is particularly relevant given the current inconsistencies in PCPs across the nine

health districts in Nova Scotia, and the purported desire within the province to move towards a more unified palliative care approach (Provincial Palliative Care Project, 2004). This research has demonstrated that socioeconomic indicators have predictive capacity for SDTD. Using this knowledge and returning to the full Andersen model to incorporate patterns of health care usage and availability of resources could offer an evidence-based planning tool for service delivery and resource allocation.

The results of this research should also make health care decision makers consider whether the current method of palliative care delivery, which appears to be developing along the specialist delivery model that is prominent in acute care, is the most efficient and efficacious means of providing end-of-life care. In a province where the aging population is indicative of the increasing number of deaths across the health care system, there may be more value in considering a model of care that integrates palliative philosophies and knowledge as fundamental tenets of care for people with chronic illnesses. While this would involve a great deal of effort and resources initially, the long-term rewards, reaped in economic sustainability of the health care system and improved quality of overall care, would likely justify the initial costs. The current lack of cohesiveness and direction for palliative care in the province, while currently a barrier to provision of care and measurement of outcomes, also provides an opportunity for health care leaders to explore new ways of understanding barriers and improving care for populations at risk and creating a comprehensive plan for palliative care delivery that meets the needs of individuals across the province.

Ethical Considerations

An important consideration in this research was whether the current health care system had the capacity to respond to an identified need for increased services. While the

proportion of individuals with a SDTD time frame is small (6.17% of all CRC deaths in the study population), the health care system has a obligation to provide appropriate care, and even a small increase in human, capital, or financial resources would need to demonstrate economic viability and utility. Literature evaluating the economic impact of palliative care services encompasses a host of methods, populations, programs, and purposes that make it difficult to generalize the results. However, one review of end-of-life and palliative care research for evidence of effectiveness and resource utilization concluded that there was clear potential to reduce costs associated with unplanned hospitalization, length of stay, and use of critical care services through provision of palliative care services in the home, hospice environment, and palliative care hospital units (Hatziandreu, Archontakis, & Daly, 2008). In addition, Hatziandreu et al. (2008) found that a shift from use of acute care services to palliative care services was aligned with the preferences of the individuals requiring palliative care. This review was conducted for the National Audit Office in England, however literature from a wide selection of developed countries was reviewed. Though evidence seemed to indicate cost savings associated with appropriate palliative care, those savings would only be realized with evidence-based planning for service delivery that accounts for the needs and characteristics of the population.

Conclusion

The results of this research study clearly demonstrated that it is possible to define SDTD for a population using CART methodology. The resulting SDTD of less than 18.5 days, though specific to the study population, suggested that short time frames such as 30 days that were arbitrarily employed in prior research may not be short enough to adequately evaluate the risks and needs faced by individuals who die shortly after a CRC

diagnosis. Differences between the SDTD group and non-SDTD group suggested that the indicators currently believed to be most influential for mortality and access to end-of-life care for CRC in general may not be the most important indicators for people who die shortly after receiving a CRC diagnosis. Additional investigation into the differences between these groups is needed.

The study also demonstrated that socioeconomic indicators hold value as predictors of SDTD. Results showed that individuals were more likely to have a SDTD time frame upon diagnosis if they lived in communities where more than 26.6% but less than 37.8% did not graduate from high school; lived in communities where less than 2.7% of the population were immigrants and less than 14.2% were separated, widowed, or divorced; and were residents in long-term care facilities. Aboriginal origin and median household income, which also appeared in the initial results, but not in the cross validated results, might also benefit from further investigation.

While additional research is needed to determine whether the socioeconomic predictors identified in this study carry through to other populations, the demonstrated ability to distinguish predictors for a population holds value for future research. The number of unexpected outcomes and omissions that resulted from the CART method further strengthened the idea that SDTD predictors may differ from indicators that have been strongly associated with general CRC mortality in the past. Further research into these exploratory findings will increase the utility of socioeconomic predictors for health care providers and especially health administrators in the future.

Limitations.

Limitations in this study were related to: data quality and availability, key assumptions about provision of palliative care, methods, and applicability of the model

outside the study population. One limitation related to data quality was rooted in the different means by which the PCPs in the study's two health districts defined enrolment in a PCP. The CDHA PCP defined enrolment in a PCP by the date of assessment by a palliative health care provider (either a phone call or physical visit), while the CBDHA PCP defined enrolment by the date of referral, which was not reliant on contact with a health care provider in the palliative care program. The length of time between referral and assessment in CBDHA was unknown. Additionally, there was no means of determining with certainty that all referrals received assessment or care prior to death. This was consistent with findings by Johnston and Lethbridge that showed referral dates that were consistently available in CBDHA were not available for more than 90% of individuals who died in CDHA, necessitating the use of first visit dates for defining registration, and that the lengths of time between referral and initiation of care were not readily available in many cases (G. Johnsont, personal communication, June 25, 2012). This has implications in particular for objective A, which used receipt of palliative care as reported in these two PCP registries as its outcome variable. While these registries represented the best available data, this discrepancy demonstrates a need to establish clear, consistent measures related to palliative care access in the province. Consistency of information and reporting was identified as a challenge for PCPs throughout the other districts in the province, resulting in their exclusion from the ACCESS database (Porter et al., 2012). There is also a need for collection of data around individual care needs and preferences as noted in much of the existing literature (Walshe et al., 2009).

Other limitations were related to availability of data. One instance of this was census measures. The majority of census variables used in this study measured the variable in the proportion of the DA population that was over the age of 15 (Statistics

Canada, 2003). However for some variables, such as high school graduation and unemployment, this may not present an accurate picture of socioeconomic risk. For example, in Nova Scotia, the vast majority of high school students graduate at age 18 or 19 (Statistics Canada, 2010). Thus, a DA with a higher proportion high school age youth would show up as having a high proportion of its population that had not graduated from high school, though this would not appropriately represent the risk that was associated with that variable in the study.

Another instance of limitations in data availability was the use of postal codes to link decedents to DAs. This was based on the assumption that individuals were affected by the socioeconomic conditions of their DAs of residence. However, these postal codes reflected the individual's address at the time of diagnosis. This meant that residents of long-term care facilities were linked to the DA of the care facility, rather than the DA they lived in prior to admission. This may not accurately reflect the socioeconomic environment in which these individuals lived the majority of their lives.

Beyond matters of consistency, the use of registration in a PCP as a proxy for access to palliative care was potentially problematic. While research clearly demonstrated that participation in a PCP was indicative of high quality end-of-life care (Earle et al., 2003; Gelfman et al., 2008; Grunfeld et al., 2008), PCPs are by no means the only ways of obtaining palliative care. It would be useful to establish other means of assessing receipt of palliative care such as care provided through long-term care facilities, acute care units that are not palliative care specific, or family physicians with strong palliative knowledge and focus in their practices. Such measures would establish a clearer picture of palliative are access in the province. There is work underway by

researchers in Nova Scotia to address this issue (R. Urquhart, personal communication, May 24, 2012).

Additionally, there are limitations related to the method. CART methodology does not allow for calculation of effect size, and therefore cannot be used to assess independent effects of indicator variables on the outcome variable (Teng et al., 2006). Though patterns and trends in the research could be identified for discussion, it was difficult to compare results with the majority of existing studies, which used statistical methods more common to health research such as logistic regression. Two previous studies conducted analyses either using CART methods and multiple linear regression concurrently (Gao et al., 2011), or evaluating the predictive capacity of a CART model by comparing it with the predictive capacity of an existing prognostic model (Chow et al., 2008). Such comparisons, while informative, were beyond the scope (comparison with linear regression) or capability (comparison with existing models) of this study.

A final limitation is the lack of a similar population for comparison. A second similar population would have strengthened the study in two ways: First, determination of SDTD in a second population would either provide further evidence of the need to investigate shorter diagnosis to death time frames, or show a time frame that is more congruent with the existing SDTDs of 30 days or more. And second, external validation of the model resulting from objective B would have provided information about whether the various partitions in the model held up in other populations, improving capacity to assess the model within this study.

Implications for Nursing Research

There are two broad implications for further research suggested by this study: exploration of recursive partitioning methods such as CART for the purposes of

increasing nursing knowledge, and exploration around the specific topics of socioeconomic predictors, SDTD, and end-of-life care.

Recursive partitioning in nursing research. This study demonstrated the capacity of one method of recursive partitioning, CART, to identify patterns and predictors in large volumes of diverse data. The primary informatics challenge in health care is shifting from the ability to collect and store data to the ability to access, analyze and interpret relevant data. Researchers in life sciences, medicine, and pharmacy have started to employ CART or similar methods to glean information from the large volumes of data stored in health care databases and identify research hypotheses that are relevant to their fields (Berger & Berger, 2004). Such methods have been used rarely by nurse researchers, however those who have employed recursive partitioning in nursing research have had great success translating results into practice, in part because of the accessibility of outcomes in the form of decision trees for nurses and other health practitioners (Goodwin, VanDyne, Lin, & Talbert, 2003).

Additionally, recursive partitioning offers a relatively quick way of answering simple questions that are relevant to nursing practice. If the data is available and accessible, recursive partitioning can provide almost immediate feedback that can be rapidly interpreted in clinical and administrative settings. The arrival at a SDTD time frame in the present study is an example of this. While translation and implementation of such findings require in-depth clinical and health systems knowledge, the growth of advanced practice nursing roles in settings across the health care continuum would support these activities (Goodwin et al., 2003).

Socioeconomic predictors and palliative care. As a first step in examining the predictive capacity of socioeconomic variables in SDTD and palliative care access, this

research suggests several opportunities for future research directions. In order to assess whether socioeconomic variables could be used to support existing prognostic tools, it would be useful to compare and contrast the predictive success of a socioeconomic model such as the one produced in this study with the success of existing prognostic models used by health care providers. Unless such models were systematically applied as part of the initial PCP assessment in CDHA and CBDHA, this type of research would require a prospective approach.

The lack of consistent palliative programming provides an opportunity to build evaluative frameworks into programs and services as they are developed across the province and across the country. Related to this, there is an identified need for exploration into design issues for population-based prospective studies that would allow comparison of outcomes for provision of palliative care and evaluation of palliative interventions (Johnston, Burge, Boyd, & MacIntyre, 2001).

Nurses are integral members of palliative care teams, and there is an opportunity to build on previous research and best-practice guidelines that have been developed by organizations such as the RNAO. From a practice perspective, there is an opportunity to capitalize on the strong qualitative research skills that exist within the nursing profession in order to address the gaps in knowledge that have been identified around individual's perceptions and experiences that could offer insight into some of the socioeconomic predictors noted in this study, as well as gaps around individual and family preferences related to palliative care and PCPs. From an administrative perspective, there is an opportunity to take a leading role in creating an evidence base for policy development and decision making around palliative care, an area that is highly reliant on expert opinion because of the lack of available research evidence (RNAO, 2011).

Finally, while this study focussed on CRC in Nova Scotia, it implies a broader discussion about access to palliative care for individuals with chronic illness in a country where the population is rapidly aging and the death rate is increasing. Further research into the barriers to access related to socioeconomic status for all cancers, as well as other chronic diseases, may facilitate improved planning, care, and quality of life and death for individuals in need of palliative care.

Summary

In summary, this study of 894 adults diagnosed with CRC in Nova Scotia between 2001 and 2005 and died between 2001 and 2008 demonstrated that socioeconomic variables could be used as predictors of SDTD. Using CART methodology, the predictive effect of time from diagnosis to death on registration in a PCP was used to establish a SDTD time frame of 18.5 days. The ability of selected socioeconomic indicators to predict whether an individual would fall within the risk group for SDTD was subsequently investigated. The results clearly showed that socioeconomic indicators have predictive capacity, and predictors for the study population were identified. The study highlighted the importance of socioeconomic indicators, which are not commonly considered as predictors for CRC outcomes by health care provider or administrators.

New research findings in this study include the identification of an evidence-based measure of SDTD that is shorter than what has been previously considered in the literature, and identification of socioeconomic predictors of SDTD. In particular, the results indicate that predictors of SDTD my differ dramatically from widely accepted predictors of CRC mortality in general. Given the exploratory nature of this research, further investigation into the identified predictors and other populations is warranted.

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Appendix A

Table A1. Variables Used in the Larger Study

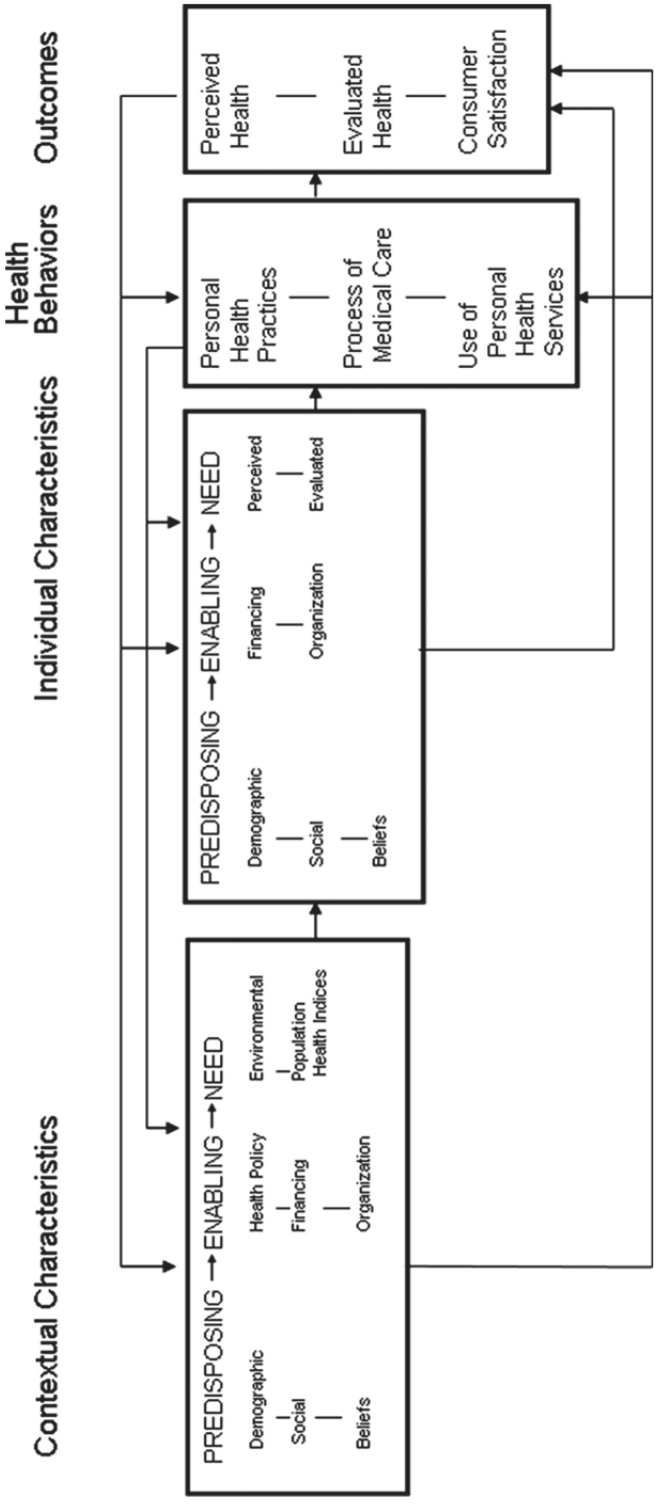
Category and Variable Name	Measure
Clinical variables	
Cancer type	Colon or rectum
Cancer stage at diagnosis	Stage I, II, III, IV, or unknown
Collaborative cancer stage at diagnosis	Stage I, IIA, IIB, IIIA, IIIB, IIIC, IV, or unknown
Frailty	Seen by physician for frailty within two years prior to CRC diagnosis (yes/no)
Organ failure	Seen by physician for organ failure within two years prior to CRC diagnosis (yes/no)
Presentation for CRC resection surgery	Emergent, elective, no surgery, or unknown
Xeloda exposure	Had at least one exposure to Xeloda within one year before death (yes/no)
Received chemotherapy	Received chemotherapy within one year before death (yes/no)
PCP enrolment to death	Time from PCP enrolment to death (days)[a]
Died in hospital	No; terminal care only; or yes
Died within 30 days of diagnosis	Yes/no
Died within 183 days of diagnosis	Yes/no
Died within 365 days of diagnosis	Yes/no
Died within 548 days of diagnosis	Yes/no
Died within 730 days of diagnosis	Yes/no
Cause of death	CRC, other cancer, or non-cancer cause
Health services use variables, general	
Enrolled in a PCP[a]	Yes/no
Medical oncology consult within one year prior to death	Yes/no
Health services use variables measured over two years prior to CRC diagnosis	
Total hospital admissions	Number in two years (any cause)
Total emergency department visits	Number in two years (any cause)
Total family physician visits	Number in two years (any cause)
Number of different family physicians seen	Number in two years
Total visits to specialist physicians	Number in two years (any cause)
Number of different specialists seen	Number in two years excluding specialist physicians seen in emergency department
Health service variables measured six months prior to diagnosis	
Number of physician visits in a nursing home	Number in six months (any cause)
Total emergency department visits	Number in six months (any cause)
Demographic variables, individual-level	
Age at diagnosis	Numeric age (years) at time of CRC diagnosis
Sex	Male/female
Rural/urban residency	Rural/urban classified according to SACtype[b]
Distance from individual's home to nearest PCP	Distance in kilometers
DHA of residence	One of the nine DHAs in the province
Long-term care resident	Yes/no
Demographic variables, population-level	
Median household income	Median household income for decedent's DA of residence
No high school diploma	Proportion of people over age 15 who had not graduated from high school in decedent's DA

Category and Variable Name	Measure
	of residence
Live alone	Proportion of people who lived alone in decedent's DA of residence
Unemployed	Proportion of people over age 15 who were unemployed in decedent's DA of residence
Separated, widowed, or divorced	Proportion of people who were separated, widowed, or divorced in decedent's DA of residence
Single parent household	Proportion of households headed by a single parent in decedent's DA of residence
Age 80 and older	Proportion of people age 80 and over in decedent's DA of residence
Age 85 and older	Proportion of people age 85 and over in decedent's DA of residence
Immigrants	Proportion of people who immigrated to Canada in decedent's DA of residence
Recent immigrants	Proportion of population in decedent's DA of residence who immigrated to Canada between 1986-2001
First generation immigrants	Proportion of population in decedent's DA of residence who were first generation immigrants
Aboriginal identity	Proportion of population in decedent's DA of residence who identified as North American Indian, Métis, or Inuit
Aboriginal origins	Proportion of population in decedent's DA of residence who had Aboriginal ancestry
Black	Proportion of population in decedent's DA of residence who identified as black
Francophone	Proportion of population in decedent's DA of residence who identified French as their mother tongue

Note. PCP = palliative care program. CRC = colorectal cancer. DHA = district health authority.
[a]Time from PCP enrolment to death only available for people who live in Capital District Health Authority and Cape Breton District Health Authority. [b]SACtype is a measure developed by Statistics Canada to designate census subdivisions as rural or urban.

Appendix B

Figure B1. Andersen's Behavioural Model of Health Services Use



Andersen (2008), pp. 651

Appendix C

Table CI. Potential Predictors of SDTD for the Study Cohort

Variable	Description	Origin of Data	Studies that Support Inclusion* (Author, Date)
High school grad	Proportion of the population in the decedent's dissemination area (DA)[a] of residence over the age of 15 without a high school diploma	Statistics Canada 2001 Census Information	Byers, 2010
Unemployed	Proportion of the population in the decedent's DA of residence over the age of 15 that was without paid work the week prior to enumeration, were available for work, and had actively looked for paid work in the past four weeks; or were temporarily laid off a job to which they expected to return; or had arrangements to start a job in four weeks or less. (Statistics Canada, 2003)	Statistics Canada 2001 Census Information	Byers, 2010; Kelsall et al., 2008
Single parent household	Proportion of households in the decedent's DA of residence that were headed by a single parent	Statistics Canada 2001 Census Information	
Separated, widowed, or divorced	Proportion of the population in the decedent's DA of residence that were separated, widowed, or divorced	Statistics Canada 2001 Census Information	Wang at al., 2011; Cavalli-Björkman, et al., 2009
Live alone	Proportion of the population in the decedent's DA of residence that was living alone	Statistics Canada 2001 Census Information	Walshe et al., 2009
Aboriginal identity	Proportion of the population in the decedent's DA of residence that was identified as North American Indian, Métis, or Inuit	Statistics Canada 2001 Census Information	Austin et al., 2002; Johnson et al., 2008; Redwood-Campbell et al., 2011
Aboriginal origin	Proportion of the population in the decedent's DA of residence that had North American Indian, Métis, or Inuit ancestry	Statistics Canada 2001 Census Information	Austin et al., 2002; Johnson et al., 2008; Redwood-Campbell et al., 2011
Immigrant	Proportion of the population in the decedent's DA of residence that immigrated to Canada (Citizenship and Immigration Canada, 2005)	Statistics Canada 2001 Census Information	Austin et al., 2002; Johnson et al., 2008; Redwood-Campbell et al., 2011
Black	Proportion of the population in the decedent's DA of residence that identified as black.	Statistics Canada 2001 Census Information	Austin et al., 2002; Byers, 2010; Johnson et al., 2008; Redwood-Campbell et al., 2011
Francophone	Proportion of the population in the decedent's DA of residence that identified French as their mother tongue	Statistics Canada 2001 Census Information	Redwood-Campbell et al., 2011; Wu et al., 2005
Income	Median household income for the individual's DHA of residency.	Statistics Canada 2001 Census Information	Byers, 2010; Holmburg et al., 2010; Kelsall et al., 2008; Moller et al., 2011; Morris et al., 2011
Rural/urban	Designation of place of residence as rural, urban, or unknown based on Statistics Canada's statistical area classification	Statistics Canada 2001 Census Information	Gao et al., 2011; Lavergne et al., 2010; Maddison et al., 2010;

	(SACtype) system. Urban designation includes: census metropolitan areas (CMAs), census agglomerations (CAs), and CMA/CA influenced zones (MIZs) classified as strong. Rural designation includes MIZs classified as: moderate, weak, or no MIZ.		Maddison et al., 2011
Age	Age at time of CRC diagnosis	Oncology Patient Information System (OPIS)	
Sex	Male/female	OPIS	
DHA of residence	District health authority in which the decedent resided (South Shore, South West, Annapolis Valley, Colchester-East Hants, Cumberland, Pictou County, Guysborough-Antigonish Straight, Cape Breton, or Capital Health)	OPIS	
Long-term care resident	Whether or not the client resided in a long-term care facility (yes/no) as determined by at least one physician visit billed to a long-term care facility in the two years prior to diagnosis	Nova Scotia Medical Services Insurance Physician Services Database (MSIPS)	
Cancer stage at diagnosis[b]	Stage of cancer according to summary staging at diagnosis: Stage I (cancer has spread from mucosa to submucosa or muscle layer of colon); II (cancer has spread through muscle layer to the outer colon wall, through the colon wall, or through the colon wall to nearby organs); III (cancer may or may not breach the colon muscle layer and wall, but has spread into nearby lymph nodes); IV (cancer has spread to other parts of the body); or unknown (National Cancer Institute, 2011)	OPIS	
Hospital admissions	Number of admissions to a hospital, for any cause, in the two years prior to CRC diagnosis	Hospital Discharge Abstracts Database (DAD) for NS	
Emergency visits	Number of visits to an emergency room, for any cause, in the two years prior to CRC diagnosis	DAD	
Family physician visits	Number of visits to a family physician in the two years prior to diagnosis	MSIPS	
Specialist physician visits	Number of visits to a specialist physician in the two years prior to diagnosis	MSIPS	

Note. SDTD = short diagnosis to death. All studies listed are cited within this paper and listed alphabetically by author in the reference list. DHA = district health authority.

[*]Supporting studies are provided for socioeconomic indicators based on the review of literature. [a]DAs are small geographic units containing 400–700 people. [b]Cases of CRC designated stage 0, where abnormal cells are found in the mucosa or innermost layer of the colon , were not included in the ACCESS database (National Cancer Institute, 2011).

Appendix D

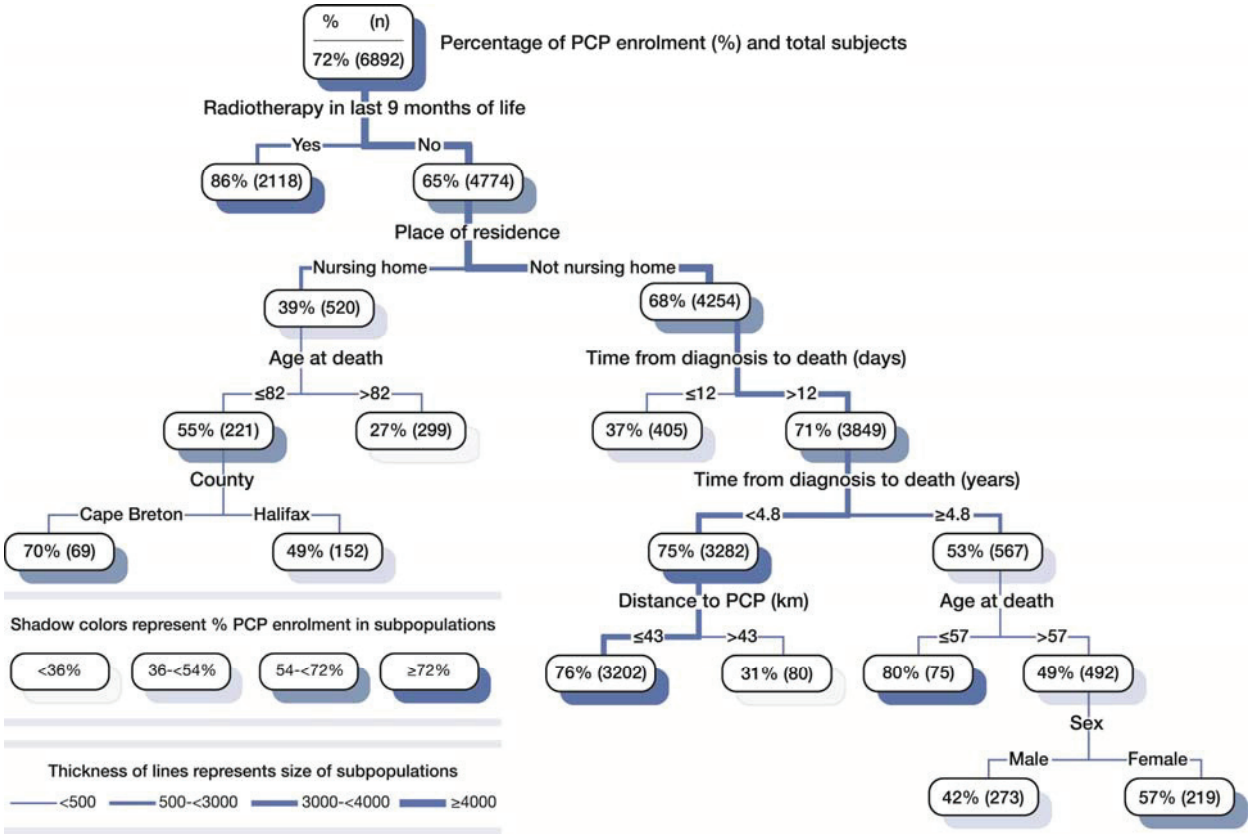
Table D1. Data Sources in the ACCESS Database

Database	Description
Nova Scotia Cancer Registry (NSCR) and Oncology Patient Information System (OPIS)	A unified database that contains information on medical and radiation oncology appointments and treatments at Nova Scotia's two cancer centres (Halifax and Sydney)
Nova Scotia Medical Services Insurance Physician Services Database (MSIPS)	Contains information on billing claims for fee-for-service physician services as well as shadow billings for physicians on alternative payment plans
Insured Patient Registry	Includes individuals' demographic information (i.e., sex, date of birth) and geographic information (i.e., county, postal code) as well as insured health benefits program eligibility dates for all individuals registered as beneficiaries of provincial MSI health care services
Licensed Provider Registry	Contains demographic and education-related information about registered physicians licensed to practice in NS
Hospital Discharge Abstracts Database (DAD)	Contains information compiled and provided for use by the Canadian Institute for Health Information on all people admitted to and discharged from Nova Scotia hospitals
Palliative Care Program databases (CDHA and CB only)	Contains information for all individuals registered in a palliative care program in Halifax or Sydney.
Seniors' Pharmacare Prescriptions database (PHARM)	Contains information about provincially-funded pharmaceutical prescriptions to program beneficiaries over the age of 65
Vital Statistics	Contains data on all mortalities in Nova Scotia (i.e. date of death, cause of death)
Statistics Canada Census information (2001)	Using the Postal Code Conversion File, neighbourhood socioeconomic measures from the census (i.e. income, education, employment) as well as rural/urban residency can be linked to individuals that comprise the ACCESS database
Patient Geography Database at the Population Health Research Unit	Contains additional geographic data held at the Population Health Research Unit that can be linked through probabilistic record linkage to individuals in the ACCESS database
Mental Health Outpatient Information System (MHOIS)	Contains patient encounters, demographic information, and diagnoses from all mental health clinics across Nova Scotia

Note: ACCESS = Access to Colorectal Cancer Services in Nova Scotia. CDHA = Capital District Health Authority. CBDHA = Cape Breton District Health Authority.

Appendix E

Figure E1. Classification and Regression Tree of Subpopulations Differentiated by PCP Enrolment for Cancer Decedents in Cape Breton and Halifax Counties, 2000-2005



Reproduced with permission from Gao et al., 2011.

Appendix F

Table F1. Full List of Community-Level Characteristics of Adults diagnosed with CRC who Died from 2001-2008 in CDHA and CBDHA compared to Nova Scotia

Variable	CDHA and CBDHA (n = 894)				Nova Scotia (N = 1,733)			
	Range		Mean	Median	Range		Mean	Median
	Min	Max			Min	Max		
Household income	$0	$138,930	$40,918	$38,357	$0	$138,930	$38,768	$36,590
Unemployment	0.0%	91.9%	47.9%	46.7%	0.0%	91.9%	48.5%	48.7%
Did not graduate	0.0%	75.7%	30.7%	30.4%	0.0%	75.7%	33.8%	35.2
SWD	5.2%	66.2%	19.2%	17.7%	5.2%	66.2%	19.3%	18.0%
Immigrants	0.0%	34.0%	5.4%	3.5%	0.0%	34.0%	4.6%	3.1%
Aboriginal origins	0.0%	99.4%	2.7%	1.9%	0.0%	99.4%	3.2%	2.2%
Live alone	0.0%	81.1%	12.6%	9.3%	0.0%	81.1%	11.9%	9.4%
Single parent households	0.0%	69.7%	19.1%	17.0%	0.0%	69.7%	17.6%	15.6%
Blacks	0.0%	92.1%	2.8%	0.0%	0.0%	92.1%	2.2%	0.0%
Francophones	0.0%	64.7%	1.0%	0.0%	0.0%	65.8%	1.3%	0.0%

Note. CDHA = Capital District Health Authority. CBDHA = Cape Breton District Health Authority. All variables measured in percentage are proportions within the Census Canada dissemination area (DA) where each individual in the cohort resides. Unemployment = proportion of DA population over 15 years old without paid work. Did not graduate = proportion of the DA population over 15 years old that have not graduated high school. SWD = proportion of DA population who are separated, widowed, or divorced. Immigrants = proportion of DA who immigrated to Canada prior to 1986. Aboriginal origins = proportion of the DA who have Aboriginal ancestry.

Appendix G

Table G1: Individual- and Community-level Variables used in Present Study

Category and Variable Name	Measure
Individual-level variables	
Age at diagnosis	Numeric age (years) at time of CRC diagnosis
Sex	Male/female
Rural/urban residency	Rural/urban classified according to SACtype[b]
DHA of residence	One of the nine DHAs in the province
Long-term care resident	Yes/no
Community-level variables	
Median household income	Median household income for decedent's DA of residence
No high school diploma	Proportion of people over age 15 who had not graduated from high school in decedent's DA of residence
Live alone	Proportion of people who lived alone in decedent's DA of residence
Unemployed	Proportion of people over age 15 who were unemployed in decedent's DA of residence
Separated, widowed, or divorced	Proportion of people who were separated, widowed, or divorced in decedent's DA of residence
Single parent household	Proportion of households headed by a single parent in decedent's DA of residence
Immigrants	Proportion of people who immigrated to Canada in decedent's DA of residence
Aboriginal origins	Proportion of population in decedent's DA of residence who had Aboriginal ancestry
Black	Proportion of population in decedent's DA of residence who identified as black
Francophone	Proportion of population in decedent's DA of residence who identified French as their mother tongue

Note. PCP = palliative care program. CRC = colorectal cancer. DHA = district health authority. [a]Time from PCP enrolment to death only available for people who live in Capital District Health Authority and Cape Breton District Health Authority. [b]SACtype is a measure developed by Statistics Canada to designate census subdivisions as rural or urban.

Appendix H

Figure H.: Effect of all Andersen Model Variables on Time from Diagnosis to Death